Ongoing Issues for Donor-Conceived People After the Assisted Reproductive Treatment Act 2008

Submission to the Parliamentary Law Reform Committee

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Note: I request notice of any public hearings to be conducted by the Law Reform Committee in regards to the donor conception enquiry.
1. **Recommendations**

The Law Reform Committee should frame its recommendations for changes to the current arrangements for donor conceived Victorians 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 some 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 30 September 2010 interim report should recommend the extension of the Donor Information Registers to safeguard pre-1988 records which do not have any special status and could be destroyed at any time. All records pertaining to donor conception should be compulsory acquired and protected in perpetuity. 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.
   
   a. The preservation of existing records which are the link for donor conceived people to important information such as medical history should be given paramount priority

2) Section 59 of The Assisted Reproductive Treatment Act 2008 should be amended to allow all donor conceived persons aged over 18 to apply for information about their biological donor parent(s) and siblings on the newly created Donor Information Registers. For the sake of clarity, it should be stated that this applies regardless of when the donation was made.

3) The keystone to the functioning of a reformed system based on openness and honesty is resourcing the Authority holding the records to offer donor linking services with specialised counselling. The Victorian Assisted Reproductive Treatment Authority should be reinstated as the Authority for all Donor Information Registers. VARTA should be properly resourced to employ counsellors who are able to act as intermediaries, facilitating contact between donors, donor conceived people and their half-siblings
   
   a. VARTA has a wealth of experience from its previous incarnation as the Infertility Treatment Authority that make it ideally suited to perform this specialised role
   
   b. Alternatively, an alternative organisation should be properly resourced to perform this same function
   
   c. Counsellors with specialised experience in this field are available within VARTA and within the donor conception program at the Royal Women’s Hospital (Melbourne IVF).

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.

2. Problems with the Current System

1. 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 the mode of their conception and when and where they were born. This issue has a precedent. In 1984 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 by all other states of Australia.

2. Conflict With the Government Sponsored “Time to Tell” Campaign
   The Victorian Assisted Reproductive Treatment Authority (VARTA) is responsible for an ongoing “Time to Tell” public education campaign. This campaign encourages parents to be open and honest with their children about their donor origins. The government message is confused. It promotes telling, but also says it is illegal to have information for the questions that will inevitably follow, forcing parents to make cruel choices about what to do.

3. Conflict With the Guiding Principals Of The Assisted Reproductive Treatment Act
   The guiding principles of the ART Act are listed in order of importance. The first principle is (a) the welfare and interest of persons born or to be born as a result of treatment procedures are paramount. The use of the word “paramount” means the welfare and interests of offspring is held above all others. The other relevant principle is (c) children born as the result of the use of donated gametes have a right to information about their genetic parents. Clearly the clauses of the ART Act denying people access to information about their genetic parents is in direct violation of both of these guiding principles.

4. Pre-1988 Donor Records Are Unprotected
   Pre-1988 donor records still held by clinics and doctors have no special status and like other medical files may be destroyed after 7 years, i.e. at any time. For many donor conceived people these paper records represent the last tenuous link to their genealogical identity and important information such as medical history. These records should be accorded a protected status in recognition of the important information they contain.

5. Individual Clinics And Doctors Are Being Forced To Make Policy Decisions Without Guidance From Legislation
   Royal Women’s (Melbourne IVF) have a policy of contacting pre-1988 donors at the request of their offspring, helping them to establish contact if this is mutually desired. Other clinics (e.g. Monash IVF) do not. Some clinics have closed down. This current system is not tenable because people are being discriminated against depending on where they were conceived. It should not be left to individual clinics and doctors to decide what to do, they require guidance from legislation.
6. Loss Of Counselling Services Previously Provided By The Infertility Treatment Authority

Donors and their families can no longer access counselling concerning their decision to consent to release of information. This service is crucial to provide the best outcome for the donor conceived people who require their donor’s consent to access information. Furthermore, under the new system offspring may first learn they are donor conceived via a letter from Births Deaths Marriages without redress to specialised counselling.

3. 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 people 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.

Terms of Reference Criteria (a) and (b)

(a) The legal, practical and other issues that would arise if all donor-conceived people were given access to identifying information about their donors and their donor-conceived siblings, regardless of the date that the donation was made;

(b) The relevance of a donor’s consent or otherwise to the release of identifying information and the National Health and Medical Research Council’s ethical guidelines on the use of assisted reproductive technology in clinical practice and research;

4. Summary - Terms of Reference Criteria (a) and (b)

- Prior to 1988 Victorian donors were not given a choice as to whether they wished to be anonymous or not. In order to be accepted as a donor, they had to agree to anonymity.

