

Inquiry into Donor Conception in Australia

Submission to the Standing Committee on Legal and Constitutional Affairs

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1. Recommendations

The Committee should frame its recommendations for changes to the current arrangements for donor conceived Australians in terms of the broad guiding principles of openness, honesty and disclosure. Reform guided by these principles is required in order to replace the failed policy of secrecy and lies that has led to parents being afraid to disclose the truth to their children. This policy failure has also created discriminatory practises whereby donor conceived people are denied full information about their genetic identity, including such basic information as who they are, and who they are related to. An intermediary service is required that is adequately resourced to provide counselling to assist donor conceived people, donors and their respective families.

- 1) The preservation of all records linking donor conceived people to their biological identity and kin, including important information such as medical history, should be given paramount priority. All records pertaining to donor conception should be compulsory acquired and protected in perpetuity in a National Donor Register. A National Donor Register will be able to keep track of donors who move interstate and may have donor children across several states. Where records have been destroyed, past donors should be encouraged to add their details to the Register via a Public Education campaign. They should have the option to undergo free DNA testing to assist in matching them to their biological relatives. Legal children of donors should also be encouraged to add their details to the Register.
- 2) Federal legislation should be enacted allowing all donor conceived persons aged over 16 to apply for information about their biological donor parent(s) and siblings on the newly created National Donor Register, regardless of when they were born. This information should be available earlier with the consent of the child's legal parents.
- 3) The keystone to the functioning of a reformed system based on openness and honesty is resourcing the Authority managing the National Donor Register to offer donor linking services with specialised counselling available in each state to any person who requests it. The Authority must be properly resourced to employ counsellors who are able to act as intermediaries, facilitating contact between donors, donor conceived people and their half-siblings. The Victorian Infertility Treatment Authority could be used as a best practise model for providing such services to donor conceived people, donors and their families.
- 4) If cost is a barrier to the government providing counselling services to those affected by donor conception, the Committee could consider the paradigm of infertility treatment clinics contributing towards the cost of providing these services, in recognition of their duty of care towards the people they helped create.
- 5) In cases where donors do not agree to voluntarily release identifying information about themselves to their offspring after counselling provided by the intermediary service, they should be advised of their right to place a 'contact veto' on their donor register record, which applies only to themselves and not other members of their family, similar to provisions of the NSW Adoption Act.
- 6) After donor-linking and counselling has been supplied by the intermediary Authority, donor conceived people should be permitted to apply for identifying information about their donor, but be required to comply with any contact vetoes placed by the donor. This process should also apply in the reverse when a donor is seeking information about their donor offspring.

- 7) Donor conceived people should have the right to apply for information about their half-siblings via the intermediary Authority. In cases where information within the records is insufficient to locate the half-sibling, the Authority should contact the parents of the half-siblings.
- 8) That National Donor Register should be linked to the Registers of Births, Deaths and Marriages so that birth certificates of donor conceived people will have an appended note available only to the donor person, which gives information about the nature of their conception. This process has recently been enacted in Victoria as per the provisions of the Assisted Reproductive Treatment Act.
- 9) People deserve at least as much protection as embryos. Public information should be available as to the adherence or otherwise of assisted reproductive treatment clinics to NHMRC guidelines as per the requirements of the Research Involving Human Embryos Act. Accreditation of assisted reproductive treatment clinics should be conducted by an independent licensing committee who are obliged to regularly report to government on key issues such as information collection, use of anonymous gametes, and number of children born from each donor.

2. My Story

One afternoon in early January 2005, when I was 21 and my sister 24, my mother sat us down and said she had something to tell us. She sat on the creased leather couch, eyes downcast, hands shaking softly. In an awkward conversation she revealed the truth, that we were both donor conceived. Finding out so late was a huge shock. My identity was splintered and the social and biological aspects of parenthood carved up. I learned my biological father was a vial of frozen sperm labelled C11.

