

Infertility Network

Donor Conception

(NB. Some aspects of donor-assisted conception have changed in Canada as a result of the Assisted Human Reproduction (AHR) Act which became law in March 2004. More will change once all the regulations are in place. See the section on "Canadian legislation" at the end of this document.)

Sperm and egg donation helps many people to have a family they would not enjoy otherwise – children who are much wanted and loved. However, using donated gametes, or becoming a donor, is a decision which will *forever* affect the lives of everyone involved, especially the child's. Both patients and donors should thoroughly inform themselves about the issues *before* deciding whether to proceed.

Unfortunately, in most of the publicity surrounding gamete donation, there is rarely much mention of any related psychosocial issues, now and for the future, for the recipient and her partner (if she has one), the donor *or* the child. Many clinics, and even some counselors, persist in viewing gamete donation as little more than a "medical treatment for infertility" whereas it is really an alternative form of family-building, with much in common with adoption.

It can be difficult to fully understand and absorb all of the information and issues, both for patients dealing with their own emotional reaction to infertility, as well as for those motivated to donate, either for altruistic or financial reasons.

Talking to a knowledgeable, supportive counsellor can help, i.e. someone who:

- is a trained, experienced, accredited mental health professional.
- has professional expertise with infertility & birth origins information, & preferably adoption as well.
- understands the similarities between donor conception & those in adoption, especially from the offspring's point of view.
- makes it a point to stay up-to-date with current psychosocial research & practice in the field of gamete donation, both in Canada & abroad.
- focuses on the long term welfare of families beyond the current crisis of infertility & having a baby.

Most countries which permit gamete donation require counselling for both the recipient & the donor, as well as their partners, so that they are in a position to give informed consent. In Canada, while some clinics have offered limited counselling for egg donors/recipients, most have not done the same for sperm donation; the AHR Act will now require counselling for all donors, recipients and their partners, as set out in the regulations (which have yet to be passed into law).

Listening to adult offspring, as well as to parents of donor-conceived children and their older children, discuss the realities and lifelong implications of building a family this way can also help a great deal. This can be accomplished by:

- attending seminars or support groups
- purchasing DVDs/CDs/tapes of such seminars or documentaries
- taking part in internet discussion groups
- reading some of the excellent books available

Counselling and networking with others give potential parents and donors the chance to *think* through their repercussions of donor conception *before* making the decision. Hearing how other families deal with some of the same issues can also help those who already have donor children.

SOURCES OF INFORMATION

Infertility Network:

- extensive information package
 - books, seminars & documentaries on DVD, CD & tape
 - seminars & support groups
- which explore the issues and include personal stories by patients, donors & offspring. (See enclosed lists & www.infertilitynetwork.org/store)

Support Groups/Internet Discussion Lists/Websites

(See www.infertilitynetwork.org/donor_conception)

For families created through donor gametes and for those thinking of using a donor; some groups also welcome donors as members. Joining is an excellent way to connect with others.

Counsellors (see enclosed list)

Payment for Sperm/Eggs/Embryos

The Canadian AHR Act bans payment, or the exchange of goods or services, for egg, sperm & embryos; the penalty for breaking this law is a maximum of 10 years in jail and/or a \$500,000 fine.

However, genuine expenses which result from the act of donation and meet regulated guidelines are still allowed. This ban is in keeping with the ban on organ trafficking & with AHR laws in almost all other western industrialized nations (except for the USA where AHR is almost completely unregulated & market forces prevail).

DONOR EGG (See the attached list of IVF Clinics.)

(Approx \$20,000+ per attempt (including drugs))

The wait for an anonymous donor egg can be long (1–2 years) unless the recipient is able and willing to pay large sums of money and travel to the USA or abroad, where women in financial need are recruited to sell their eggs. Some women ask friends or family to donate. Some clinics have arrangements whereby you can share the eggs of 1 donor with 1 or more other patients, thereby reducing your cost (but also the number of eggs you receive and your chance of conceiving).

N.B. There can be significant risks to an older mother and her child from gestational diabetes, hypertension, kidney disease, thromboembolic conditions and premature labour.

DONOR SPERM (See the attached list of IVF Clinics.)

(\$1,000 - \$3,000 per attempt including drugs)

Sperm Banks

- Can-Am Cryo Services Corp. (888-245-3471, www.CanAmCryo.com) extensive info on donors including photos; some identity-release donors.
- Rainbow Flag Health Services (RFHS) (510-763-7737, www.GaySpermBank.com – both gay & heterosexual donors & recipients): all donors are identity-release when the baby is 3 months old.
- ReproMed (877-249-4282, www.RepromedLtd.com): extensive donor portfolios.
- Sperm Bank of California (510-841-1858, www.TheSpermBankofCA.org): A non-profit sperm bank which pioneered the concept of identity-release donors 20+ years ago; offers extensive donor portfolios.
- Xytex, (800-277-3210, www.Xytex.com): extensive info on donors; some identity-release donors.