- The concept of the anonymous gamete donor was invented by the infertility treatment industry, without the authority of the Victorian judiciary or supporting legislation.

- Releasing identifying information to offspring would not contravene legislation, because Victoria never had a law that specifically gave donors the right to remain anonymous.

- The legality of donor contracts has never been tested in court. In the case of the Royal Women’s Hospital, releasing information to the offspring would not even necessarily contravene the terms of the donor contract.

- In the continuum of the adoption precedent, not wanting contact is insufficient reason for either party to be denied information about the other, as this can be dealt with as a separate issue. Knowledge about the identity of close biological relatives should not be compromised by the wishes of either party because the testimony of many people affected by donor conception indicates that denial of knowledge about genetic identity and kinship can cause grief and great psychological distress.
• All those involved are adults and people who do not want contact can simply make their wishes known. This could be done through the availability of contact vetoes as under the provisions of the NSW Adoption Act 2000.

• People should retain autonomy in their decision to form relationships with close biological relatives, e.g. a donor should not have the power to prevent his legal children from getting to know their half-siblings, which is a consequence of allowing vetos on release of information.

• Clinics must legally abide by the NHMRC guidelines only in relation to research on embryos because of the federal Research Involving Human Embryos Act. Otherwise they are guidelines and not legally binding.

• The NHMRC guidelines paragraph 6.1 states “Persons conceived using ART procedures are entitled to know their genetic parents.” (pg 25) and paragraph 6.13, “Clinics must not release identifying information to another person without the consent of the person to be identified.” (pg 29)

• The guidelines give no information on how to resolve the conflict where a donor conceived person wishes to know their genetic parent and the donor parent has not given consent to the release of this information, i.e. clearly paragraphs 6.1 and 6.13 cannot be simultaneously upheld. However 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 guidelines also state that access to further information beyond voluntary exchange of information exchanged between donor conceived people, donors and gamete recipients may occur as specified by the law (pg 25).

• 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 federal 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.

4.1 Legal Structures and the ‘Anonymous’ Donor

It is important to note that the concept of the ‘anonymous’ gamete donor – a person who provides genetic material to create a child but taking no further part in the child’s care or upbringing – was created by the infertility treatment industry in order to proceed with the technology of Artificial Insemination by Donor (AID). The concept was intended to allay confusion as to how the parental obligations contained within the Family Law Act applied to donors who were biological parents, and protect recipients of donor conception from donors claiming parental rights. In 1987 the FLA was amended to include a section on “children born as a result of artificial conception procedures” but it is not clear whether this change was retrospective.

In Victoria donor anonymity was never endorsed by a judicial authority, such as a judge, or by legislation. The only way that clinics could guarantee their promise of total secrecy and anonymity was by keeping poor records and/or destroying donor records. This may explain why both of these practices occurred prior to the 1984 legislation guaranteeing minimum standards of record keeping.
Despite the flimsy legal structures in Victoria underpinning the promise of donor anonymity, it is recognised that the practical outcome from this promise was that donors believed they would not be contacted by any of their donor biological children. This promise was unfair in that it impinged on the donor conceived person’s right to knowledge about their medical, social and genetic heritage and identity and the basic right to know who they are related to.

Infertility treatment clinics required donors and recipients (women who received artificial insemination by donor) to sign contracts. The content of these contracts was not standardised but varied between clinics. However the terms of these contracts were broadly similar between clinics.

An example of a donor statement and consent contract from the Royal Women’s Hospital dating from 1977 is shown in the Appendix (Figure 4). It can be seen that the contract focuses on the agreement not to disclose identifying information between the donor and the recipient, with the child barely mentioned. It is important to note the contract does not preclude disclosing the identity of the donor to the offspring.

The experience of the donor linking programs within the Royal Women’s, and the ITA is that with the passage of time, and donor conceived people now being adults, the vast majority of donors who have been contacted are receptive to providing information to their offspring. However the Committee may consider that a small percentage of donors may have a strong desire 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.

