

## LAW REFORM COMMITTEE INQUIRY

### Inquiry into Access by Donor-Conceived People to Information About Their Donor

#### Submitted by Kate Bourne

Thank you for giving me the opportunity to tender this personal submission as an Infertility Counsellor who has been working for the past eighteen years in Donor Conception practice. I have worked for the two major IVF clinics in Melbourne, Monash IVF and Melbourne IVF, where I counselled donor egg/sperm/and embryo recipients, donors and their partners, facilitated groups for mothers who have used donor eggs and single women who have used donor sperm to have their children. I have written the book, "Sometimes it Takes Three to Make a Baby- Explaining Egg Donation to Young Children", and spoken at Donor Parent Seminars to assist them to talk to their children about their donor conception. I have served on the Board of Directors of the Fertility Society of Australia, and currently on the Australian and New Zealand Infertility Counselors Association Committee.

More recently I have specialised in donor-linking counselling and worked in this capacity at Melbourne IVF with a pre-1988 donor-linking program and later at the Infertility Treatment Authority (ITA) providing counseling to those making applications to the Donor Registers and those contacted as a result of an application. I now work as a community education officer at the Victorian Assisted Reproductive Treatment Authority (VARTA).

**(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 the donation was made.**

Victorian legislation essentially creates three differing entitlements for donor conceived people to information about their donor. Two Central Registers and two Voluntary Registers exist, covering different time periods. If the donor signed consents prior to 1988 the only legal option to gain information is to make an application on the Pre-1988 Voluntary Register and hope that the donor has also applied and there is a corresponding link. Options falling outside this remain dependent upon where the donor-conceived person's mother accessed her treatment. If she received treatment from the Royal Women's Hospital, assistance is provided by their counselling service provided by Melbourne IVF, to contact the donor their behalf and request information. If treatment occurred elsewhere this option is not possible. If treatment took place at Prince Henry's the records are stored at the Office of Public Records, however only the treating doctor has legal authority to contact the donor. If treatment was performed at the Epworth Hospital, current Monash IVF policy does not support contacting pre-1988 donors. It is hoped that this clinic policy may change in the future.

If the donor signed consents after 1988 and prior to 1998 then it is possible to make an application to the Central Register and request the donor to give consent to identifying information. If the donor signed consents post 1998 then there is automatic entitlement to identifying information after the donor-conceived person reaches 18 years of age. In 2016, the

first of donor-conceived people conceived within this legislation will be able to apply for information. Parents can apply on behalf of their children prior to this date; however the donor's consent is required before information is released. Identifying information about genetic half siblings is only given with consent only after a Voluntary Register link is made, regardless of when the donor signed consents.

Consequently, this complexity of time periods of the legislation and variance in assistance provided by different infertility clinics, gives rise to vast disparity in eligibility to information, much confusion about entitlement to information and to which Register to apply to. It means also that siblings from the same family can have differing rights to information about their donor.

I support the right of the donor-conceived person to have full information about their genetic origin. This is in accord with Article 26 of the International Covenant on Civil and Political Rights and Article 7 of the United Nations Convention on the Rights of the Child. In my professional experience donor-conceived people have normal, appropriate, healthy non-pathological questions regarding their donors and their genetic siblings. They often want to know:

- Who am I related to?
- What is my donor like? For example, appearance, personality, interests, occupation?
- Are we alike in any way?
- Why did my donor donate?
- Does my donor know I exist?
- Does my donor ever wonder about me?

I believe these are reasonable questions and deserve to be answered or at least put to the donor. Not having the opportunity to resolve these questions can cause much distress.