N.B.

1. *Although most clinics deal primarily with 1 sperm bank, a clinic can usually order sperm from **any** bank, including those outside Canada, as long as the sperm meets Canadian screening regulations. Contact the sperm bank and ask which clinics they work with near you.*
2. *Single and lesbian women sometimes have difficulty accessing treatment in some parts of Canada, especially Quebec; however, in most large urban centres, marital status &/or sexual orientation are not obstacles.*

VARIATIONS BETWEEN CLINICS/SPERM BANKS

The following vary widely from one doctor, clinic or sperm bank to another. Even if this seems **not** to matter much at the moment (when your focus is on having a baby or becoming a donor), people's personal stories and research indicate these things may well matter in the future to you, your partner and most especially **to the person conceived**.

Number of Donors

The larger the number, the more the recipient has to choose from, the more likely they are to find one who matches their needs, and the less chance there is of intermarriage between half-siblings.

Number of Births/Donor

Because of the expense of screening a donor, sperm banks typically require him to donate 3-5 times/week for at least 6 months, preferably longer. However, this can result in dozens, even hundreds, of children being born using a single donor, which in turn has very serious implications: an increased risk of intermarriage between half-siblings and of an undetected genetic problem being transmitted to a large number of children, a reluctance on the part of the donor to make himself known to any of the adult children (for fear that many more may also ask), and a certain 'yuck' factor for the offspring when they realize they were part of 'a batch'.

Ethnic Diversity of Donors

The greater the number of donors from your racial group, the better, both for patient choice and to minimize the chance of intermarriage among offspring.

Amount of Non-Identifying Information

Some programs provide an extensive portfolio on the donor, photos/ videos; others only basic physical characteristics (e.g.

hair & eye colour) and may refuse even the donor number or the name of the sperm bank used.

Availability of Identity Release Donors

Some donors have agreed to have their identity released upon request to the offspring at age 18, or to the family if there is a medical need before this (e.g. bone marrow transplant, more information because of illness, etc.). Several Canadian & American sperm banks now offer ID release donors.

A growing number of countries have banned donor anonymity as a violation of the human rights of the offspring; the UK, Netherlands, Sweden, Norway, Finland, Switzerland, Austria, New Zealand, & the states of Victoria, New South Wales & Western Australia all require potential donors to agree to have their identity released to the offspring at the age of majority (usually 18) if the offspring request it. German case law has established that offspring have the right to identify a biological parent, although no case has yet been tried in the courts.

In 2008, a class action lawsuit was launched by offspring Olivia Pratten in order to preserve donor-recipient-offspring medical records beyond the 6 years required by the British Columbia College of Physicians & Surgeons, and to allow offspring access to those records. See

www.arvayfinlay.com/news/news-oct28-2008.html

Updated medical information on the donor

Donors are typically young, their parents only in their 40s or 50s. Family medical history will change over time as the donor, their parents and relatives, and the offspring age. New medical conditions may emerge which weren't known at the time of donation. Moreover, science will continue to discover new genetic links to cancer, diabetes, heart disease, Alzheimer's, etc. Responsible clinics will update the donor's medical history on a regular basis and pass pertinent information on to recipients so they can make appropriate, informed decisions about their children's medical care. This should work both ways, with medical information about the children passed back to the donor where there are implications for the donor, the donor's family or children, as well as for children in other families who were conceived using the same donor.

Process of Selecting a Donor

Some programs encourage the recipient and her partner to take an active role in selecting the donor and provide lots of information to assist them, while others discourage patient participation and may insist on choosing the donor.

Not all programs make an effort to match appearance; however, if a child looks very different from their parents, the family could be faced with questions from almost everyone they meet. This can be difficult for both the parents and the child to deal with, even for families who have decided not to keep donor conception a secret.

Having decided on the donor, some clinics still reserve the right to use a different donor at the time of treatment, with the result that it is then unclear as to who the genetic parent is. This could have serious implications in the future for the offspring because 1/2 of their genetic health history could be missing, and there could be confusion on a personal level in terms of identity issues. It could also make finding the donor impossible even in cases of medical emergency.

TELLING YOUR CHILD ABOUT THEIR ORIGINS

Some clinics point out the trend towards disclosure, the parallels with adoption and what society has come to accept as the needs & rights of children to know their origins, and the likelihood a registry will be established in the future to facilitate adult donor offspring contacting the donor should they so choose (as has happened with adoption in Canada and elsewhere, and with donor egg/sperm in several other countries). These programs encourage patients to think about when/how to tell their child about their conception, provide patients and donors with material to read and refer them to a knowledgeable counsellor.

Other programs ignore this crucial issue, leaving the patient, the donor and the child to deal with the consequences of uninformed decisions, while some even encourage everyone involved to keep it secret despite the overwhelming evidence that this is an enormous burden which eventually becomes a very destructive family secret.

