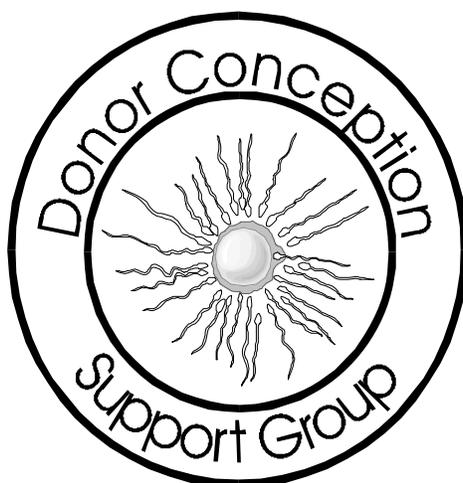


SUBMISSION
TO
the INQUIRY INTO ACCESS BY DONOR-CONCEIVED
PEOPLE TO INFORMATION ABOUT DONORS
by the Parliament of Victoria
Law Reform Committee



FROM
THE DONOR CONCEPTION SUPPORT GROUP
OF AUSTRALIA INC.

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Introduction

Victoria has always been at the forefront of donor conception legislation. A review of donor conception legislation began in Victoria in 2004 this resulted in the new *Assisted Reproductive Treatment Act 2008*. The current inquiry is being held because of serious concerns which arose as a result of this act and on going issues about access to information by donor conceived people. This inquiry is showing us that Victoria is still at the forefront of discussion of the issues in donor conception.

In the past nearly seven years the Victorian Government has heard the views of many people and organizations in regard to donor conception and the vast majority of them have agreed that ALL donor conceived people regardless of when they were born should have access to identifying information on their donors. We need to bring donor conception legislation in line with that of adoption and we need to do it now.

Donors & Consent

It is indeed true that many fertility clinics did require donors to sign anonymity agreements but our group has been contacted by donors who have stated that signing these documents was not an option; they signed them or they would not be considered suitable to donate. So anonymity was not necessarily requested by donors but by the medical profession.

Further to the article in the weekend papers, I was a sperm donor during 1997-1998.

Attached to the Hospital in Melbourne, my donations were during the period when Donors had to sign away any future contact. This was a condition of participation and I only wanted to help people – but at the back of my mind was the hope that the rules would change to allow the resultant children to trace their donor fathers, if they wished to do so.¹

Many clinics also had parents sign similar forms which stated that they would not try and seek out the identity of their donor.

¹ “P” DCSG written communication with donor

The Committee was very accurate in stating that in the early days donors (and parents) received no counselling and no information on the long term consequences of donation. This brings up the question of whether the forms signed by both donors and parents were signed with informed consent.

I received no counselling, nor can I remember undergoing a medical check, other than completing forms outlining my medical details and history. I was given the assurance that my anonymity would be preserved which wasn't- and still isn't – a concern.²

And, of course, donor conceived people never had a chance to have a say in the nature of their conception; never signed any forms to say that they would not seek out identifying information about their donors.

Donor conceived people should be given access to identifying information on their donors (where it still exists) and all parties should be given the ability to place contact vetoes on their files, as in adoption. In this way the privacy of all parties will be respected while still giving donor conceived people the ability to access information that is vitally important to a great many of them.

If donors wished it, the power to put contact vetoes in place would involve virtually no disruption to the lives of donors and their families.

If the Victorian government does as we suggest and implements retrospective legislation a public advertising campaign could help give donors the opportunity to revisit donor conception issues and put contact vetoes in place if that is what they wish.

Move of Registers to BDM

One of the recommendations of the Victorian Law Reform Commission was that the agency responsible for administering the registers should do more to facilitate approaches to donors and help increase awareness of options in relation to providing identifying information.

Unfortunately since the move of the registers to BDM nothing is being done to facilitate approaches to donors.

