

## Submission to the Victorian Parliament Law Reform Committee

### Inquiry into Access by Donor Conceived People to Information about Donors

On behalf of the Fertility Society of Australia and its subcommittees

- The IVF Medical Directors Group
- Scientists in reproductive Technology
- The Australian and New Zealand Infertility Counsellors Association
- The Fertility Nurses Association

### **Executive Summary**

The Fertility Society of Australia would like to make the following points to the Victorian Parliament Law Reform Committee

- We strongly support the rights of donor-conceived individuals to have identifying information about their genetic origins.
- We strongly oppose compulsory retrospective access to a donor's identity being released without consent.
- We do however support the donor being contacted in a confidential and sensitive manner with a request to consent to provide identifying information, similar to the process outlined in the Infertility (Medical Procedures) Act 1984 (Vic).
- If the donor does not provide consent to release of identifying information, it is suggested that the donor be asked to provide detailed non-identifying information.
- We support the establishment of a service to enable donors, donor-conceived persons and recipient parents to enable them to pass information to each other confidentially without having to release their identifying details.
- We draw your attention to the ANZICA guidelines as a practice model for facilitating contact between donor-conceived people, donors and recipient parents.

Nowadays, there is widespread acceptance of the right of a donor-conceived individual to have access to identifying knowledge of their genetic origin.

The Fertility Society is strongly supportive of the right of a donor-conceived individual to have access to identifying information of their genetic origins. This principle is now enshrined in the practices and procedures of our Society and is subject to audit, with the Reproductive Technology Accreditation Committee Code of Practice, where the introduction states:

*“Fundamental to the delivery of ART services is that patients and their offspring remain the most important consideration in all decisions. Organisations aspire to deliver services in a manner that recognises patients’ cultural and individual values and beliefs, upholds their dignity and privacy, and acknowledges the rights of children born through ART to know their genetic origins and health outcomes.”*

Modern infertility practice using donated gametes is therefore based on an understanding of the needs of donor-conceived individuals and the consequent principles of being open with all participants about future identification and the consequences that follow from that.

However, we fully recognise that this has not always been the case. Sadly some of the infertility practices of the past, although thought appropriate and “best practice” at the time have resulted in unforeseen long-term consequences for some individuals involved. The Fertility Society of Australia acknowledges the serious difficulties that this has caused in some cases and is committed to the welfare of all individuals whilst being at the forefront of the continuing evolution of practice in this area.

- 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 donations were made.**

In the early days of donor treatment it was accepted and understood that all parties (except the potential donor conceived person) would remain anonymous to each other. This reflected the current community views of that era. Consequently donors volunteered to donate on that basis. The Fertility Society of Australia does not support the retrospective release of identifying information of donors who donated at this time as it breaches the donor’s right to privacy and confidentiality. We would therefore recommend that donors be contacted in an extremely sensitive, confidential and respectful manner and asked their wishes in relation to this. This is consistent with the provisions of the Infertility (Medical procedures) Act 1984 (Vic).

Donors who donated some years ago are unlikely to be aware of the outcome of their donation. They are also likely to need reassurance that claims cannot be made against their estate as a result of an approach by a donor-conceived individual and that they do not have legal obligations as a parent or guardian. It is also recommended that counselling assistance be provided to discuss the implications of exchanging information or having contact. If they have not disclosed their donation to their partner or children, they may

need advice and support to assist them with this also and support to their family members where required. See attached ANZICA guidelines.

Donors should also be protected from a direct approach from a donor-conceived person. This is best managed by an intermediary who can convey the wishes of the donor-conceived individual to the donor so the donor can determine how they wish to respond. If the donor does not wish to release identifying information, they may be prepared to supply comprehensive non-identifying information which the donor-conceived person requests e.g. family medical history, and personal information which doesn't identify them. They may also be prepared to receive a letter written by the donor-conceived person and/or they may be prepared to write to the donor-conceived individual, if they could be guaranteed that this was passed on in a confidential way and didn't require the release of identifying information about them.

The possibility of donor conceived individuals being given identifying information about donor conceived siblings we believe is even more problematical. The possibility would arise that individuals could be contacted about their donor origins of which they might be totally ignorant. Whilst it might be argued that it is their right to know this information, the circumstance might arise where the release of this information results in current family dynamics being irreparably damaged.

We support the maintenance of a voluntary register whereby individuals who are aware of their donor origins might make contact with donor conceived siblings who are similarly aware of their donor origins.