While some of these differences may not matter to you now, or may even make you uncomfortable (e.g. the idea of a photo/video, or of the donor's identity being released), they may, in fact, become very important to you and/or your child at some point in the future.

Those who struggle with infertility tend to think about having "a baby," but the child won't be a baby for long; in fact, before too long, they will be an adult, probably a parent themselves, and they may have a very strong desire, and perhaps a medical or psychological need, to know as much as possible about their genetic background. On the other hand, donors often detach themselves from the fact that as a *result* of their donation, a child will be born who is genetically their own, the half-sibling of the children they themselves are raising, as well as the grandchildren of their parents.

Most people, before they become parents, or even while their children are still young, find it difficult to really imagine their child as an adult, a person who is *separate* from themselves, someone who will eventually have needs, interests, views & rights that may conflict with their own.

Today's parents realize that, while they may be able to offer advice, they certainly won't be able to *decide* what city their 30 year old 'child' will live in, what job they take, which house or car they buy, who they marry... etc. So, how then, can parents decide *for* their donor-conceived adult "child" what they can or cannot know about *themselves*, their genetic connections and their family health history?

It is clearly in the child's best interests for you to make the best choice possible, to ensure access to as much information-sharing as possible. This leaves the door open for the future when the person born as a result of sperm/egg/embryo donation may want or need more information than you do at present, and when the social climate has changed to make disclosure & donor identity release the norm, instead of the exception.

In the past, adoption was often kept secret, with the adopted person sometimes finding out about their origins during a family crisis (e.g. death, divorce). Today, this sort of secrecy is recognized by adoption and mental health professionals as destructive to individual development and family relationships. In fact, if prospective adoptive parents say they *don't* plan to tell the child of their origins, their social worker will usually not approve their homestudy, and will suggest they look more deeply into adoption, as well as their own motivations, until they are ready to proceed.

Search and reunion have become very important within the adoption community and are now also an issue for many adolescents and adults conceived through donor gametes who want to find their donor and their half-siblings, both those conceived using the donor's gametes as well as the donor's own children. This is not because they don't love their non-biological parent, but rather because, as one offspring has said, "I'm missing 1/2 of the pieces of the puzzle that make up who I am." The millions of people worldwide who use the internet daily for genealogical research are strong evidence that family is much more than just "a social construct."

Our information kit on donor conception contains several stories by offspring. Some write poignantly of the pain they experienced at finding out their parents had not been honest with them about their origins and of their strong desire to know more about their donor; those who were raised in openness often still want to know about their donor and to have access to their medical background, but do not carry the pain caused by parental deception.

Some offspring would like to see the practice of donor conception completely banned because of the deliberate fracturing of genetic kinship ties that it entails, while others just want the system changed to use only identifiable, altruistic donors. (See the comments by offspring later in this document and at www.infertilitynetwork.org/dc_blogs)

It is best to leave all the doors open for the future. What seems like the right decision today (e.g. using an anonymous donor, opting for secrecy instead of disclosure, etc), could turn out to be the wrong decision in 20 years time when it is no longer an abstract idea or the yearning for "a baby," but a major issue in *another adult's* life (i.e. that of the offspring). Rather than think, "Who does this child belong to?," it is far better to ask, "Who belongs to this child?" If you deliberately select an anonymous donor over an identity-release one, how will your **adult** child will feel once they learn that, in doing so, you *chose* to deny them the opportunity to know their roots?

If you *don't* plan to tell your child about their origins, please consider the following:

- What will the impact be on you & your partner of keeping that secret every day of your life? What if one of you becomes so uncomfortable that they decide they *must* disclose, but the other partner objects? What if you split up as a couple?
- Does anyone else know about the method of conception? If just one other person knows, there is always the risk that your child will find out, perhaps under very unfortunate circumstances.
- The notion that "what people don't know, won't hurt them" is now long out-dated and has been disproved many times over. *The truth is that lies hurt.* When these lies are told in the context of otherwise loving relationships, they have the power to erode and even destroy those relationships.
- Parents usually bring their children up to tell the truth, *not* to tell lies; how will you justify to yourself (& to your child if they find out as many eventually do) that you lied to them about the very nature of how they came into the world, about their relationship to their parents & family members, and about their health history & risks?
- How will you deal with the inevitable questions – from family, friends & the child himself – about the child's resemblance (or lack thereof) in looks, talents, interests, etc. to the non-genetic parent?

- Will you tell your child's doctor the truth so that they can provide appropriate medical care? If not, what medical background will you give should an illness or medical condition arise that has a possible genetic link?
- What family medical information – or *misinformation* – will your child have as an **adult** to give to their doctor, as well as to their own children (i.e. your grandchildren) and to their children's doctor?
- If donor conception is so shameful – to you, your family, your culture or religion – that it has to be kept a secret, should you really be using this method to build your family? What will the long term consequences be for all involved?

