

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

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“Inquiry into Inclusion of Donor Details on the Register of Births”

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**

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All responsibility for the opinions expressed in this submission lie with the Board of the Fertility Society of Australia.

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Recommendations of the Fertility Society of Australia

- 1. It is recommended that the name and details of a gamete donor should only be placed on the birth certificate where this has the consent of BOTH the gamete donor AND the birth mother.**
- 2. All birth certificates should be annotated that further information is available from the Register of Births Deaths and Marriages.**
- 3. Further details about the use of a gamete donor should be provided as an addendum to the birth certificate at age 18, where this has been applied for.**
- 4. A tribunal or advisory body be established in NSW with resources to meet the needs of consumers and clinics, to provide public education and the flexibility to respond to sensitive consumer needs, encompassing both the NSW ART Act 2007 as well as provision of donor details in birth registration.**

1. Background

1.1. The Fertility Society of Australia (FSA) is strongly supportive of the right of a donor-conceived individual to have access to identifying knowledge of their genetic origins and this principle is now enshrined in the practices and procedures of all our sub-committees, including the Reproductive Technology Accreditation Committee Code of Practice (RTAC COP) where the introduction in the latest version 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.*

The RTAC COP clearly states the requirements of clinics to counsel donors and patients using donor gametes to support a child’s right to know their genetic origins. All Assisted Reproductive Technology (ART) Units in NSW accredited through the RTAC COP are compliant with these requirements such that modern infertility practice using donated gametes is based on an understanding of the needs of donor-conceived individuals and the consequent principles of being open with all participants (parents and donors) about future identification and the consequences that follow from that.

2. Rights of Donor Conceived Persons and Disclosure

2.1. Whilst the NSW Central ART Register has been a significant step to uphold the rights of donor conceived persons it is also necessary to address the issue of disclosure. In order to make a choice about accessing information, donor conceived adults must first know about the method of their conception.

2.2. It is noteworthy that recipients of donor gametes fall into 2 groups, identifiable as non traditional (lesbian couples and single women) and traditional families (heterosexual couples where the either partner is infertile). Non traditional families are generally open with their children about donor conception but research evidence suggests that heterosexual couples may not disclose this information to their children with such ease, though this trend is slowly changing.

2.3. Whilst legislative change removing donor anonymity may itself play a part in facilitating parental disclosure there may be other ways to encourage disclosure. A possible mechanism to encourage disclosure could be that there is some reference to donor conception on the birth certificate of a donor conceived person, activated when a donor conceived person turns 18 years of age.

3. Concerns about placing donor details on a birth certificate.

Some may argue that parents in this situation are being forced into disclosure to their children. However the rights of donor conceived individuals to information about their genetic origins are paramount.

3.1.1. However, if parents have not told their child(ren) about their donor conception it would be extremely traumatic for a person to find out that they were donor conceived by way of application for a birth certificate.

3.1.2. It is currently generally accepted that gamete donors have no legal parental rights or responsibilities. This enables families created from donated gametes to be confident about their legal responsibilities and status, particularly privacy. To place the donor's details on the birth certificate against the will of the birth parents may put that certainty at risk.

3.1.3. Finally, having a different birth certificate that clearly denotes donor conception could result in a donor conceived person feeling stigmatised or resenting that information about their conception is available to others when for example they are joining a primary school soccer team, getting a driver's license or any of the multitude of things for which a birth certificate is required.

Possible mechanisms for making the relevant information available to donor-conceived people without the above risks, could include:

- Placing a standard notice on ALL birth certificates that further information may be available from the NSW Registry of Births, Deaths and Marriages at age 18.
- Providing an addendum to the birth certificate at age 18 that provides the necessary information.

An annotation on a birth certificate only after the donor conceived person reaches maturity would give traditional parents the flexibility in inform their children of their donor origins in their childhood with the knowledge that they will need to do so by maturity. Such a change following the example of the Victorian model is proposed prospectively.

It is recommended that a donor conceived adult can apply for a copy of their birth certificates at 18 years of age from the NSW Registry of Births, Deaths and Marriages. An addendum to the certificate on a separate page will inform the adult that additional information about their birth is available.

4. Implementation

- 4.1. Concerns of members of the FSA in NSW relate to the absence of any resources, advisory body or tribunal of persons experienced in ART to manage the complex and sensitive matters arising from legislation. There remains a need in NSW for the provision of public education and resources for professionals and the community on fertility, and issues related to assisted reproductive treatment. It is noteworthy that such advisory bodies exist in Victoria (Victorian Assisted reproductive Technology Authority) and in Western Australia (the Reproductive Technology Council) to the benefit of both consumers and clinics.
- 4.2. Any recommendations for changes recommending total disclosure in donor conception must also recognise the needs of families in telling their children about how they were conceived. Parents still may require support and education re telling their children of their donor conception and it is noteworthy that tribunals such as in Victoria and Western Australia have a role in community education and support of parents to tell their children. The “Time to Tell” programme established by the Victorian Infertility treatment Authority (now ITA) is a prime example of this.
- 4.3. Whilst ART Units provide counselling to donors and recipients prior to conception, counselling in relation to donor conception needs to be available to families and donors on an ongoing basis. Parents need to be assisted in telling their children about how they were conceived and helping the family address issues they may face in relation to donor conception. Donors may need support in recognising that their donation has resulted in the life of another person who may wish to access information about their genetic heritage.
- 4.4. The FSA does not hold a strong position on whether the Dept. of Health or the Registrar of Births Deaths and Marriages manages records of donor details and their provision to donor conceived adults. The Dept of Health has a strong record in management of confidential information and the Register of Births Deaths and Marriages has relevant experience in working with records relating to adoption. However neither of these departments currently has the resources needed to provide for the flexibility and sensitivity in meeting the needs of consumers and clinics in ART. Provision of further information to a donor conceived adult about their genetic origins from birth registry enquiries will need to be managed sensitively, with access to counselling and linkage to the Central ART register.

It is recommended that a tribunal or advisory body be established in NSW with resources to meet the needs of consumers and clinics, to provide public education and the flexibility to respond to sensitive consumer needs, encompassing both the NSW ART Act 2007 as well as provision of donor details in birth registration.