² “PH” DCSG written communication with donor

Ever since this change was put in place our group has been receiving calls asking if there is any way that the registers can revert to VARTA. VARTA as we, and many others, have said was a “one stop shop”, a place where people could go to have all their questions answered, to get help in accessing information and if necessary access counselling. VARTA also provided a much appreciated service of being a “letterbox drop” so that parties involved in donor conception could communicate with each other with out meeting or invading each other’s privacy.

National Health & Medical Research Council’s (NHMRC) Guidelines.

The NHMRC Guidelines are in many instances rather vague about their intentions. The guidelines state that:

6.11 _Provide donor-conceived persons with information about their gamete donor

People conceived using donated gametes are entitled to know their genetic parents. On request, clinics must arrange for either a medical practitioner, or an appropriately qualified health professional, to provide at least the following information, to a person conceived through ART procedures, provided that he or she has either reached the age of 18 years or acquired sufficient maturity to appreciate the significance of the request (including any implications for his or her younger siblings):
all medical and family history information as specified in paragraph 6.10;
identifying information about the gamete donor (subject to paragraph 6.1); and
the number and sex of persons conceived using the gametes provided by the same gamete donor, the number of families involved, and any identifying information that these siblings have consented to being released (see paragraph 6.1.3).

Unfortunately this paragraph has been taken by many to mean that all donor conceived people regardless of when they were born should be able to access identifying information on their donors. Of course our group knows that this is not the case and in fact many older records no longer exist or have barely any information at all.

Our group has for many years been seriously concerned about whether clinics are following the guidelines because of the lack of transparency in the accreditation process. In Victoria it is possible for VARTA to enter registered ART premises to ensure that the clinic is complying with the Victorian legislation but the Victorian Government relies on the normal RTAC accreditation to ensure that clinics are abiding by the NHMRC guidelines. One section of these guidelines states:

6.1.3 Working with relevant professional organisations, clinics should use forums for public information to encourage people who were donors before the introduction of these guidelines, and those previously conceived using donated gametes, to contact the clinic and register their consent to being contacted by their genetic children or genetic siblings and half-siblings, respectively.

6.13.1 When approached by a person who was conceived using donated gametes and who now seeks identifying information about his or her genetic parents, the clinic should examine the consent form of the gamete donor and proceed as follows:

If the consent form does not include permission for release of identifying information (because the donation was made before the introduction of these guidelines and the gamete donor has not come forward in response to the public information campaign outlined in paragraph 6.1.3), the clinic should make an appropriate effort, consistent with the original consent document and the privacy rights of the donor, to contact the gamete donor and obtain his or her consent to the release of information.

Our group has never known a clinic anywhere in Australia, or for that matter the Fertility Society, to have conducted any public education campaigns to encourage past donors to come forward. If clinics are not following this very important guideline it surely must raise a flag as to what other sections of the guidelines they may be failing to follow.

Disclosure

Some hesitancy on the part of parents to tell their children the truth may be able to be attributed to the lack of donor information but we feel that the majority can be directly attributed to the lack of support in how to tell children. In adoption education in how to speak to children about their adoption begins even before an adoption has occurred and continues throughout the childhood of the adoptee. In donor conception there is no formal support available before the conception and birth of a child and indeed does not really exist after this either. Our group provides some support within our very limited resources (because of our nature as a self help group relying on volunteers) and VARTA also provides some support but they are basically reliant on people coming to them to ask for help whereas in adoption education on talking to children is an inherent part of the adoption process. In this way adoption does well in placing the needs of the child at the forefront. In donor conception while it is stated that the welfare of the child is paramount in reality the welfare of the child is often lost in the desire of adults to become parents.

Half-sibling information

ITA used to be able to give out information to donor conceived people about their half-siblings but under the latest legislation this information is no longer available to anyone but Donors. A result of this is that the children from a donor's relationships may well be able to have information on the number, sex and year of birth of their donor half-siblings and may therefore be able to avoid inadvertently forming a relationship with one of their half-siblings. This change of policy has legally denied a vital piece of information to donor conceived people.