Many parents don't know *how* to go about telling their children. It can become easy to postpone, to rationalize, to deny, to justify – to do anything in order to avoid having the tough conversations with those one loves most. But that is just it: it is *because* we love our children that we *must* tell them the truth. Counsellors and support groups hear over and over again from families created through adoption or donor conception that family bonds grow strong and resilient when parents engage in open, honest, direct and compassionate conversations with their children.

Regardless of the way children join their families, they need to know that they can trust their parents, and those who have created their families in alternative ways need to trust their children. They must believe that it is their right, privilege and responsibility as parents to tell the truth to their children. They must know also that their ability to do so will provide their children with a strong foundation as they go forth in the world.

The Infertility Network offers many excellent books, 2 video documentaries & previous seminars on DVD/CD/tape to help parents deal with the complex issues in donor conception. See book list & order form (enclosed, or at www.infertilitynetwork.org/store)

Both donors and recipients should give careful consideration to the following issues, among others:

- Any child(ren) born are the genetic children of the donor. How will you feel about this, as a donor or as a recipient? Now? In the future? How might your spouse, children, parents, siblings feel?
- There is increasing recognition adult that offspring have the right/need to seek out their donor, as well as other genetic half-siblings, including those from the donor's marriage. It seems likely egg/sperm/embryo donation will go the same route of adoption, and that a government registry will be put in place to support this (as has already happened in a number of other countries, and by a charity – the Donor Sibling Registry – in the USA). How will you/your partner/your family feel about this? What impact might it have 20 years from now on your life when the "child" reaches adulthood?
- Egg donors must take fertility drugs to increase the number of eggs they ovulate, yet the long term effects of the drugs are unknown; there is some indication they may increase the risk of ovarian or other cancers.
- Even in a well-run, ethical clinic, the donor still has a 5%-10% chance of developing Ovarian Hyperstimulation Syndrome, which can lead to significant pain,

hospitalization &, in extreme cases, even death. In an unethical, or poorly run clinic, donors may be deliberately overstimulated with fertility drugs in order to maximize the number of eggs retrieved, pregnancy rates and profits.

- There is a slight risk to the donor from the invasive and somewhat painful process of egg retrieval.
- Donating eggs may decrease the donor's chance of conceiving, either now (if she too is a patient) or at a future date.
- When a woman can only afford treatment if she gives up some of her eggs (to the clinic or to another patient), is she really making this decision of her own "free will" or is this coercive? Some women agree now out of desperation to conceive, but regret their decision later.
- Is it ethical to ask, or even allow, a woman who is infertile or who has not yet had children to donate eggs? What if she never has a baby? Might she spend the rest of her life wondering if someone else is raising *her* biological child?
- Is it ethical to *allow*, and even to *induce* (by paying), one woman to undergo medical treatment (i.e. egg donation) for the benefit of another woman, especially when it is not required to save a life (as is the case for kidney/liver donations)? The risks inherent in egg donation are significant enough that, in 2003, some United Kingdom fertility specialists called for a ban, saying 'it is neither ethically nor medically sound, given the long-term risks are poorly understood, and as the donor has no therapeutic or pecuniary benefit in risk taking.' (See: "IVF egg donors risking their health," *The Guardian*, Feb. 9, 2003. www.observer.co.uk)
- Is it ethical to *pay* a sperm/egg/embryo donor when all other donations (e.g. blood, organ, tissue) are done only on an altruistic basis and payment is absolutely forbidden – even when required to save a life?
- Many ethicists, family counsellors, donor families and offspring, along with some infertility support groups, find it morally repugnant anyone's life should be based on a commercial transaction; they feel that payment to donors "commodifies" the building blocks of life. (With the passage of the AHR Act, Canada has now joined many other countries, including members of the European Union, that have discontinued the practice of paying donors.)
- Some clinics fear banning payment to donors means an end to sperm/egg donation. However, the experience of other countries indicates it is still possible to have donors volunteer without reimbursement. Typically, the donor pool changes from young, university students to men and women who are older, whose families are complete, and who recognize the enormous joy a much-wanted child can bring a family. To ensure success, it is necessary to proceed carefully, educate the public about the need for donors and have the co-operation of fertility clinics and sperm banks.
- Children born as a result of egg/sperm donation or "egg sharing" are half-siblings. What about their desire to know each other, as many of the current adult offspring do? What about the chance of your son/daughter unknowingly marrying their own half-sibling?
- Using donor sperm/eggs not properly screened exposes the recipient, her partner and their child to the risk of

contracting AIDS, hepatitis, etc. in the same way that having unprotected sex with a stranger would. In addition to these diseases, the child is at risk of inheriting genetically transmitted diseases. Even if the donor is a family member or a close friend, they **should** be screened. Most clinics will screen known donors, as well as anonymous ones.