**Reasons for Rejecting a Veto on Release of Information**

i) **Removing Discrimination**

The current arrangement of secrecy and anonymity is not benign. The Committee should consider the testimony of people affected by donor conception, and the effect that denial of knowledge about genetic identity and close biological relatives has on people’s lives. All those involved are adults and those not wanting contact can simply make their wishes known. In the continuum of the adoption precedent, not wanting contact is insufficient reason for either party to be denied information about the other, giving consideration to the testimony that denial of this information can cause grief and great psychological distress.

ii) **Retaining Autonomy – Every Person Should Have the Right to Decide for Themselves**

The Committee should consider that donors are likely to act as a conduit for controlling information about their biological 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.
Clinics must legally abide by the NHMRC ethical guidelines on the use of assisted reproductive technology only in relation to research on embryos because of the federal Research Involving Human Embryos (RIHE) Act. Otherwise they are guidelines and not legally binding.

Paragraph 6.1 of the NHMRC guidelines states, “Persons conceived using ART procedures are entitled to know their genetic parents.” (pg 25) and paragraph 6.13 states, “People have a right to privacy. Clinics must not release identifying information to another person without the consent of the person to be identified.” (pg 29)

The NHMRC guidelines give no information on how to resolve the conflict where a donor conceived person wishes to know their genetic parent and the donor parent has not given consent to the release of this information. Clearly in this situation paragraphs 6.1 and 6.13 cannot be simultaneously upheld, and in a sense this is the vexed question at the heart of this Law Reform Committee enquiry.

However, similarly to the guiding principles of the ART Bill, 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 guidelines also state that access to further information beyond voluntary exchange of information exchanged between donor conceived people, donors and gamete recipients may occur as specified by the law (pg 25).

Although outside the terms of reference, it is worth noting that 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. There is an embryo licensing committee (offshoot of the NHMRC) which checks that clinics are abiding by the RIHE act who report every six months to the federal government. However there is no auditing of other clinic practices in regards to the rest of the guidelines. 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 on key issues such as information collection, use of anonymous gametes, and number of children born from each donor.
Any practical difficulties in releasing information about donors who provided their gametes before 1 July 1988, because in many cases records are not available either because the procedure was carried out privately or records were not stored centrally;

5. Summary - Terms of Reference Criteria (c)

- Pre-1988 Prince Henry’s donor records are physically located in the Public Records Office
- The Prince Henry’s records feature a Central Treatment Register dating back at least to July 1980 (possibly further) which contains the name of the recipient (commissioning mother) and the name & date of birth of the donor whose sperm she received
- The Central Treatment Register preserves the name and date of birth of the donor, which should normally be enough information to identify him
- The Central Treatment Register contains records of half siblings, by identifying which recipient received sperm from the same donor
- Royal Women’s Hospital (Melbourne IVF) have preserved their donor records
- Surviving Queen Victoria Epworth Hospital donor records are located at Monash IVF

5.1 Record Keeping

Prior to 1988 donor conception was carried out at three main infertility treatment clinics;

1) Prince Henry’s Hospital: Amalgamated ~1990 into Monash IVF, records were moved to Monash IVF and later the Public Records Office.
2) Queen Victoria Hospital (donors used by the Epworth hospital in Richmond): Amalgamated ~1990 into Monash IVF, records were moved to Monash IVF.
3) Royal Women’s Hospital (now Melbourne IVF): The only continuously intact clinic

Prince Henry’s Hospital Pre-1988 Donor Records

I am familiar with the story of the Prince Henry’s Hospital records because this was the clinic where I was conceived, and I spent some years tracking down these records for the purpose of learning the identity of my biological father.

Prince Henry’s Hospital closed in the early 1990s and was amalgamated with Moorabbin Hospital and the Queen Vic to Form Monash IVF. Records from the Prince Henry’s records were transferred to the Monash IVF premises. However at some point they were transferred to the Public Records Office where they remain today. They are physically paper records (i.e. not stored electronically).

The Prince Henry’s records feature a Central Treatment Register. The Central Treatment Register contains the name of each donor insemination recipient (commissioning mother), together with the name and date of birth of the donor whose sperm she received. I know that the Central Treatment Register dates back to at least July 1980 (possibly further), because it records the birth of my older sister in this month and year. The existence of the Central Treatment Register should ensure the completeness of the Prince Henry’s Records. Furthermore, the Central Treatment Register contains records of half siblings by identifying which recipients received sperm from the same donor. However it may only contain enough information to be able to contact the parents of half siblings, rather than the siblings themselves, since the name of the donor conceived child may not be recorded.
Other Pre-1988 Donor Records

The Royal Women’s Hospital (now Melbourne IVF) have preserved their donor records, and since about 2001 have run a policy of acting as an intermediary for pre-1988 offspring who wish to contact their donor.