If all donor-conceived people were given access to identifying information regardless of the date their donor signed consents to donate, this would in fact simplify and harmonise this legal disparity. There is of course a precedent for introducing retrospective access to identifying information when legislation introduced in 1984 gave adoptees the right to access identifying information. Great anxiety surrounded the introduction of retrospective adoption legislation however, it is now well accepted that adopted people have needs and interest in information about their birth parents and vice versa. It is now considered conventional practice and most of us know someone who has traced their birth family and the many positive outcomes of this. Where outcomes have not been positive there has at least been some resolution and knowledge of origins. It is my hope that donor-conceived people, their parents and donors will also have similar entitlements and that such linking will become as common place and mainstream as adoption linkages are today

**(b) The relevance of a donors consent or otherwise to the release of identifying information and the National Research Council's ethical guidelines on the use of assisted reproductive technology in clinical practice and research.**

It is often argued that as donors did not give consent to the release of information; this should be respected and that legal impediment takes precedence over donor-conceived people's right

to access information. Many argue that donors have a right to anonymity; however, do we really know this is what donors really want? Surely it is courteous to ask them rather than presume their wishes have remained unchanged in the many years since they donated. In my experience from contacting many donors (including donors who donated prior to the 1988 legislation when I worked at Melbourne IVF) in fact many do not necessarily wish to remain unknown. Donors, in my professional experience, have been only too willing to give information and make themselves available to be contacted and appreciate the genuine need for this information by the people they helped create. Most have been expecting they would be contacted as they anticipated a need for more information about them.

Donors also have needs and interests in knowing who they are related to. Many donors have also spent years wondering about the people they helped to create. Most do not know the outcome of their donation and who was born. How old are they? And what gender? They wonder if they are healthy and happy, if they look alike or have characteristics in common, and question if they were well loved and looked after. Binding them to consents they signed many years ago, forbidding them to request information about the people they helped create is also unjust. They deserve to be asked what their current wishes are rather than automatically assuming they will prefer to remain unknown.

In my experience, even when donors have not been comfortable to provide identifying information, they have often been prepared to provide important non-identifying information giving specific medical and genetic information and background information about their personality, interests, occupation etc. This was vital information for the donor-conceived person. Many have been prepared to communicate this information by letter if it was forwarded via an intermediary. In time this would often lead to providing identifying information once the donor felt more comfortable and had a sense that he knew the donor-conceived person and trusted them. In the rare instances that a donor was not comfortable to provide any information whatsoever, this at least provided some resolution to the donor-conceived person rather than wondering without the possibility of any outcome.

**(c) 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 not carried out privately or records were not stored centrally.**

In the early days of donor conception practice records were not kept or limited information was recorded. It is vital to preserve any of the records which do exist. This is exacting work requiring specialised knowledge to be able to interpret the records. Where no records are in existence the only option may be to have a DNA bank of donor-conceived people and donors to establish genetic links in this way. Great care will need to be taken so that genetic connections are properly verified.

**(d) The options for implementing any changes to the current arrangements, including non-legislative options.**

**Option 1.** Change legislation to reflect 1995 legislation giving all donor-conceived individuals access to identifying information from 18 years of age.

**Option 2.** Change legislation to reflect 1984 legislation giving donor-conceived people the right to request identifying information however this is given only with the consent of the donor.

**Option 3.** Fund IVF clinics to provide a donor-linking service similar to the Melbourne IVF model in which donors are contacted and consent required prior to information release. Give Authority to a private clinic or appropriate service to administer Prince Henry's records and any others available.

All of these options have significant merit and could work effectively. Option 2 and 3 are similar as the consent of the donor is required prior to the release of the donor. Realistically for Option 1 to work in a satisfactory way for the donor-conceived person; the donor would need to agree to contact and/or information exchange as knowing the donor's identifying details does not equate to meaningful contact/information without the donor's co-operation. It is of vital for any option to work effectively that the donor is contacted considerately, fully informed of his options in a sensitive manner and respecting of his privacy and decision.

These options are contingent, however, on an effective donor-linking counseling service to 'broker' the transmission of information. Donor-linking counselling needs to be an integral component of any process for accessing information both for the person applying for information and the person they wish to contact. This should be provided only by specialised counselors in this field.