- Because of the time it takes for the HIV virus to appear, the standard worldwide is for donor sperm to be frozen and quarantined for 6 months, with the donor re-tested before it can be released for use. For the same reason, some countries also require donor eggs to be frozen after fertilization, with the egg donor re-tested in 6 months time before embryo transfer can take place; Canada does not yet do this.
- In most Canadian provinces (including Ontario), there are currently no laws regarding the status of the parties involved (donors, parents, children), i.e. no legislation to:
 - guarantee that the non-biological parent (i.e. the social father or female co-parent in the case of lesbian parents) is the legal parent.
 - clarify the rights or responsibilities of donors towards the children conceived through their anonymously donated sperm.

(Custody cases involving donor-conceived children have been rare, but have resulted in the social father who has raised the child being given the same consideration as a biological father.)

It is usual for a heterosexual couple to put both of their names on the child's birth certificate.

Non-conceiving partners in lesbian relationships are less assured of their legal rights; therefore, such partners may wish to consider either privately adopting their partner's biological child or consulting a family lawyer to develop a parenting agreement.

Single women, as the only guardian of their child, should ensure that they have made provision for additional legal guardianship.

LEGISLATION IN CANADA

The Assisted Human Reproduction (AHR) Act

laws.justice.gc.ca/en/A-13.4/index.html

(Received Royal Assent on March 30, 2004)

The Act is a long, complex bill dealing with both reproductive and genetic technologies. Although its passage into law may have seemed 'sudden' or 'rushed' to people who hadn't been following its progress closely, and was criticized as such by many opposed to the bill, in fact this was **not** the case at all: rather, legislation had been 'in the works' for more than a decade.

Moreover, until the AHR Act was passed in March/04, Canada was almost the **only** western industrialized nation without legislation to govern reproductive and genetic technologies (RGTs) and protect the interest of those most directly affected, especially women and children. In fact, some countries – e.g. the United Kingdom and Australia – have had legislation in place for many years, along with a well-established process for consultation and review.

The legislative void had continued, despite more than 20 years of calls for action from various quarters, continuing consultations by Health Canada with a wide range of

stakeholder groups as well as provincial and territorial representatives, and promises made (and broken) by 6 successive Ministers of Health to enact legislation. In the intervening years, the use of RGTs proliferated, largely in the sphere of private, for-profit medicine, something Canadians have said that they do not want.

During these years, a number of initiatives were undertaken by the federal government:

Royal Commission on New Reproductive Technologies

(1989-1993)

dsp-psd.pwgsc.gc.ca/Collection-R/LoPbDP/MR/mr124-e.htm

Four years and \$28,000,000 were spent examining activities related to assisted human reproduction in Canada. The RCNRT consulted widely via private & public hearings across the country; briefs submitted; public surveys; toll-free telephone lines; projects & analyses in a variety of disciplines, including the social sciences, ethics, law & medicine conducted by more than 300 researchers at various institutions. In all, some 40,000 people were involved. The final report, *Proceed with Care*, called upon the federal government to establish legislation and a national regulatory body, and included a detailed list of recommendations.

Federal/Provincial/Territorial Working Group on RGTs

(1993-96)

Co-operation among federal, provincial & territorial governments is an important part of any matter dealing with the health of Canadians as all levels of government have responsibilities in the health area. This group provided advice to the Deputy Ministers of Health.

Discussion Group on Embryo Research (1995)

Submitted a report to Health Canada in Nov/95.

Interim Moratorium (Instituted in 1995)

A voluntary moratorium on 9 "problematic" new reproductive technologies, including:

- the buying/selling of eggs, sperm & embryos
- egg donation in exchange for IVF
- commercial surrogacy

Advisory Committee (1996 - 2003)

Established to advise Health Canada on compliance with the moratorium, track the development of emerging new reproductive & genetic technologies, and identify other questionable practices that might warrant inclusion in the moratorium. The members were selected for their expertise in the areas of women's health, bioethics, reproductive medicine, minority rights, religion, consumer, children & ethnocultural issues.

Government white paper, New Reproductive & Genetic Technologies: Setting Boundaries, Enhancing Health (1996)

Outlined the government's intention to establish a regulatory framework to enhance the protection of Canadians using AHR to build their families.

Bill C-47: Human Reproductive & Genetic Technologies Act

(Introduced 1996)

Proposed prohibitions based on the voluntary moratorium. Although approved by the House of Commons Standing Committee on Health, the Bill died on the order paper with the dissolution of Parliament for the 1997 election.

Reproductive & Genetic Technologies overview paper (1999)

Workbook on Assisted Human Reproduction (2000)

Summarized the key elements of proposed legislation, provided a description of the areas for regulatory development, and described possible models & functions of a regulatory body. Circulated to stakeholder groups for input.