**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;**

The NHMRC guidelines state that:

*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.*

*And:*

*Voluntary exchange of information between persons conceived using donated gametes, gamete donors and gamete recipients, with the consent of all parties, is desirable. .... Access to further information may occur only with the consent of all parties involved or as specified by the law.*

The Fertility Society of Australia supports these guidelines and believes consent is fundamental to the release of identifying information. The Society supports donors being contacted to request the release of identifying information, providing this occurs in a manner which does not breach their privacy. We support the right of the donor to

make an informed decision with regard to whether identifying information be released or not and for that decision to be respected.

- 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 carried out privately or records were not stored centrally;**

The Fertility Society of Australia is aware of the difficulty of accessing records where clinics have closed down or doctors have retired or records were not kept in the early days of treatment. As information may no longer exist in many cases, the donor-conceived person should be provided supportive counseling.

The Society also supports the archiving of the donor records which are available and giving authority to an appropriate body to access whatever records are preserved to enable the donors to be contacted and asked for consent to release identifying information. Again any contacting of donors should occur as described previously

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

ART clinics that continue to operate are bound by NHMRC guidelines to assist donor-conceived people in contacting their donor on the donor-conceived person's behalf. If this is occurring as it should, there should be no need for further legislative change. There is a need for assistance however, to be given to donor-conceived people whose mothers' treating doctor or clinic has since closed down. This could occur by giving a government Authority the legal responsibility and onus to assist in the search for their donor e.g. The Registry of Births, Deaths and Marriages or the Victorian Assisted Reproductive Treatment Authority. As discussed previously this needs to occur in the context of the provision of an intermediary counseling service to assist all parties

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

The process of donor-conceived persons accessing identifying information about their genetic origins is new and uncharted territory and people need support and education to guide them through what is usually a very challenging process. If changes occur there should be a public education campaign to educate people of the altered legal situation and the implications this may have for them and supportive facilitative counseling should be an integral part of any attempt to link parties.

There could also be an impact on the donor's family as they might be unaware of their partners or parents prior donation. The mandatory or enforced release of this information might have unexpected and possible poor outcomes.

The inevitable media attention that would occur if donor's wishes and rights were retrospectively ignored would likely mean that a majority of current and future donors could withdraw from treatment as they could not be sure as to which of the current arrangements might be changed in the future i.e. property rights etc .Whilst that might seem alarmist Donors prior to 1988 would not have envisaged that their consent to disclosure might be ignored in the future.

**f. The impacts the transfer of donor registers currently held by the Infertility treatment Authority to the registrar of Births, Deaths and Marriages.**

The Fertility Society supports the ANZICA guidelines which outlines the role of a counselor to assist the donor-conceived person with a request for information about their donor. This model works on the principle that the counselor acts as a mediator facilitator and works to find common ground between parties to assist in reaching a solution which is acceptable to each party. Where this is not possible the counselor gives support to the affected party.

This practice model was previously followed by the counselors who worked at the Infertility Treatment Authority. It is disappointing that this practice model is not now possible given the wording of the Assisted Reproductive treatment Act 2008 (Vic). It is also of concern that the service enabling parties to communicate with each other without providing confidential information is no longer in operation again due to limitations of the Act.

The Society is also concerned that the transfer has meant that people affected need to contact a number of different government bodies when their enquiry is of such a sensitive nature.

**g. The possible implications under the Charter of Human Rights and responsibilities Act 2006**

The Charter of Human Rights states:

A person has the right-

- (a) not to have his or her privacy, family, home or correspondence unlawfully or arbitrarily interfered with

The Fertility Society of Australia in upholding this Charter advocates that any approach to a donor needs to be taken with the utmost respect and in a manner which is highly sensitive to the situation of the donor and in a manner which does not compromise the donor's privacy. The Society strongly objects to the possibility of retrospective legislation that would diminish or wind back these rights.



# **DONOR LINKING ANZICA GUIDELINES**

## **SUGGESTED PROCEDURE**

### **Guiding Principles:**

**The client** (donor or donor conceived person)

- Should be provided with clear information
- Should be offered the opportunity for discussion
- Should be treated with respect
- Should be assisted with the process and in their adjustment to the outcome
- Should have choice and should have their choices clearly spelt out
- Should make their own decisions about what they want
- Should have control over the pace of the steps involved

### **The counsellor**

- Should not become the advocate for one party
- Should take on the role of the mediator
- Should support the principle that people have a right to make contact with genetic offspring or donor

### **Procedure:**

#### **1. Initial**

The approved counsellor is the person who should deal with these cases. All initial inquiries should be referred to the counsellor.

At the time of the initial inquiry the needs of the client should be established. If their needs are not clear or there are issues needing further discussion an appointment for counselling should be offered.