### **Donor-Linking Service Model**

The Donor-Linking Counsellor should explore the following implications:

- The hopes, motivations and expectations of the person requesting information in the short and longer term.
- A statement of these should be developed as authorised by the client; to relay to the other party.
- The possible outcomes as a result of the enquiry i.e. no information is available, the other party is unable to be located or doesn't respond, the other party declines to give consent to information, or the other party consents to information release.
- If the other person does agree to exchange information, how would the person like to begin to communicate e.g. by letter, email, telephone or meet. What information are they prepared to give/receive? Do they want specific information e.g. medical/genetic or do they hope to form a relationship. What are expectations of this communication? Would they like to communicate annually only or would they be open to more regular contact and if so how often?

Other parties affected, such as partners, parents and children, should also be offered counselling. The counselor acts as a mediator/facilitator until an agreement is reached or it becomes clear that this will not occur. Short term counselling should continue to be offered to support the parties through the initial phases depending on what has transpired and the client's reaction to this. Young donor conceived people are still likely to find the process emotionally confronting even though they may have initiated the contact. Their parents are also likely to be affected. As contact between donors and the people they have helped to create is still very new; people do not know what is considered 'appropriate' and often have difficulty communicating initially.

As mentioned previously, many clients find it useful to communicate via an intermediary. The donor-linking counselor prepares a list of questions formulated by the donor-conceived person to pose to the donor that are of significant importance to them if the donor is not prepared to give consent to releasing their full identity. For example, the donor may be prepared to answer these and might write a letter which is then forwarded on by the Donor-Linking Counsellor rather, than providing identifying details immediately. This enables the parties to get to know each other safely. Donors are often initially suspicious about releasing information until they feel they can trust the other person. Donor-conceived young people are often quite wary about having direct contact with their donor until they get to know them. For these reasons, parties often prefer to get to know each other by writing until they do not feel like strangers and feel comfortable and safe enough to meet. For some, this is enough and they have no wish to ever meet but are very grateful to have more information, for example, medical/genetic information.

This contact through an intermediary may appear to be quite involved but in practice the role of the Donor-Linking Counsellor is to convey the wishes of each party to each other get the arrangement going and then retreat into the background and only re-enter momentarily, if there are concerns, and again retreat as soon as possible. This model closely reflects sound Adoption Linking practice.

### **Contacting Genetic Siblings**

As many donor-conceived people have not been informed of the details of their conception great care needs to be exercised to sensitively manage an outreach for information on behalf of their donor-conceived sibling. This is similar to the sensitivity required when a donor makes an application for information about their genetic children. This approach should also be provided by a donor-linking counselor who could contact the parents initially to establish whether the young person has already been informed and if not guide them carefully through the process of telling their child and informing them of the application for information about them. This prevents the donor-conceived person from discovering they were donor-conceived from a letter from a government body.

### **(e) The impact that any such changes may have on the donor, the donor conceived person and future donor programs.**

Naturally any change to legislation needs to be accompanied by appropriate education and support to those affected by it: Donor-conceived people, parents and the donors and respective partners and families. Many donor-conceived people are unaware of their origins and consequently of their entitlements to information. Their parents have often been reluctant to inform them of their origins, if they cannot also provide information about their donor as they fear this may do more harm than good and send them on a fruitless quest for information they will never find. Some parents feel insecure about their children being able to find out more about their donor and fear rejection by them as a result. As in adoption practice this rarely occurs. Donors and their partners and children are also likely to be highly anxious about the changes and will need sensitive education and support as to the possible implications of these. VART A would be the most appropriate organization to assist with public education about any changes to legislation.

**(f) The impacts of the transfer of the donor registers from the Infertility Treatment Authority to the Registry of Births, Deaths and Marriages.**

Whilst the changes under the new Act were, I am sure, very well intentioned there have been unfortunate operational consequences as a result of this. The main concern is the separation of the **administration** of the Donor Registers to the **service provision and counselling** component rather than this service operating from the same organization and providing a more integrated service.

The Registry provides the administration of the Donor Registers. There is inadequate support for people considering making an application to the Registers. This is a big step for people to take and they often require very sensitive information and support. They need to consider such issues as what register do I apply to, what information can I request/am I entitled to, what do I hope to achieve from my application, what are my options, is this the right time for me to apply.

