

**INQUIRY INTO INCLUSION OF DONOR DETAILS ON
THE REGISTER OF BIRTHS**

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Government of **Western Australia**
Department of **Health**
Office of the Chief Medical Officer

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Legislative Assembly
Committee on Law and Safety
Parliament of New South Wales
Sydney 2000

Dear Mr Barilaro

Inquiry into inclusion of donor details on the register of births ref: D11/13367

Thank you for your invitation to contribute to the inquiry into inclusion of donor details on the register of births.

Our submission provides an overview of the legal requirements for recording artificial fertilisation procedures, a description of the system for recording information and an overview of the legal requirements for Western Australia.

I hope that this information will be of assistance to the Committee. Please do contact me if you require any further details.

Yours sincerely

A/Associate Professor Maureen Harris
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Reproductive Technology Unit

Inquiry into inclusion of donor details on the register of births

Legislative Assembly, Committee on Law and Safety, Parliament of New South Wales

Terms of Reference

That the Committee inquire into and report on whether there should be provision for the inclusion of donor details on the register of births maintained by the Registrar of Births, Deaths and Marriages. As part of the inquiry, we will be exploring how donor details are recorded in other Australian jurisdictions.

1.0 Introduction

The Office of the Chief Medical Officer, Department of Health, thanks the Legislative Assembly, Committee on Law and Safety for the opportunity to describe the management of recording gamete and embryo donor details in Western Australia. This submission provides an overview of the legal requirements for recording of artificial fertilisation procedures involving donation, the *Artificial Conception Act 1985* (WA), the operation of the Reproductive Technology Registers (RT Registers) and the Voluntary Register. The submission concludes with a commentary on the possible provision for donor details to be included on the register of births.

1.1 Recording of artificial fertilisation procedures in Western Australia

In Western Australia fertility clinics must be licensed and are required, under the *Human Reproductive Act 1991* (HRT Act), to make and keep proper records in relation to the use of gametes or embryos including the identity of donors, recipients, participants and where known any children born. Clinics provide both identifying and non-identifying information as required under the HRT Act to the Chief Executive Officer (CEO), Department of Health, Western Australia. This information is stored on a central computer database known as the RT Registers.

The RT Registers contains individual records for all artificial fertilisation procedures carried out in this State from **April 1993**, when relevant provisions of the Act commenced. This includes the identity of donors to artificial fertilisation procedures carried out by licensees or exemption holders. [NB. Artificial fertilisation procedure includes artificial insemination, in-vitro fertilisation (IVF) and gamete intrafallopian transfer (GIFT)]

1.2 Information regarding donations

The HRT Act requires certain information about artificial fertilisation procedures involving donation to be provided by licensees (or exemption holders) to the RT Registers. The information includes:

Non-identifying information (donor):

- Physical description
- Family background
- Education
- Occupation
- Medical details
- Personal interests
- Demographic information

Identifying information

- The identity of participants.
- The outcome of procedures and genetic origins.
- The identity of children born as a result of an artificial fertilisation procedure.
- The identity of the donor/s.
- Relevant demographic and clinical information.

1.4 Access to information

The RT Registers enable a person to have access to information that relates to them as a participant in an artificial fertilisation procedure. Information may also be provided to a person if it does not identify, but relates to a biological parent of that person or a child to whom that person is a biological parent.

The HRT Act was amended in 2004 with the effect that donations of gametes or embryos after this time may no longer be anonymous, in the sense that any child born from use of the donor reproductive material will be able to access donor identifying information from age 16 years.

1.4.1 Donor offspring born after 1st December 2004

Donor offspring born after 1 December 2004 may, on reaching the age of 16, access donor identifying information. In such circumstances, the explicit consent of a donor to provision of identifying information to the donor offspring is not required at the time of release of the information. A donor offspring must undertake approved counselling before the identifying information is released.

A child under 16 years of age cannot give consent for release of such identifying information. Parents or persons with parental responsibility may consent on behalf of a child. The consent of all participants is required. Approved counselling must be undertaken before the release of identifying information. Disclosure of information must not reveal the identity of any participant who has not given consent.

1.4.2 Donor offspring born before 1st December 2004

A donor offspring born before 1 December 2004 does not have an automatic right of access to identifying information about the donor. However, identifying information may be provided where the donation was made prior to the date the amendments came into effect and a donor has provided consent to the use after this date. Where donations were made prior to the amendments, identifying information may also be provided if the CEO is satisfied there is clear evidence that the donor was aware at the time of donation that this information may later be provided to any resulting child. Past donors who are willing for their identity to be disclosed to a donor offspring may register their interest with the Voluntary Register.

The Voluntary Register was established in 2004 to facilitate access to information (identifying and non-identifying) for persons involved in donation, on a voluntary basis through mutual consent. Donor offspring 18 years and over, parents of donor offspring and donors can join the Voluntary Register. Identifying information can only be released with consent and after mandatory counselling of the relevant parties.

1.4.3 Donors

Donors are entitled to know the number of recipient families involved in the donation and number of children born through use of the donated reproductive material. Donors have no right of access to identifying information about any child that has been born as a result of their donation without the consent of the donor offspring or parent/s of the offspring.

1.5 Consent, eligibility for an artificial fertilisation procedure, and the *Artificial Conception Act 1985 (WA)*

Under the HRT Act, gametes and embryos cannot be stored or used without the written consent of the gamete provider or person for whom the embryo was developed, respectively. Section 23 of the HRT Act sets out the requirements in order to be eligible for an in-vitro fertilisation (IVF) procedure. An IVF procedure may only be carried out where each of the participants required to do so have given effective written consent to the procedure. Essentially, the HRT Act permits married couples, de facto couples of the opposite sex, and single women to access an IVF procedure for medical reasons. There are no such specific eligibility criteria for artificial insemination, although written consent is required by a gamete provider for use of his/her gametes in an artificial fertilisation procedure.

