Western Australian Department of Health:
Submission to the Legal and Constitutional Affairs Committee Inquiry into Donor Conception in Australia.

Past and present practices of donor conception in Australia, with particular reference to:

(a) donor conception regulation and legislation across federal and state jurisdictions;

Since the early 1980s an increasing number of children have been born as a result of assisted reproductive technology (ART) procedures. Some of these children were born as a result of gamete donations. Until 1993 when the Western Australia (WA) *Human Reproductive Technology Act* 1991 (HRT Act) became operational, medical practitioners and fertility clinics provided assisted reproduction services in accordance with national standards and guidelines.

The HRT Act regulates ART practices in WA, inclusive of donor conception. Administration of the Act is vested in the CEO of the Department of Health (DOH), subject to the Minister for Health. Fundamentally, the CEO is responsible for the licensing of reproductive technology practices, for issuing of directions to licensees, for maintaining registers of reproductive technology procedures, for issuing complaints for any offences under the Act and is involved with disciplinary action and appeals.

Essentially, the HRT Act prohibits a person from storing (freezing) any egg undergoing fertilisation or embryo or egg intended for use in an artificial fertilisation procedure, unless they hold a storage licence. A storage licence is also required by those who keep sperm collected from more than one man, such as sperm banks and fertility clinics.

A practice licence is required by those who carry out any artificial fertilisation procedure (defined to include in-vitro fertilisation, gamete intrafallopian transfer and artificial insemination), other than artificial insemination authorised by an exemption.

The HRT Act was intended to promote the safe and beneficial treatment of those who use reproductive technology in order to have a child. The HRT Act seeks to ensure that participants utilising donor services have adequate counselling and objective information to guide decision-making. The objects of the Act include ensuring the wider community is kept informed and involved as the policies relating to the regulation of these technologies continue to evolve. Additionally, the HRT Act establishes the Western Australian Reproductive Technology Council (Council), which has a central role in the regulation of ART practices and related research in Western Australia.

In WA, fertility clinics are required under the 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 (Section 44). Clinics provide both identifying and non-identifying information as required under the HRT Act to the CEO of the DOH, who is responsible to keep the reproductive technology

registers (RT Registers). Donor information (for donors who have achieved one or more clinical pregnancy) includes details of personal health history, family history, donor's blood group, number of existing children whether donor or otherwise, ethnicity, ancestry, educational levels, occupation, religion and physical details such as height and eye colour (Form 4 of Schedule 1 to the Directions). As such, the fields captured will include any siblings resulting from use of donor reproductive material from the donor, but not necessarily details of any natural children of the donor born subsequent to the donation.

In addition, information concerning artificial fertilisation procedures is kept in the RT Registers, including information from licensees respecting -

- the identity of participants to such procedures;
- the identity of children resulting from such procedures including their biological parentage;
- the outcomes of procedures and genetic origin of gametes and embryos used; and
- other relevant demographic and clinical information as required by the HRT Act (Section 45).

This information has been collected since April 1993. Records prior to this time are those held by fertility clinics and medical practitioners.

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.

The 1999 Report of the WA Parliamentary Select Committee that reviewed the HRT Act considered that donor offspring should be able to obtain information about their origins, including identifying information. Based on this consideration, the Voluntary Register (VR) was established in 2002. The establishment of the VR was an indication that the Western Australian government recognised a growing awareness in the community of the importance for some donor offspring to find out more about their genetic origins. The VR provides a means for participants to and children born from donor artificial fertilisation procedures to share information on a voluntary basis. The VR attempts to match the records of a person who joins the VR with the records of another person involved in the donation. An important consideration in establishment of the VR was to accommodate people involved in donation before the commencement of the HRT Act in April 1993.

The implication of a national register of donors, assuming that it is intended to deal with identifying information, may raise some difficulties in terms of possible contravention of provisions of the HRT Act. By way of example, the 2004 amendments to the HRT Act incorporate provisions that are not retrospective in terms of access to identifying information and maintain donor anonymity prior to this time, unless the donor otherwise consents to release of such information. In the past, donations were made with the assumption that the HRT Act would protect donor anonymity and the Act seeks to respect the undertakings of privacy and

confidentiality given to donors in this regard. There may also need to be some consideration of the common law. For example, in terms of the clinics, it could be said that health professionals are under a legal and ethical duty not to disclose confidential information concerning a patient which has been identified in the course of their professional attendance upon that patient. That legal duty may arise in contract or in equity. A third party who comes into possession of confidential information which he or she knows is confidential falls under an obligation not to pass that information on to anyone else. Other considerations relating to a national donor register may include compliance with the provisions of Commonwealth Privacy Act 1988. There is currently no State privacy legislation.

