

**INQUIRY INTO ACCESS BY DONOR-CONCEIVED PEOPLE TO  
INFORMATION ABOUT DONORS**

**Parliament for Victoria  
Law Reform Commission**

**Response from The Reproductive Technology Council Western Australia**

The Reproductive Technology Council (the Council) has a central role in the regulation of artificially assisted human conception (*Human Reproductive Technology Act 1991*) in Western Australia. The Council has a broad range of expertise and interests from its own membership, and welcomes the opportunity to comment on access by donor-conceived people to information about donors.

**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-related siblings regardless of the date that the donation was made.**

- In Western Australia (WA) there would be significant legislative change required if donor offspring were able to receive retrospective (prior to 2004) identifying information about donors and donor related siblings.
- The HRT Act prohibits release of identifying information about a donor who donated material prior to 1 December 2004, unless the donor gives consent to such release or the CEO is satisfied that prior to the donation the donor was adequately informed that the law might change to permit release of the donor's identity without the donor's consent. In other words, this protects the anonymity of donors who donated material at a time when it was understood that their identity was to remain confidential
- In WA until 1 December 2004, persons donating eggs, sperm or embryos could remain anonymous. The HRT Act was amended in 2004 to reflect the growing recognition of the rights of donor conceived children to have access to information regarding their genetic origins. Donors must now be made aware that when a child conceived using their donated reproductive material reaches 16 years of age, the child will be able to access identifying information about the donor.
- Council recognises the issues of moral rights and justice and considers there are relevant lessons from adoption, where research and public debate informed and drove legislative change. A similar situation is emerging in donor conception.
- Research and informed public debate will be the driving force for change where the rights of the donor-conceived person may outweigh the rights of donors to retain their anonymity.

### **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**

- Consent for anonymous donation was often not informed and people may consider that they have been exploited. Additionally as previously stated, the legislation in WA protects the identify of donors who donated prior to 2004. Donors who donated at that time (prior to 2004) did so with the belief that they could remain anonymous if they so desired. The Department of Health (WA) established the Voluntary Register in 2002 to facilitate the exchange of identifying information between matched donor parties. This release of identifying information is done with the consent of all parties and under the guidance of counselling with experienced infertility counsellors.
- The NHMRC ethical guidelines recognise the need for uniform legislation for assisted reproductive technology, the primacy of the welfare of people born from ART and the need for legislation to consider the autonomy and long-term welfare of individuals who take part in ART. The risks and benefits need to be clearly established with processes in place to mitigate possible adverse consequences of identifying data being released without consent.

### **Any practical difficulties in releasing information about donors who provided gametes before the 1 July because many case records are not available either because the procedure was carried out privately or records were not stored centrally**

- In WA, ART records have been a legislative requirement since the HRT Act became law in 1993, and the Reproductive Technology Register (RTR) came into existence.
- Practical issues that may arise from data include; poor quality (or unverified data), the lack of records prior to 1993 which may have been destroyed and the prospect of people receiving distressing information. This might include information about the death of the donor or the presence of high number of donor related siblings (as has happened with donors prior 1993 and the introduction of the five family limit).

### **The options for implementing any changes to the current arrangements including non-legislative options**

- Non-legislative changes should be the first course of action.
- Clinics could attempt to contact the relevant donors, explaining the situation and provide them with a telephone help line, counselling services or similar to provide support.
- Consult with professional groups (RANZCOG; Fertility Society of Australia) to discuss the implications of breach in trust over donor anonymity and

possible loss of that assurance through legislation that retrospectively removes that right.

- Clinics may wish to contact individuals and seek consent for the release of information prior to any legal changes. Clinics could inform donors of retroactive changes, thereby giving them an opportunity to prepare. Public / popular media could be used to inform and educate the general population of any such changes.

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

Possible adverse publicity may impact further on donor recruitment and exacerbate the shortage of donor gametes.

### **The impacts of the transfer of the donor register currently held by the Infertility Treatment Authority to the register of births, death and marriages**

- The Council consider it difficult to comment on the processes in place as we have no real experience or knowledge of how this operates apart from anecdotal information.
- However the Council consider that the provision of resources and programmes that encourage and enable parents to disclose the genetic origin of children is paramount.
- Depending on the nature of the information, and the way it is provided the recipient may experience distress or even emotional shock if their donor-conceived status has not been disclosed.

### **The possible implications under the charter of Human Rights and Responsibilities.**

- There may be conflicts between the charter section 17 (Protection of families and children) and section 13 Privacy and reputation:
- Section 13 states that families are entitled to protection. Children have the same rights as adults with added protection according to their best interests. Whereas section 13 states that everyone has the right to keep their lives private. For example, family, home or personal information cannot be interfered with, unless the law allows it.
- Council acknowledges that all children should know their genetic heritage and kinship. However, the consequences of legislative changes and the impacts on donors and their families should also be given due consideration as many anonymous donors were not fully informed or aware of the implication of their actions at the time of donation.

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