The counseling required under the The Assisted Reproductive Treatment (ART) Act 2008 is currently provided by the Adoption and Family Records Service (AFRS). As this is a separate body from the Registry, due to privacy restrictions, the Registry is not able to communicate the particular situation of the applicant to the AFRS counselors. Therefore the counsellors are not able to be given any background information about the person or who the person the applicant is linked to even though they will be counseling each party. They are not in a legal position to convey to the other party the motivations and aims of making the application. This means the counseling provided can then be generic only and not truly 'donor-linking' as the counselor is unable to work effectively as a facilitator/mediator to broker an arrangement that is acceptable to both parties. This is a highly unsatisfactory situation for the applicant and the outreached party. This means that the person who has been contacted as a result of an application has no information upon to make their decision whether to give consent to release information. The applicant is also not informed of the preferred wishes of the person they want to contact to guide them as to their preferences. A donor-conceived person unaware they are donor-conceived as their parent has not informed them, can be contacted as a result from an application by their donor; and discover their origins by a letter from the Registry with no specialised counseling or support provided.

Following the counseling as required under the Act, AFRS notifies the Registry that this requirement has been fulfilled and the Registry contacts the affected parties by letter only.

Due to funding constraints there is no counseling apart from the one generic session to support the early stages of the parties' early exchange of information. If the outreached party declines to give their consent there is no support or explanation as to the reason, for the applicant. In addition, no intermediary service is provided to forward letters between parties so that they can communicate together without releasing their private details.

Previously when the Donor Registers administration and service provision was provided by the Infertility Treatment Authority (ITA), it was possible to provide an integrated comprehensive service to donor-conceived people, their parents and donors, their partners and children. This was provided from first point of enquiry, to application, to counseling to mediating and facilitating a successful arrangement comfortable to both parties, to assistance and support to

navigate exchange of information and occasionally to facilitate a meeting between parties. As the ITA also ran the successful 'Time to Tell Campaign' it was possible to assist parents from helping them to talk to their sons and daughters about their origins, through to assisting a donor-conceived cope with this revelation, to considering finding out more about their donor and the resulting application process and contact, information exchange with the donor. If a donor made an application it was also possible to mediate an arrangement whereby with the donor's agreement, parents were given time to inform their children about their conception in a sensitive way and relay the outreach. This worked very effectively and no donor-conceived people were informed of their conception directly by the Authority during this time and were always informed by their parents.

As many parents of very young children ( particularly single and lesbian mothers) were accessing the Central Register early , this service translated into careful counselling of both the parents and their donors to a comfortable arrangement given parent's natural concerns about protection of their young children and the role of the donor in the child's life, and the donor's , and often his partner's, concerns of agreeing to a long term commitment when he is likely to be contacted by many parents and their children. (Donors routinely donate to 10 families)

This integrated service was also a very cost effective service. It was administered by a pro rata: 0.4 Donor Registers Officer and 1.2 Donor Linking Counsellors. This service was not reviewed prior to the changes occurring nor were the applicants or affected parties surveyed as to their level of satisfaction with the service before changes to the legislation were made.

Changes to the legislation have also resulted in a difference in information provided by the Registry to donor-conceived people and their parents. Under the previous legislation it was routine practice for donor-conceived people to be provided with non-identifying information about their genetic siblings. This included details of the number of other people conceived by the same donor, their gender, month and year of birth. This information was also routinely given to parents making application on behalf of their children. This information was invaluable. It provided vital information about who they were related to. Many donor-conceived people and their parents have genuine concerns about the risk of consanguinity. Having this information meant they at least know how many other people they are genetically connected to and gave them at least some information so that they could easily 'rule in or out' potential future partners by asking them their month and year of birth even if they couldn't know more identifying details about them. Unfortunately this information is no longer released by the Registry to parents and donor-conceived people. Only donors are given a list of the people they helped create.

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

As argued previously that it is important that the donor is contacted respectfully, confidentially and sensitively with consideration to the situation surrounding his donation. Provided this occurs with corresponding information and support, I do not believe the Act would be contravened.

**Kate Bourne**