Access to identifying information held under the RT Registers is not permitted unless one falls within one of the exceptions set out in Section 46 or 49 of the HRT Act. Section 46 provides in part -

> (3) A person may, on payment of the prescribed fee, be furnished with information in a register kept under section 45 if –
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> (a) it does not identify, but relates to –
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> (i) a biological parent of that person*;* or
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> (ii) a child of which that person is a biological parent;
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> (b) it is sought by a person so authorised by the CEO;
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> (c) it discloses only the social or public health connotations of reproductive technology*;* or
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> (d) a written law so provides,
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> but not otherwise, unless subsection (2) applies.

Subsection (2) relates to information sought by a participant in their capacity as a participant in an artificial fertilisation procedure.

The reference in (b) to an authorisation by the CEO may well be qualified by Section 48 of the HRT Act, which provides as follows:

> **48. Exchange of information**
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> The CEO may disclose, or authorise the disclosure of, information gained in the course of the administration of this Act to –
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> (a) authorities vested with the administration of laws relating to reproductive technology or surrogacy in other States and Territories of the Commonwealth*;* or
>
> (b) any other bodies that may require the information for the purpose of discharging duties of a public nature,
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> respecting the affairs of any person or the administration of this Act, but not in such a manner as to disclose the identity of any person who is, or was, a donor of human gametes or a human embryo, a participant, or a child conceived through artificial fertilisation, unless authorised by that person or by any other written law**.**

Section 49(1) of the HRT Act prohibits a person from divulging or communicating any information disclosed or obtained by reason of the Act respecting the identity of a donor, participant or child born as a result of an artificial fertilisation procedure. The exceptions are set out below:

> (2) Information to which subsection (1) applies may be divulged or communicated –
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> (a) for a purpose necessary to the carrying out of any procedure, or the conduct of any research, to which this Act applies;
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> (b) for the purposes of and in the course of the administration of this Act, or pursuant to a request of the Minister made for the purposes of section 5;
>
> (c) as may be authorised or required by the Code or the regulations;
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> (d) subject to subsections (2a) to (2c), with the consent of each donor, participant or child in question or other person whose identity may be disclosed in so far as it does not identify any person who was a participant in the relevant procedure and who has not given such consent*;* or
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> (e) under an authorisation conferred by another written law.

Section 49 (2) (c)(d)(and (e) appear most relevant here.

Section 49(3) also prohibits a person from releasing a record that discloses or may disclose the identity of a person and has been obtained in the course of administration of the HRT Act or for the purposes of this Act. One exception applies where access is authorised under any other written law, but in such a case so far as is practicable the information which is necessary in respect of that matter must only be provided in a manner that will not identify the relevant individual.

A person who contravenes Section 49 (1) or (3) commits an offence, with a penalty of up to $5,000 or imprisonment for 12 months.

It is worth noting that if there was a proposal to establish a national voluntary register where persons give consent to the collection and disclosure of their identifying information concerning donor assisted conception for this purpose, this may overcome the difficulties arising under the provisions of the HRT Act and the potential for breach of confidentiality.

(b) the conduct of clinics and medical services, including:
(i) payments for donors

Under the HRT Act, it is unlawful to give, offer or receive valuable consideration for the supply of a human gamete or embryo. Only altruistic gamete/embryo donation is permitted in WA. However, fertility clinics are permitted to reimburse donors for reasonable expenses (section 53Q of the HRT Act).

(ii) management of data relating to donor conception

In WA, fertility clinics are required 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 child born as a result of an artificial fertilisation procedure.

As previously indicated, clinics provide both identifying and non-identifying information to the RT Registers kept by the CEO of the DOH, in accordance with the requirements of the HRT Act. Such information includes a Donor Information Form (the DI Form) for each donor who has achieved one or more clinical pregnancy. The DI Form requires a range of information including a personal health history, family history, donor's blood group, number of existing children, ethnicity, ancestry, educational levels, and occupation, religion and physical details such as height and eye colour.

A person may have access to non-identifying information held in the RT Registers if it relates to a biological parent or child of that person.

The HRT Act prohibits the release of identifying information obtained by reason of the Act about a donor, participant or child born as a result of an artificial fertilisation procedure, unless an exception applies. This is set out in some detail in response (a) above. One exception applies where there is consent from each donor, participant and child in question or other person, so far as it does not disclose the identity of any person who was a participant in the procedure and does not consent. A person who has parental responsibility may give such consent on behalf of a child born as a result of such procedure (where the child is under 16 years). Where a child has reached 16 years, the child may give consent and also may have access to identifying information about their donor. Approved counselling is required in all such cases.