Feedback Report: Discussions & Written Comments on Proposed Federal RGT Legislation (June 2000)

Report on meetings held by Health Canada with provincial & territorial colleagues, as well as stakeholder organizations, to discuss the proposed federal legislation; also included written comments from a variety of individuals & groups.

Draft Legislation (May 2001)

The Minister of Health asked the House of Commons Standing Committee on Health to review draft legislation & provide recommendations.

House of Commons Standing Committee on Health

(May - November 2001)

After holding hearings for a number of months with a wide range of stakeholder groups, professionals & individuals, the Committee issued a report, *Assisted Human Reproduction: Building Families*, in Nov/01.

The Assisted Human Reproduction Act

laws.justice.gc.ca/en/A-13.4/index.html

(Introduced into the House of Commons as Bill C-56 in May 2002. Renamed C-13, then C-6 - An Act Respecting Assisted Human Reproduction & Related Research) Royal Assent: Mar/2004

Until the AHR Act was passed:

- All donor/patient records were kept by the individual doctor/clinic/sperm bank, rather than centrally.
- Until very recently, little or no information was kept on donors.
- Records could be legally destroyed after 10 years, and were sometimes lost/destroyed when a doctor retired, died or moved.
- There was no birth register for maintaining information about, or linking, donors, recipients & offspring.
- There were no national standards for clinics to adhere to, other than those for screening sperm.
- There was no law or regulations limiting the number of children that could be conceived using any 1 donor.
- There was little acknowledgment of any issues beyond that of achieving a pregnancy for an infertile couple.
- There was a thriving trade in sperm & eggs in the private, for-profit medical sphere (which still continues in some quarters as an unregulated black market, in direct violation of the AHR Act, which – so far – is unenforced by government).
- Clinics were not required to report their success rates. Any reporting was done on a voluntary basis, not independently verified, and only reported on an aggregate basis by the Canadian Fertility & Andrology Society, rather broken down by clinic. (By contrast, American clinics have been required since 1992 to report their statistics to the Centres for Disease Control; these statistics are published annually and are available to the general public on a clinic-by-clinic basis, just as they are in the UK.)
- There was no national reporting mechanism to collect information on treatments & outcomes, such as pregnancy & live birth rates; risks of ectopic pregnancies, miscarriages, multiple & premature births, congenital malformation. Such information is important in compiling success rates, enabling the long-term study of genetic

disorders or other serious conditions in children born via AHR, and providing information to patients so they can make informed decisions about treatment.

The parts of the AHR Act that pertain to payment are outlined below. **None of these provisions is new**: they were present in the Royal Commission Report of 1993, and have been part of every report and Bill since then. Other than the USA (where payment is allowed and AHR is not regulated), they are also similar to legislation in most other western industrialized nations, except those countries that are more:

- restrictive and ban the use of donor sperm, egg &/or embryos (e.g. Italy which bans all 3, Germany which prohibits egg & embryo donation)
- progressive and allow only identity-release donors

Nevertheless, it is true that some services which had flourished in the legislative void, and which infertility patients had come to see as a potential route to having a family, are no longer legally available, in particular:

- Buying/selling of sperm/eggs
- Donating eggs to another patient in return for some or all of their treatment costs being paid.
- Commercial surrogacy

It is extremely unfortunate that patients were caught in the middle between the government (which promised, but failed, to enact legislation for so many years, largely because of opposition from the medical community) and some of the private fertility clinics (which ignored the Interim Moratorium's call for an end to these practices).

If only:

- the clinics had respected the Moratorium

OR

- the government had resisted the considerable pressure on it from the reproductive technology industry, and instead had followed through on its stated intentions & enacted legislation right after the Royal Commission issued its final report

these practices would never have been allowed to develop in Canada, patients would not have come to expect them to be available, and would not now feel angry & betrayed over an abrupt change in the options previously open to them, nor would there likely now be a thriving black market, aided and abetted by some medical practitioners, lawyers and counselors who seek creative ways to circumvent the intent of the law.

Health & Safety Of Canadians

Extracted from:

www.hc-sc.gc.ca/english/media/releases/2004/2004_10bk4.htm

One of the key goals is to protect the health and safety of Canadians, particularly those undergoing AHR treatments and children born from such procedures. The prohibited activities are those considered ethically unacceptable &/or which may pose significant human health & safety risks, including the commercialization of reproduction. The Act contains significant penalties for the contravention of any of the prohibitions. The legislation also establishes controlled activities which are prohibited unless carried out pursuant to a licence and in accordance with the regulations.

There is a growing understanding of the role parental medical histories and genetic information can play in predicting, preventing and treating medical conditions. Until now, there

has been no consistency as to what information, if any, patients using donated sperm, eggs or embryos were provided about the donor.