For the next three years I didn't discuss being donor conceived, but I thought about it a lot, almost every day. I mourned the human face behind that vial, somebody I had never and would never meet. I wondered about my missing kin, who they were, what they looked like and where their interests lay. I empathised with people whose relatives have gone missing. They don't know if they are alive or dead, happy or miserable, and when, if ever, they might see each other again. It is important to recognise that the impact of the status quo is not benign. It can place children in an awful limbo. I thought about carrying this burden for the rest of my life and I was afraid.

In the early days I had only a vague notion of the laws governing my situation. I knew enough to know the law gave me no protection and I was held liable to a promise of anonymity that I had never agreed to. Eventually in 2007 my mother wrote to the Infertility Treatment Authority who revealed non-identifying information about my donor and the existence of three half siblings, two boys and a girl born in Dec '81, July '84 and Aug '81, all to separate families. My sister joined the voluntary register, but there were no matches.

Things began to change when for the first time I met other donor conceived people, through an organised called Tangled Webs. I could finally talk about the questions I dared not articulate to my family and people who didn't have a personal experience of my situation.

As my awareness of the legal situation increased, so did my sense of injustice. I found it incredibly frustrating that the ITA had my donor's name, but were not empowered to write to him on my behalf because of a lack of legislation. Eventually I found a loophole by writing to the actual doctor who facilitated my conception who had since gained high status in the Victorian community. I

found this doctor to be a man of high integrity who actually listened to my concerns. In July 2009 he emailed to tell me he had sent the letter. However he could have easily made the opposite decision. A common theme of being donor conceived is being powerless, and beholden to other people's decisions when it comes to crucial information.

After that things moved quickly. Just a few days later he received a response from my donor. In fact, I never again had to refer to him as my donor. He has a name and it is Ben. I was most fortunate in that I found myself in the capable hands of the counsellors at the ITA, who were wonderful in helping Ben and I forge our fragile connection. We exchanged letters and photographs and talked on the phone. In November 2009 I went to visit him for the first time and met his teenage children, my half siblings, two girls and a boy. I was very nervous prior to the meeting, but when I arrived I felt at ease. We all share many characteristics, both in appearance and temperament, and even mannerisms.

The overwhelming feeling I took from this meeting was relief. Relief that I had found a small chink in the imposing wall of legal structures designed to separate me from truth. Most of all, relief that I finally had answers to questions about the source of my personality and interests and no longer faced an uncertain future of missing knowledge concerning my biological heritage and identity.

I still feel tremendous empathy for other donor conceived people who don't have the opportunity to make contact with their kin. Driven by the injustice that some donor conceived people are still second class citizens when it comes to basic personal information motivated me to seek redress through the political system. I also want to send a message to my three lost half siblings or their parents who might be reading this submission. I hope someday we can meet. I miss you and I am waiting for you.

3. (a) Donor conception regulation and legislation across federal and state jurisdictions

Conflict with Natural Justice/ Procedural Fairness

Everyone has essentially the same need to know about their genetic, medical and social identity and heritage. Donor conceived people are currently being discriminated against depending on arbitrary factors such as their mode of conception and when and where they were born. This situation is grossly unfair and therefore untenable. All donor conceived people should be given the same rights, and not discriminated against based on what state or what year we were born.

The issue of liberalising access to information about biological identity to a group who have previously been denied this information is not unprecedented. In 1984 the Victorian Parliament made the groundbreaking decision to give ALL adoptees access to their adoption files, regardless of previous assurances of anonymity, because this was in the best interest of the child. This legislation was so successful it was subsequently copied around Australia.

4. (b) (ii) Management of data relating to donor conception

National Health & Medical Research Council (NHMRC) Ethical Guidelines

Currently there is no way of knowing if clinics are abiding by the NHMRC guidelines because the accreditation process is opaque. The government who funds them is not privy to the accreditation.

An embryo licensing committee (offshoot of the NHMRC) checks that clinics are abiding by the Research Involving Human Embryos Act and must report every six months to the federal government. There are no auditing of other clinic practices and no report to government on key issues such as information collection, use of anonymous gametes, and number of children born from each donor. Surely people deserve at least as much protection as embryos. **Public information should be available as to the adherence or otherwise of assisted reproductive treatment clinics to NHMRC guidelines.**

Locating Past Donors

From my conversation with staff at the Victorian Infertility Treatment Authority, the general consensus is that locating past donors is not difficult. The normal procedure is for the Authority managing the Register to check the donor's name against the non-public Electoral Roll. In my personal case, this procedure was successful in locating the current address of my donor, even though he has a very common surname.