From my friendship with other donor conceived people, I know that the Queen Vic Epworth Hospital records are in existence and stored at Monash IVF, although some of them may have been redacted.

Other records of donor insemination carried out by private doctors could be requested via a publicised amnesty system, with the option for dealing with this situation on a case by case basis, if a donor conceived person who wishes to make an enquiry can name the doctor who performed the donor conception.

5.2 Locating Past Donors

Summary

- The Authority managing a pre-1988 register (such as Births Deaths Marriages, or the Victorian Assisted Reproductive Treatment Authority) would have authority to search the non-public Victorian Electoral Roll. Normally this is sufficient to locate the current address of past donors
- In cases where this approach is not successful, expertise is available from VANISH, who have systems in place to conduct more complex searches, and 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

From my conversation with staff at the ITA the general consensus is that locating past donors is not difficult. If a Donor Register for pre-1988 records was created, the normal procedure would be for the Authority managing the Register (e.g. BDM or VARTA) to check the donor’s name against the non-public Victorian 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 Central Donor Registers or Voluntary Register could not be found via the Electoral Roll, a past practise of the Infertility Treatment Authority was to subcontract these more complex searches to VANISH. An agreement exists (dated from 2008) between VANISH Inc and the Infertility Treatment Authority to search for the location of a person about whom information has been sought, in relation to the Donor Information Registers.
Terms of Reference Criteria (e) and (f)

(e) the impact that any such changes may have on the donor, the donor-conceived person and future donor programs;

(f) the impacts of the transfer of the donor registers from the Infertility Treatment Authority to the Registrar of Births, Deaths and Marriages;

6. Summary - Terms of Reference Criteria (e) and (f)

- Since 1 January 1998 all new donors recruited by Victorian clinics have had to consent to the release of identifying information to their donor offspring after they turn 18. Therefore any changes to standardize this arrangement to include pre-1998 donor arrangements are unlikely to impact on future donor programs.

- Liberalising access to information will encourage openness, honesty and disclosure from recipient parents towards their donor conceived children, and from donors towards their family. It will also allow donor conceived people full information about their genetic identity including such basic information as who they are, and who they are related to, which will alleviate a potential source of much suffering and grief.

- Availability of specialised counselling is crucial to the success of any reform to liberalise access to information in donor conception.

- From 1 January 2010 the donor registers were transferred from the Infertility Treatment Authority (ITA) to Births Deaths Marriages (BDM), with services to be provided by the Adoption and Family Records Services (AFRS)

- This resulted in the loss of services previously provided by the ITA, which are currently not replicated by either AFRS or the Victorian Assisted Reproductive Treatment Authority (VARTA). This has been a huge blow for donor conceived people and donors who are seeking information and connections.

- 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.

- The issues of donor conception are similar, but not the same as adoption, and it is inappropriate to refer donor conceived people to counsellors who have expertise only with the adoption experience. A wealth of donor conception counselling experience is still pooled within VARTA and the Melbourne IVF donor conception program.

In my own personal experience the availability of counsellors who are expert in these issues is crucial to nurture 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.
6.1 **Services Provided by the ITA 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

6.2 **Services Provided by BDM and AFRS after 2010**

- Persons making an application to access the donor registers are seen once by AFRS. However this session will not relate to their personal circumstances and will be a more generic notification of what their rights are in regard to access to information
- No counselling upon request available for donor conceived people or their families
- No counselling available at all for donor conceived people born prior to 1988 who are not eligible to make an application to access the donor registers
- No counselling available for donors and their families
- No donor linking. When a person makes an application to the donor register a letter is sent to the donor asking for a Yes/No response as to whether they consent to release identifying information to their offspring, without the opportunity for them to discuss the implications. If they respond ‘Yes’ their details will be passed onto their offspring who will then be put in the scary situation of having to make the first contact themselves
- No mailbox service
- In cases where a donor makes a request to contact their offspring, a letter to this effect will be sent to the offspring, **regardless of whether they are aware they are donor conceived**. This may be doubly damaging because a person who finds out they are donor conceived in this manner will also no longer have access to counselling from a specialised provider such as the ITA.
7. **Terms of Reference Criteria (g)**

*(g) The possible implications under the Charter of Human Rights and Responsibilities Act 2006*

The LRC should consider that the Charter incorporates the principles of the International Covenant on Civil and Political Rights which guarantees that all people be guaranteed equal and effective protection under the law against discrimination on any ground, including birth or other status.