The HRT Act requires that all donors and recipients are given extensive information regarding their rights and the implications of donation in order that informed consent may be obtained. Donations may be made by “known” or “unknown” donors. An unknown donor means that the person who is making the donation is not known to the recipients. Conversely, a known donation means that the person making the donation is known to the recipient (this may be a friend or a relative). In the case of a known donation, psycho-social counselling is required so that all parties consider the implications.

All donors are required to be informed of the impact of the *Artificial Conception Act 1984 (AC Act)* on the legal parentage of any child born as a result of an artificial fertilisation procedure.

The AC Act provides certain legal presumptions (rebuttable) in relation to parentage of a child born as a result of an artificial fertilisation procedure. A child born as a result of such a procedure involving the use of donated gametes or embryos (e.g. donor insemination or IVF), is the legal child of the recipient(s) who have consented to the procedure. For example, where a woman in a de facto relationship with another woman consents to her de facto partner undergoing an artificial fertilisation procedure, the de facto partner of the pregnant woman is a parent of any child born as a result of the pregnancy. There is no requirement to state the method of conception on the birth certificate of the child. In the eyes of the law, the recipient(s) has the rights and duties of responsibility as if the child was their natural child. The 2002 amendments to the AC Act provide conclusively that a donor of gametes or embryos used in an artificial fertilisation procedure is not a parent of any resulting child. This means that a sperm or ova donor, or embryo donors, including a known donor, has/have no parental rights or responsibilities in respect of a resulting child.

Accordingly, it is not the practice in WA to have a donor of reproductive material named on the birth certificate of a child born from use of the donor material.

2.0 Operation of the RT Registers

The RT Registers and the Voluntary Register are maintained and managed by officers assisting the CEO, Department of Health.

2.1 Data Collection

The records for the RT Registers are provided in an encrypted electronic format, by all fertility service providers in WA. This information is downloaded to the RT Registers. Western Australia has a small number of exemption holders who provide donor insemination services. Those practitioners provide the required information on specific forms.

2.2. Links to other databases

The confidentiality requirements of the HRT Act are such that links to other databases must be for a purpose permitted under the Act, approved by the Reproductive Technology Council, and have Human Research Ethics Committee approval. A link to another database may only be undertaken by the Data Linkage Branch, Department of Health and only by officers authorised under the HRT Act. The link is not permanent and the extracted data set must not contain any identifying information.

3.0 The Voluntary Register

The Voluntary Register is a computer database of the records of people who have provided information about themselves / their children, of their own volition. This Register provides a means for people to obtain information about their biological relations (donor, sibling, donor-conceived person). The type of information that is shared and the extent of sharing are decided by the individuals. However, identifying information cannot be released without consent of all the people involved. Approved counselling is also required before the identifying information is released. A registration form is completed and the applicant indicates the choice of options, which include:

- Registration.
- Access to non-identifying information.
- Notification if there are other children born from the same donor.
- Access to identifying information.
- Notification of a serious heritable condition.

4.0 Commentary on a potential to link to Births, Deaths and Marriages Register

In Western Australia the HRT Act sets strict constraints on access to information relating to the identity of participants, donors and children born as a result of an artificial fertilisation procedure. The RT Registers can only be accessed by Authorised Officers under the HRT Act and for specific purposes set out in the Act. Legal consideration may be required as to whether access to identifying information held in the RT Registers would be required and/or permitted for such a purpose. The Reproductive Technology Unit considers that there are several issues that might be worthy of consideration in exploring the possibility of inclusion of donor details on the register of births -

- It is vital that there is clarity about the core purpose of including donor details on the register of births. In this State, the HRT and AC Acts provide for clarity of parentage, protection of participants, and the best interests of the child born as a result of an artificial fertilisation procedure carried out by a licensee or exemption holder. An emerging area of concern is private arrangements where people by-pass fertility clinics and a friend provides sperm for self insemination or more recent trends such as buying sperm on the internet. This is fraught with legal uncertainty and considerable health risks for the recipients and is unlikely to be in the best interest of the child.
- There is increasing public concern about identifying information being held on central registers and links to different databases, which can increase the vulnerability of inadvertent release of highly sensitive information.
- There would need to be a confirmatory process that the donor treatment was related to the specific birth. The system would also need to be able to have the functionality to accommodate the number of families and children that a donor can be linked to (in WA the maximum is 5 families). Importantly, donor offspring may want to be able to

use this proposed function of the register of births to avoid a relationship with a genetically related person.

- There may be reactions from donors to the proposal to include donor details on the birth register and this may impact on the already severe donor shortage:
 - The release of identifying information before an agreed time period;
 - Fears regarding possibility of child support or claims on estates;
 - Impact on donors (donations prior to 1 December 2004) and their families who only donated on the understanding that their donation would be anonymous, should the proposal be retrospective in effect.

- There are social and ethical implications of placing the name of a donor on the birth certificate where traditionally only the parents' names were recorded.
 - Expectations of 'parental responsibilities' when a donor has not entered into any agreement in relation to parenting.
 - There needs to be a consideration of the wishes of parents of a donor offspring as there has been commentary about the need to avoid terminology that might vest donors with any kind of 'parental' status.