When information to locate individuals on the Register cannot be found via the Electoral Roll, a past practise of the Infertility Treatment Authority was to subcontract these more complex searches to VANISH who have systems in place to conduct more complex searches. VANISH have been providing search and support services for adoptees and other people who have experienced separation from family of origin (e.g. Forgotten Australians) for over 20 years.

5. (b) (iii) Provision of appropriate counselling and support services

In my own personal experience the availability of counsellors who are experts in the issues related to donor conception is crucial to reducing the stress and nurturing tenuous connections between close biological relatives who are social strangers. It is unreasonable to expect donor conceived people and donors to approach each other directly, and this scenario will likely be a huge source of stress for the people involved, and their families.

Services Provided by the Victorian Infertility Treatment Authority (prior to 2010)

- Counselling available for ALL donor conceived people and their families
- Counselling available for ALL donors and their families
- Donor Linking: Providing expert counselling to address the concerns of donors and their families, and discuss their options to consent to release of information and/or contact with their biological offspring.
- Mailbox Service. Acting as an intermediary to allow donors and offspring to exchange letters, in cases where one or both parties do not yet wish to reveal their identities

There is much to learn from the experiences of the donor linking programs that have been running within the Royal Women's Hospital (Melbourne IVF) since 2001, and the Infertility Treatment Authority since 1998. They have found that that the vast majority of donors who have been contacted are receptive to providing information to their offspring.

6. (d) The rights of donor conceived individuals

It is generally accepted that the rights of children born from Assisted Reproductive Treatment procedures are paramount. The Australian Health Ethics Committee (AHEC) recognises that “*the welfare of people who may be born as the result of ART is paramount.*” (pg 9). The first guiding principle of the Victorian Assisted Reproductive Treatment Act is, “*(a) the welfare and interests of persons born or to be born as a result of treatment procedures are paramount;*”

My personal experience as a donor conceived person, and the testimony of many other donor conceived people is the systematic denial of information about our genetic, social and medical history can have a large impact on people’s lives and potentially be a source of grief and great psychological distress.

The only fair solution to this situation is to allow **all** donor conceived people to apply for information about their biological identity and kinship links, regardless of when or where they were born.

Furthermore, the Committee should consider that donors are likely to act as a conduit for controlling information about the existence of their donor children from other members of their family. Donors should without question be able to decide if they want to have contact with their donor children, but should not be given the power to make this decision on behalf of other members of their family. For example, a donor may not want contact with his donor children, but his legal children, or his parents may wish to have contact with their biological half-siblings or grandchildren.

Giving donors the right to veto the release of information effectively means giving them the right to decide that every member of their family should be denied the chance to get to know and form a relationship with a close biological relative.

In the continuum of the adoption precedent, not wanting contact is insufficient reason for either party to be denied information about the other. However the Committee may wish to consider that a small percentage of donors may have a strong wish not to be contacted by their donor children. In these cases, a compromise option would be the availability of a contact veto similar to the provisions in the NSW Adoption Act 2000. This would require the applicant to sign an Undertaking Not To Make Contact before the Authority can release identifying information about the other party. The contact veto prevents the person receiving the information, (or anyone on their behalf) making contact with the other party.