7.1 **Section 8: Recognition and equality before the law**

The LRC should consider the principal of procedural fairness, which is an implied right in the Australian Constitution and stated in Section 8 of the Charter. Donor conceived people are discriminated against by the nature of their birth as they are the only group of people who are actively denied the right to know the identity of their biological parents even when this information is known and recorded.

Donor conceived people are discriminated against depending on their age (prohibited by the Equal Opportunity Act), because of the arbitrary cut-off dates as to who is eligible to apply for information. Those born before July 1988 suffer the worst discrimination, in that they are denied any avenue to apply for information regarding the identity of their biological donor parent, in contrast to donor conceived people who are born in the present times.

7.2 **Section 13: Privacy and reputation**

The Charter states

*A person has the right: a) not to have his or her privacy, family, home or correspondence unlawfully or arbitrarily interfered with;*

The right to privacy is not an absolute right, and must be balanced against competing rights, including the right of offspring not to suffer discrimination, and have information about their genealogical identity. Providing donor offspring with this essential information is not an arbitrary interference with privacy.

Donors and offspring should have the right to place a contact veto on their information in the Donor Information Register, in cases where they do not wish to be contacted. However, this should not prevent the release identifying information

7.3 **Section 19: Cultural rights**

The Charter states

1) *All persons with a particular cultural, religious, racial or linguistic background must not be denied the right, in community with other persons of that background, to enjoy his or her culture, to declare and practise his or her religion and to use his or her language*

One of the consequences of denying donor conceived people information about their biological donor parent, is they are denied information regarding their cultural, religious, racial and linguistic background, and hence, the right to enjoy this culture.

The only way to ensure all persons are allowed to enjoy their cultural identity is to provide them, on request, with information on their biological donor parent
**APPENDIX**

**i) Summary of Current Legislation**

<table>
<thead>
<tr>
<th>People Conceived From Gametes Donated...</th>
<th>Legal Rights for Donor Conceived People</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prior to 1 July 1988</td>
<td>No access to identifying information about their donor parent. Voluntary Register</td>
</tr>
<tr>
<td>Between 1 Jul 1988 – 31 Dec 1997</td>
<td>Can access the identity of their donor parent as long as the donor consents to the release of this information</td>
</tr>
<tr>
<td>After 1 Jan 1998</td>
<td>Unqualified right to access the identity of their donor parent</td>
</tr>
</tbody>
</table>

Figure 1  Summary of the current Assisted Reproductive Treatment Act

**ii) Effect of Legislative Changes on Donor Programs in Victoria**

The blue line indicates when the Infertility Treatment Act came into force (mandating all new donors must be prepared to be known to their donor children when the offspring turned 18). The graph clearly shows that donor numbers are not dropping but go up and down on a regular basis.
iii) Attitudes of Donors Toward Their Donor Children

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?
iv) Example – Donor Statement and Consent Form 1977

DONOR STATEMENT & CONSENT

To: Doctor Johnston
AND To: The Royal Women’s Hospital

1. I offer my services as a donor of semen with the understanding that it is your intention to use my semen for purposes of artificial insemination.

2. I understand that the identity of any recipient shall not be disclosed to me, nor shall you voluntarily reveal my identity to any recipient.

3. I am of theage...years.

4. To the best of my knowledge and belief:
   (a) I am in good health and have no communicable disease, and I do not know that I ever suffered from any physical, mental or psychological impediment, disability or abnormality, whether inherited or as a result of any disease, illness or accident except as follows:

   (b) None of my relatives have ever suffered from any inheritable diseases except as follows:

5. For the purpose of determining whether I am acceptable as a donor of semen, I consent to a physical examination including the taking of blood and other bodily fluids, by you or any other doctor or medical worker upon whom you may designate.

6. I agree never to seek the identity of any child or children born following upon the artificial insemination of any recipient of my semen or seek to make any claim in respect of any such child or children in any circumstances whatsoever.

Dated this 11th day of October 1977

SIGNED by

in the presence of:

... witness...
Figure 4  Donor statement and consent form – Royal Women’s Hospital 1977
v) 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 limited information on their donor.
   3. wanted to meet or obtain identifying information on their donors.
   4. referred 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)

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%

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 impacts 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 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 lessons that proceed this choice
   2. learn more about the lifelong challenges of having a non-genetic offspring
   3. create parental confidence for addressing those challenges.

Figure 5 Research on the attitudes of donor offspring – The voices of adult offspring of sperm donation (Mahlstedt et al. 2009)