Balancing

It is not helpful to talk about “competing rights”. All people involved in donor conception have a right to privacy and this should be upheld.

The protection of privacy works very well in adoption

In Victoria, Australia, the state granted adopted adults unconditional access to their

original birth certificate retroactively with mandatory counseling.³
There were many fears surrounding this move but as time went on these fears were not realized approaches for information and/or contact were made with sensitivity for the feelings of the other party⁴

We are referring to the adoption model on many occasions as we feel that this is a model that has worked well for many years in Australia and adoption is the closest system with which to compare donor conception.

Contact

In case study three we see an example of the fears that a number of donors have about the opening of donor conception records. While we acknowledge that some donors may feel this may it is often because of lack of information that they feel this way. Our group has met many donors over the years who do not fear contact:

My first donor child is due next month and if that child searches for me one day, I'll meet him or her⁵

*In 1975 I donated at the..... Hospital for
I have often wondered what happened and would be happy to correspond, possibly meet any offspring, or just provide mine and my parent's medical history.⁶*

I decided that I would have been more than happy for any children (now young adults!) conceived as a result of my donations, to know something about me, their biological father, and even to make contact, should they desire.⁷

This is exactly how many birth parents felt years ago and we know that these fears were never realized. While some states have full contact vetoes in place Victoria decided on a less prohibitive system in which adoptees and parents could record their wishes⁸. This system has worked well

³ Does Opening Adoption Records Have an Adverse Social Impact? Some Lessons from the U.S., Great Britain, and Australia, 1953–2007 E. Wayne Carp, PhD Adoption Quarterly, Vol. 10(3–4), 2007 by The Haworth Press.

⁴ GeraldMcPhee, MarilynWebster 1993, Marshall & McDonald, 2001; Swain, 1992.

⁵ “N” DCSG written communication with donor

⁶ “R” DCSG written communication with donor

⁷ “A” DCSG written communication with donor

⁸ Australian Institute of Health and Welfare 2010. Adoptions Australia 2008–09. Child welfare series no. 48. Cat. no. CWS 36. Canberra: AIHW.

for many years and participants have treated each other with sensitivity and respect. This experience would beg the question why would those involved in donor conception be any different?

We must at this point discuss the point that makes donor conception very different than adoption and that is numbers. In donor conception one person can have quite a number of offspring compared to adoption and this is probably the one area that worries some donors. This is why our group would recommend a more formal contact veto system than has been used in adoption in Victoria. We feel that a full contact veto system would enable those donors who are fearful a measure of protection from unwanted contact. We would suggest that if this system were to be introduced that a contact veto should be able to be altered by each party at any time.

We would suggest from our experience of talking to many donor conceived people and donors over the last nearly two decades that the number of people wanting contact within donor conception will most likely be less than in adoption. All adult donor conceived people that our group has spoken to have stated very clearly that they think they should have the right to know who their donors are but many say that they have no desire for contact that they just want information with which to complete their sense of self.

Option for Change

In the interim report it was stated that most submissions were choosing Option 3 as the preferred model. This option merely changes the levels of rights of access to information from 3 different levels to 2 different levels. There has to be just one level; all donor conceived people should be treated equally.

Protection of Records

All records wherever they are currently held must be given permanent protection; in donor conception these records are the equivalent of true birth certificates.

All records of my existence in the programme had been destroyed in 1983 – for very questionable reasons (paranoia?). In retrospect it can be said that the future needs – psychological/emotional etc for all offspring had been given zero consideration. Shame on all of us.⁹

⁹ “PB” DCSG written communication with donor

Donor conceived people are, for the most part, very realistic about the fact that records pertaining to their donor may be minimal or even no longer in existence. What they need is access to whatever does still exist and the recognition of their need for this information.

Recommendation 1

It is stated that the intended purpose of the removal of registers from VARTA to the BDM was to de-stigmatise donor conception and infertility.

To put it bluntly – this hasn't worked.