Under the AHR Act:

- Donors must be at least 18.
- Donors & recipients must receive counselling
- Clinics must collect identifying & non-identifying information from a donor (e.g. eye & hair colour, medical information, the donor's name & address.)
- Recipients will be given the donor's non-identifying health reporting information & offspring will be able to access this information. Identifying information will only be released with the written consent of the donor.
- The AHR Agency will store identifying information for health & safety reasons, e.g. consanguinity.
- The Agency will be able to disclose identifying information, in confidence, to a physician in cases of medical emergency (e.g. a child requires a bone marrow transplant; a genetic or other transmissible disorder becomes apparent in either an offspring or gamete donor.) The physician may not disclose the identity.
- On application in writing by any 2 individuals who have reason to believe that 1 or both were conceived by donor sperm, egg or embryo, the Agency will disclose to both whether they are genetically related and, if so, the nature of the relationship.

The Government of Canada recognizes the health and ethical concerns inherent in the commercialization of the reproductive capacities of women and men, and the exploitation of children, women and men for commercial ends. Altruistic donation is in keeping with the Canadian tradition and practice whereby human organs or tissues are donated, rather than sold or purchased, for the use of those in need. [It is also in keeping with practice in adoption where adoptive parents are prohibited by law from giving any money, goods or services to the birth family which could be seen as an inducement for relinquishing their child.]

The AHR Act:

- prohibits the purchase of sperm or eggs, the purchase/sale of embryos, & the exchange of eggs, sperm or embryos in return for property or services (e.g. IVF treatment or drugs)
- allows for the reimbursement of a sperm or egg donor's receipted expenditures relating to the act of donation.

Fertility Clinics & Health Reporting Information

Extracted from:

www.hc-sc.gc.ca/english/protection/reproduction/info.htm

The AHR Act provides for:

- A rigorous system of licensing, monitoring, inspection & enforcement by the Agency.
- Collection of health reporting information from fertility clinics to be stored in central information registries, protected by Common Law and by privacy legislation. Regulations will determine what information is to be provided by the clinics, justified on health & safety grounds.

Regulations

These will be written after consultation with stakeholder groups, then reviewed and passed by Parliament before they are enacted. The Act must be reviewed by Parliament within 3 years after coming into force (i.e. 3 years from 2006 when the AHR Agency was created.)

Regulations will deal with such issues as:

- Consent
- Reimbursement of reasonable expenses to donors
- The number of children created by any 1 donor
- The collection, use, disclosure & destruction of health reporting information on donors
- Counselling services

Comments/Questions re the AHR Act should be addressed to:

- Leona Aglukkaq, Minister of Health
House of Commons, Ottawa, ON, K1A 0K6
P: 613-944-7740, Fax: 613-995-9926,
minister@www.hc-sc.gc.ca
- Ms. Francine Manseau, Senior Strategic Policy Advisor
Assisted Human Reproduction Implementation Office
200 Place du Portage, 2e étage, A.L. 7002A
Hull, QC, K1A 1K8
P: 819-934-1830, F: 819-934-1828, ahr-pa@hc-sc.gc.ca
www.hc-sc.gc.ca/hl-vs/reprod/index_e.html
- Dr. Elinor Wilson
President, Assisted Human Reproduction Canada (AHRC)
2nd Floor, 301 Elgin St, Ottawa, ON, K2P 2N9
P: 1-866-467-1853, F: 613-952-5899, info.ahrc-pac@hc-sc.gc.ca
www.ahrc-pac.gc.ca

VIEWS OF ADULT DONOR OFFSPRING

There are now several hundred adult donor offspring worldwide who are advocating for reform of the donor system. Their views vary to some degree, but there is a lot of commonality in what they have to say.

- Some want the use of donor gametes banned outright (as is the case in several countries, including Italy. Donor eggs/embryos are banned in Germany.)
- Almost all want future donors to agree to have their identity released to their offspring at the age of majority (usually 18) before being accepted as a donor. (This is now the law in a growing list of countries.)
- Almost all want national voluntary registries set up (as there are in the state of Victoria, Australia and in the UK) to enable adult offspring and donors to connect with each other if they so choose.
- Some want access to identifying information to be retrospective (as it is with adoption records in most countries).
- All want access to accurate, complete and regularly updated health history on their donor (so that they can take proper care and precautionary measures for themselves and for their own children).
- Most want payment to donors banned outright, or limited to only reimbursement for expenses directly related to the act of donation.

In the chapter, "A Sperm Donor Baby Grows Up" which she contributed to the book, *The Technological Woman* by Jan Zimmerman, adult offspring Suzanne Ruben Ariel (conceived in the 1950s) described what many offspring feel – that payment to donors turns children into commodities:

"How do I reconcile my sense of integrity with knowing that my father sold what was the essence of my life for \$25 to a total

stranger, and then walked away without a second look back? What kind of a man sells himself and his child so cheaply and so easily?"