APPENDIX

i) Effect of legislation changes on donor programs in Victoria

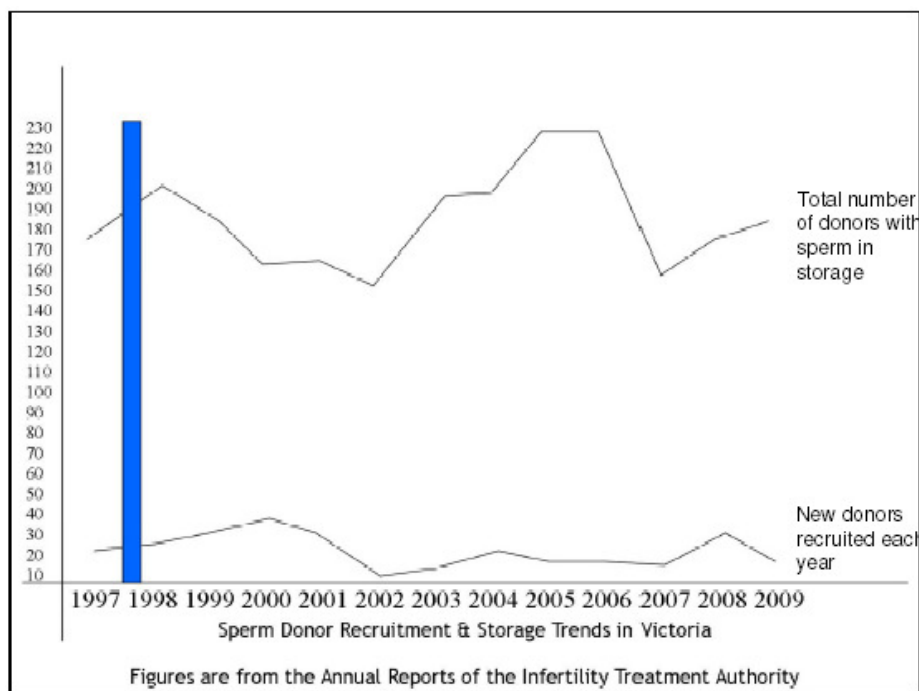



Figure 1 Effect of Legislation Changes on Donor Programs in Victoria

The blue line indicates when the Victorian Infertility Treatment Act came into force in 1998 (mandating all new donors must be prepared to be known to their donor children when the offspring turned 18). The graph clearly shows that ending donor anonymity has not caused donor numbers to drop below 1998 levels, but the recruitment of new donors goes up and down on a regular basis.

ii) Attitudes of donors toward their donor children

**VARTA**
Victorian Assisted Reproductive Treatment Authority

Register Activity in Victoria 2006 - 2009

Pre-1988 Voluntary Register

Donors 66
Recipient Parents 20
Donor Conceived People 42

Post-1988 Voluntary Register

Donors 77
Recipient Parents 79
Donor Conceived people 4
(This figure is very low because they are not able to register until they are 18 yrs.)

From the experiences of the Donor Conception Support Group and the Victorian Assisted Reproductive Treatment Authority it is a myth that donors donate and then forget. They care about the results of their donations; they wonder what these children are like and whether these children think about them. This is also the experience of the Victorian Assisted Reproductive Technology Authority. As well as 143 donors registering in this time period the Authority also contacted a further 43 donors on behalf of donor offspring. The vast majority of these donors were happy to share information, many also went on to have communication and some met.

VARTA has also contacted 43 donor not on the registers on behalf of donor conceived people born after 1988. In all but a very few cases the donors agreed to release information to the applicants. Many also exchanged letters through VARTA. Some later exchanged identifying information and met.

In the experience of VARTA donors have very similar questions to those asked by donor conceived people and their parents. They include:

- Who am I related to?
- How many people exist as a result of my donation?
- How old are they? What gender?
- Are they healthy? Are they happy? Are they loved?
- Do they look like me? Are they like me in personality?
- Have they been told about their donor conception?
- Why do they want to contact me?
- What will they think of me?
- What if they don't like me?

iii) Research - The Voices of Adult Offspring of Sperm Donation

The Voices of Adult Offspring of Sperm Donation: Forces for Change within Assisted Reproductive Technology in the United States

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Objectives

To provide an in-depth analysis of offspring attitudes toward their means of conception and the practice of sperm donation in the United States.

Design

Exploratory study.

Interventions

46-item questionnaire created by authors.

Materials and Methods

Participants were recruited through an online support group for adults conceived through sperm donation. Eighty-five (85) offspring between the ages of 20 and 65 voluntarily completed the questionnaire which was provided through a link to an online site.