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, the VR has been operational since 2002. The VR was initially established in recognition of a growing awareness in the community of the importance for donor offspring to access information about their genetic origins. An important consideration in establishing the VR was to accommodate the wishes of persons involved in donation before the commencement of the HRT Act in April 1993. The VR is not limited to the pre 1993 period and may also include names of people involved in donation after 8 April 1993. Where the other party or parties consent, the VR enables:

- donor offspring;
- donors;
- parent/s of donor offspring; and
- in exceptional circumstances, certain relatives of a donor party (such as a relative of a donor offspring, a donor or recipient)

to obtain information about each other. These persons can apply to be registered on the VR and enter their preferences for exchange of information.

The VR attempts to match the records of a person who joins the register with the records of another person involved in the donation. If a match is found, non-identifying information about another person is given to the person inquiring. Where both parties give consent, identifying information can be released about the other person. This is a managed process involving approved counselling. Related donor offspring may also share information with each other through the VR.

The VR has safeguards that protect the privacy of the parties. Identifying information is only exchanged with the written permission of the person to whom the information relates. The VR is maintained by the staff in the Reproductive Technology Unit (RTU) of the DOH.

Persons who donated human reproductive material or who were born as a result of such a donation before 1993 are advised when they join the VR that very limited information may be available. If a match cannot be confirmed by checking the available records kept by clinics or medical practitioners, no information at all may be available. When these people complete a registration form, RTU staff will seek their permission to contact the fertility clinic or medical practitioner that provided the assisted reproductive service. If the medical practitioner or clinic no longer operates, no extraordinary measures will be taken to make contact or locate further information.

(iii) provision of appropriate counselling and support services;

The HRT Act makes clear that prior to any consent being given, participants receiving certain assisted reproductive treatments in clinics licensed under the HRT Act, must be provided with a 'suitable opportunity to receive proper counselling'. The Act makes provision to 'establish criteria as to the qualifications of counsellors'. To this end the Directions given by the Commissioner of Health, on the advice of the Council, set out the requirements for counselling to be provided.

All parties to an artificial fertilisation procedure involving donated reproductive material where a potential donor is known to a recipient must receive counselling with an 'Approved Counsellor'. Where the recipient is unknown to the donor, counselling is encouraged. The cost of an IVF treatment is to include the cost of at least one consult to an approved counsellor per cycle. Participants may see the clinic approved counsellor or may decide to see an approved counsellor independent of the fertility clinic.

The Council has established criteria for the recognition of suitably trained and qualified counsellors as Approved Counsellors for the purposes of the HRT Act. To be considered suitably trained and qualified in order to provide the counselling services within clinics licensed under the HRT Act, the Directions require that an Approved Counsellor be both recognised by the Council as an Approved Counsellor' and be eligible for full membership of the Australian and New Zealand Infertility Counsellors' Association (ANZICA).

To achieve recognition as an Approved Counsellor an applicant must be able to demonstrate:

- appropriate university recognised training and qualifications in counselling theory and technique, involving counselling as an integral and recognisable part of that training;
- substantial and satisfactory supervised, post-training counselling experience in an applied setting utilising therapeutic skills; and
- reasonable knowledge of life span issues associated with infertility and psychosocial issues in infertility treatment.

(c) the number of offspring born from each donor with reference to the risk of consanguine relationships;

Under Directions to the HRT Act (which have the effect of subsidiary legislation) each donor may contribute to a maximum of five recipient families, unless the Council has given specific approval (Direction 8.1). This five family limit includes any donations made to families that reside outside WA. This has the dual effect of limiting the total number of offspring, as well as allowing the possibility for more than one child in the family using the same donor.

(d) the rights of donor conceived individuals.

Under the HRT Act, donor conceived individuals have a number of rights.

The HRT Act enables a participant to or child born as a result of an artificial fertilisation procedure to access non-identifying information about their biological child or parent respectively, from the RT Registers (section 46 HRT Act) . Where a donor conceived child has reached 16 years of age, identifying information (disclosed or obtained by reason of the HRT Act) about the donor may be released to that child even where there is no donor consent to do so provided the relevant donation was made on or after 1 December 2004. With the 2004 amendments to the HRT Act, it is also possible for the parties to share identifying information where children are aged under 16 years provided that each donor and recipient consents to sharing identifying information and the parent consents on behalf of the child (section 49 HRT Act). Approved counselling must be provided to all relevant parties (which may include the child) prior to such identifying information being released.

The *Artificial Conception Act 1985* (WA) provides certain rules relating to paternity, maternity and also parentage in relation to same sex relationships. It further provides that the donor of genetic material is not the mother or father of the child, for the purposes of the law of the State.