In the spring of 2004, several offspring wrote letters to the editor in response to media coverage about the Canadian ban on payment to donors and surrogates:

Buying and selling sperm cheapens humanity

As someone conceived via paid anonymous donor sperm, it was a great relief to see the non-payment clause become law with the passing of the AHR Act. Unfortunately, many patients seeking donor sperm or eggs forget that the lifelong implications of the buying and selling of donor gametes affect the resulting child the most. I, for example, am left forever wondering if my biological father understood the full consequences of what he did.

Did he pocket the money, thinking to himself, "Isn't this great, being paid for something I do every day?" Did he think that his sperm would not stay sperm, that it would become a person – me? Had he not been paid, I would at least know that he had the right intentions and that I am related to someone who wanted to help someone else first before helping himself.

Allowing people to sell their gametes is degrading and cheapens the essence of what it means to be human.

Fertility doctors, and patients who are blinded by the desperation to have a child at any price, forget their own children will live with the decisions that were made before they were born.

Fortunately, Health Canada, members of Parliament and senators have been able to see beyond the supply-and-demand market that currently exists in the fertility business and do the right thing.

Olivia Pratten, Donor Conceived Adult, Canada
.....

No money for life!

Donor conception is not about money, it is not about the couple seeking to have a child. It is about the person who is born as a result of these procedures.

It is very insulting to think that a human life can only exist when money trades hands. Isn't being paid for "travel expenses" enough for a donor? If not, then perhaps they should reconsider donating at all. Donors are biological parents, whether people wish to think that or not! They are not only helping a couple in need, they are creating life, giving away a part of their biology, and they should be willing to do this for nothing.

As for people going to another country or trading on the black market, that saddens me. Is no one thinking about the child/ren, who grow up to become adults, who have feelings and want to know where they come from?

If the available donors fall away, then perhaps that says something about donor conception as a modern day practice. If they are not willing to give the gift of life out of the goodness of their heart and remain present for their child, then maybe it is for the best they walk away.

Why must everything in this day and age be about money? The only reason the clinics push for these laws to be reversed is because they make so much money out of these practices. Where is the cure for infertility?! They would be silly to refuse people treatment, it is an industry now. One of the directors of one of the main programs here in Australia is a business man, has no care for medicine! Hello! Wake up everyone.

I am the child of an anonymous sperm donor and I do not know my biological father; I may never know. It saddens me that people's desire to have a baby overrides that artificially created person's rights and freedoms. I always thought that the rights of the child were paramount, but over the last few years I have realised that they are not. The rights of the desperate couple far outweigh ours.

Narelle Grech, Donor Conceived Adult, Australia
.....

I don't believe there is anything ethical about accessing a third party's genetic material to procure children, especially when monetary incentive is being offered as recompense.

I was conceived in Australia using donor sperm. My biological father was paid for his "services", \$10 per donation. I feel like a product, I was sold, bought, frozen and defrosted. I feel illegitimate and manufactured. My mother paid \$100 for the little vial containing 50% of my genetic material. Most people enter this world freely; my conception was contractual, a mere transaction between two strangers. I regard it as putting a price on the value of my creation, my existence; it's dehumanising and degrading.

I congratulate the Canadian government on their achievement with the AHR Act, and the cessation of payment for gametes, an important step with regards to the best interests of children, who (believe it or not) mature into adults like myself. Human life is precious, priceless; it seems all too often we are throwing human rights and dignity out the window in favour of needs, demand and profitable business.

Myfanwy Walker, Donor Conceived Adult, Australia
.....

What level of "compensation" would be reasonable for a woman who is prepared to risk her life and her own fertility in order to sell her biologically related potential child? One wonders if such women are actually made fully aware of the serious dangers inherent in the egg retrieval process or if their decisions to provide gametes are solely influenced by the lucrative nature of the transaction. It is possible that their judgement has been partially clouded by the effusive thanks of the recruiting clinic and the morale boosting nature of their bountiful generosity towards those who are not fortunate enough to have healthy gametes of their own..

Society has come to view Assisted Reproductive Technologies which enable couples to have their own child as morally acceptable, but with wider debate and understanding the public will eventually realise that any procedure which involves men or women giving away or selling their own potential children for others should not be regarded as socially beneficent, or even as a fertility "treatment."

Christine Whipp, Donor Conceived Adult, United Kingdom
.....

The AHR Act correctly places the offspring conceived of sperm and egg donation at the centre of assisted reproductive technologies by disallowing payment to the donors. Surely this child-centred restriction is the only sustainable moral and ethical approach when one considers the needs of real children.

The children conceived this way, as they mature into adulthood, need to always feel fully enfranchised as all other Canadians. They do not need or deserve to feel that they were bought and sold. We outlaw this practice in adoption, so why shouldn't we do this for people conceived from donor gametes? I applaud the AHR Act for putting children first.

Karen Lynn
President, Canadian Council of Natural (i.e. birth) Mothers,
www.ccnm-mothers.ca