A search of clinic records should be made to establish whether there are any records. For some case there will not be. The client should be advised and counselling should be offered.

#### **2. Non-identifying information**

If non-identifying information is requested, this should be provided by the counsellor in writing after searching appropriate records  
Follow up counselling should be offered.

### 3. Identifying information

If the request is for identifying information, an appointment for counselling should be arranged before any further steps are taken. The counselling should address the following:

- Confirm the identity of the inquirer ( e.g. driver's licence check)
- Clarification of the issues for that person
- Their needs and expectations
- Other life issues
- Possible outcomes of pursuing the request
- Potential difficulties
- Expectations of the other party
- Building a working relationship with the client
- Informed decision making
- Helping the client to develop a clear understanding of their needs and motivations

If it has been decided to proceed with the request, the following steps should be followed.

1. The request should be received in writing.
2. A search is initiated.
3. If not located the client is advised and further counselling may be necessary.
4. If located, the counsellor should adopt the role of mediator.
5. Before any attempt is made to contact, establish whether the client wishes to proceed. Some clients may have second thoughts as the possibility of contact moves closer to reality.
6. The client should provide in **writing** the information that they want communicated when contact is made. The subject of the search will question the counsellor about the inquirer (e.g. needs, motivations). The only information that should be passed on is that which was given by the client. Also establish in writing what the client wants the counsellor to ask the subject of the search.
7. Write a letter to the subject requesting that they contact the counsellor.
8. The letter should be sent by person to person registered mail and should contain information that will enable the person to recognise what it is about. However it should not spell out the details.
9. If the letter is received but no contact is made a further letter should be sent requesting the subject to communicate their wishes. If there is still no answer a third letter is sent confirming that no further correspondence will be attempted and the inquirer will be informed that there has been no response. No further attempt to communicate should be made.
10. When contact is made information may be passed on to the subject as authorised by the client. Information may also be gained to pass on to the client. The subject should be invited to attend counselling. No identifying information should be exchanged without prior counselling of both parties.
11. The counselling should aim to clarify the subject's feelings, thoughts, expectations, and wishes in relation to the enquiry. What information would they be prepared to give, would they be prepared to meet, would they be prepared to exchange letters etc?

12. The counsellor continues to act as a mediator between the two parties until either an agreement is reached to exchange identifying information or it becomes clear that an agreement cannot be reached. This should happen as soon as possible so the counsellor can step out of the mediating role and the clients can establish their own relationship independently if they agree to do so.
13. Further counselling may be required by either party depending on outcomes and emotional reactions. The needs of others in the immediate families for further counselling should also be considered. It is likely that issues that were salient at the time of the treatment or donation will resurface and will need to be dealt with ( e.g. marital conflict, dealing with infertility, grief etc).

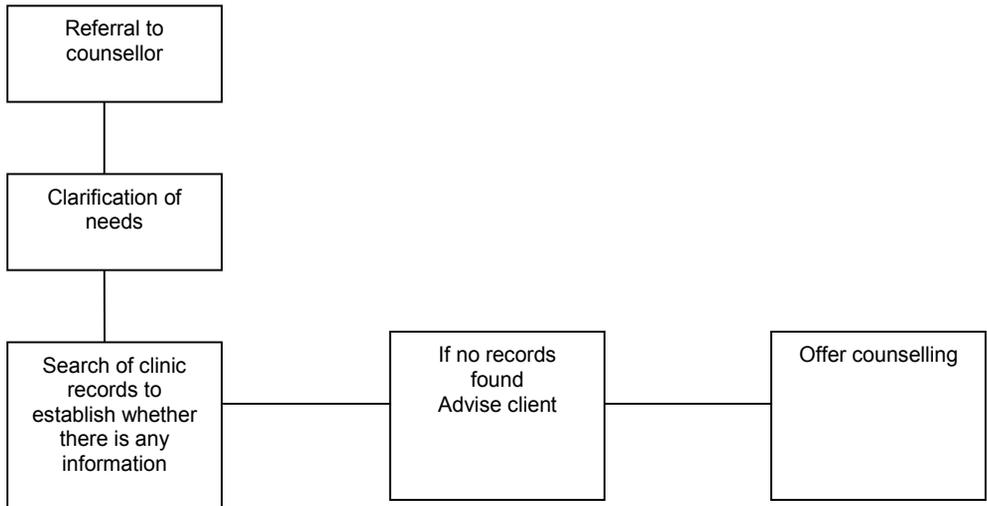
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# FACILITATING CONTACT BETWEEN DONOR CONCEIVED INDIVIDUALS AND THEIR DONOR PARENTS.

## SUMMARY



### If Located