Stigmatisation will exist until all donor conceived people have the right to access whatever information on their donors and half-siblings that still exists. Merely changing the location will change nothing worthwhile. Indeed we feel that it has had the opposite effect. Where once donor conceived people went to an organization that was created with them in mind (yes, we acknowledge that it also served infertile people and donors) and received help in accessing information from people who had amassed years of experience in this field now they go to a much larger organization that has no experience in donor conception and does not even have counselors on hand.

To put it briefly services for donor conceived people, their families and donors have decreased in all respects.

National Register

A National Register for donor conception is becoming more of a necessity as some states still resist the push for state legislation. Federal legislation and the formation of a national register would create a system that would be as equal as possible for all donor conceived people.

The blockage to the creation of a national framework appears to be the reluctance of the federal government to enact legislation in a so called "health area". Of course in the not too distant past the federal government did enact two pieces of legislation that definitely reside in the "health area" (*Prohibition of Human Cloning Act 2002* and the *Research Involving Human Embryos Act 2002*).

All it would take for the federal government to start work on legislation to create a national register is for state governments to agree that a national register is the desired model.

Impact on Donor Programs

We would foresee no adverse impact on the number of people donating gametes in Victoria if legislation was made retrospective. The use of anonymous donors stopped in Victoria at the end of 1997 with the enactment of the *Infertility Treatment Act 1995*. All donors since then have donated in the full knowledge that identifying information can be accessed by donor offspring when they reach the age of 18 years.

Donor conception would benefit from a good public education campaign which could have a number of benefits:

- Reassure all parties that their privacy will be respected
- Lessen stigmatization of donor conceived people
- Possibly encourage new donors to come forward
- Encourage parents to tell their children

Number of Families

We would like to re-iterate our call for the number of families that can be created from one donor to be limited to a maximum of 5 including the donor's own family.

We feel that perhaps the Victorian government yielded to pressure from the medical profession to place a limit of 10 families.

We are concerned that the medical profession, which has a monetary interest in using a donor for as many families as possible, is allowed to have so much say in this matter.

We also note that in the past decade or so whenever a clinic has advertised in the media potential donors have always come forward. For example:

The Age

Donors double after IVF plea

By Carol Nader

March 9, 2005

Victorian men have chivalrously responded to an appeal for sperm, with the number of donors in the state doubling in the past two months.

In January, The Age reported that Monash IVF had written to Victoria's male state MPs under 45, urging them to become donors to help replenish sperm bank supplies. The idea was to encourage other men to lend a hand.

While no politicians have yet responded to the challenge, the reproductive service received 70 inquiries from men, of which 14 have volunteered their sperm. This will bring the number of donors at Monash IVF to 27, once the new donors have been tested for infection and their sperm given the all clear. In Queensland, Monash IVF acquired one new donor.

Melbourne IVF has also profited, recruiting six new donors to bring its total to 18.

Monash IVF medical director Gab Kovacs was delighted with the response.

"To get 70 inquiries is really remarkable, and 14 out of 70 is a very good conversion rate," he said. "Ideally, we need men who are in a stable relationship and mature men who understand what they're doing - they're producing children."

Professor Kovacs said many men were put off volunteering their sperm because of time constraints and the pressure of performing on demand. Men also felt threatened by the prospect of their offspring turning up on their doorstep years later. Others were frightened off by inquiries about their sexual activities, lifestyle and drug use.

"(There are) all those jokes about having to go and masturbate, but it's not something that's so easy to do in one's lunchtime," he said. "If you've got a busy day and have to race out and produce a sperm specimen rather than have a sandwich and read the paper, it's an ask."

Melbourne IVF infertility counsellor Jenny Blood said clinics across Australia were struggling for sperm.

"It's not an easy thing to do," she said. "(Men) have to go through a medical interview, be seen by a counsellor, have blood tests - which is often when men start to have second thoughts.

"They have to have sperm analysis and they have to have time to visit the sperm bank a number of times."