Main Outcome Measures

Demographic data and statistical analyses of responses from the questionnaires.

Results

I. Attitudes toward means of conception (descriptive information)

A. Were evenly distributed from 'very bad' to 'very good'

B. A majority...

1. learned of their donor conception over the age of 18 in a planned conversation with their mothers.
2. had little to no information on their donor.
3. wanted to meet or obtain identifying information on their donors.
4. referred to their donor as 'biological father'.
5. had searched for their donor.
6. wanted to meet half-siblings.
7. would like donor's name on birth certificate.

II. Attitudes toward means of conception (statistical information)

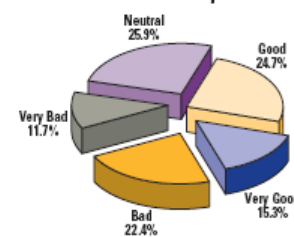
A. Showed significant relationships with three variables:

1. how they referred to their donor ('biological father,' 'donor,' 'donor dad') – ($p=.007$)
2. their perception of relationship with their mother from 'very poor' to 'very good' – ($p=.01$)
3. their perception of mother's mental health from 'very poor' to 'very good' – ($p=.01$)

Knowledge About Donor

Current knowledge		Desired knowledge	
Absolutely no information	50.0%	Meet donor once	35.7%
Some non-identifying information	40.5%	Establish relationship with donor	26.2%
Identifying information at 18	4.8%	Identifying information	25.0%
Extensive non-identifying information	3.5%	Non-identifying information	11.9%
Identifying information since childhood	1.2%	Nothing	1.2%
Searched for donor		Wanted to meet siblings	
Yes	80.0%	Yes	88.2%
No	20.0%	No	4.7%
		Undecided	7.1%

Attitudes Toward Means of Conception



B. Approached significance with one variable:

1. their perception of relationship with legal father from 'very poor' to 'very good' – ($p=.055$)

III. Attitudes toward the practice of sperm donation

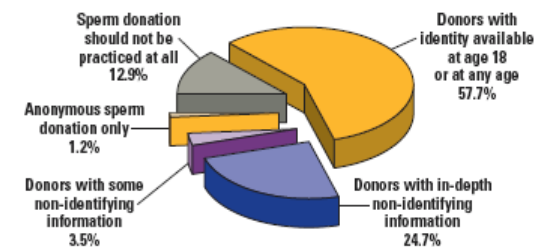
A. Would you use sperm donation as a means of conception?

1. no, would not use sperm donation 52.7%
2. yes, identity release sperm donation 15.3%
3. yes, anonymous sperm donation 8.3%
4. don't know 23.7%

B. Would you be an egg or sperm donor?

1. no 62.4%
2. yes 14.4%
3. don't know 23.2%

Attitudes Toward the Practice of Sperm Donation



Conclusions

Though conception is the **end** of treatment for physicians and patients, it is the **beginning** of life for donor offspring. As our respondents have communicated, they want to know *the truth*. They want their **parents** to feel safe in their donor choice and **confident** in their abilities to share it with them.

They emphasize that *decisions made prior to conception* concerning the choice of sperm donation impact many aspects of their future lives:

- A. Their attitudes toward the donor conception itself
- B. Their attitudes toward their parents
- C. Their accurate identity development
- D. Their abilities to make informed medical decisions throughout their lives
- E. Their options for locating the donor if they so need or desire.

The adult offspring in this study **encouraged providers of third-party reproduction** to:

- A. View donor conception as a *positive* option in which there is no need for anonymity or secrecy
- B. Encourage the use of donors who provide *identifying* information for offspring future needs
- C. Understand and acknowledge the *importance* of the donor to most offspring
- D. Integrate *counseling* into the sperm donation treatment plan in order for potential parents to...
 1. address the losses that preceed this choice
 2. learn more about the lifelong challenges of having a non-genetic offspring
 3. create parental confidence for addressing those challenges

Figure 2

Research on the attitudes of donor offspring – The voices of adult offspring of sperm donation (Mahlstedt et al. 2009)

