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

August 2010

Opening Statement

The Royal Women's Hospital Melbourne in collaboration with the Queen Victoria Hospital established a clinic, the first of its kind in Australia, to create embryos outside of the woman's body and transfer the resulting embryos into the woman's uterus in the hope of implantation and achieving a pregnancy.

1976 saw the commencement of the donor sperm insemination program. The Royal Women's Hospital and later Melbourne IVF's donation programs progressed along with developments in assisted reproductive technologies. In 1989 the Reproductive Services Unit at the Royal Women's hospital undertook its first egg donation cycle. The Egg donor program included Clinic and Recipient Recruited Egg donors. However following a review of this program in 2006 it was decided to cease our clinic recruited program as we were unable to fulfil the demand for egg donors and as such there was a 4 year waiting list. Many recipients were finding their own egg donors who were either family, friends or recruited through advertising.

Embryo donation cycles soon followed in 1991. This program relies on IVF patients who have excess embryos in storage and have completed their own treatment, deciding to donate their embryos either to the clinic for allocation to another couple/ person, or someone they know whose only chance of having a child is from donated embryos.

Melbourne IVF (MIVF) and Reproductive Services Unit (RSU) at the Royal Women's Hospital now have thriving donor sperm, egg and embryo programs. Melbourne IVF has a dedicated team of fertility specialists, registered nurses and counsellors associated with these programs providing support and clinical advice to donors and recipients and donor conceived offspring.

MIVF has long recognised and accepted the importance and value of the availability and accessibility of information about a donor conceived child's origins for the well being of donor conceived offspring.

The current system of release of information to donor conceived individuals about their donors and donor-conceived siblings is inconsistent; dependant on when a donor conceived individual was born. Siblings in the same family can have different levels of access to information depending on the legislation relevant to their date of birth.

For those born pre 1988, whether information is available and the quality of information is dependant on individual clinics and doctors who carried out donor treatments.

For those born between 1988 and 1997, parties to a donor arrangement may provide information on the voluntary register and identifying information is maintained on the central register. Donor conceived individuals may access identifying information with the donor's consent once they reach 18 years of age. Recipients may request information regarding the donor whilst their child is under 18 years of age, however the donor has the right to refuse to provide this information. The donor may also request information from

the donor register, however the recipients (If donor conceived child under 18 years of age) or donor conceived child (if over 18) has the right to refuse.

Those born after 1998 can access their donor's name once they reach 18 years without the donor's consent.

Melbourne IVF (MIVF) is currently the only clinic that assists donor conceived children born before 1988 to make contact with their donor. Generally the aim of the linkage counselling is to trace the donor based on information kept on Melbourne IVF records and provide information and support to both the donor and the offspring. This information can be identifying if the offspring has requested this and the donor is willing to provide identifying information.

Whilst the numbers in our donor linking program have been small (given that any linking has to be initiated by the donor conceived individual and most are not aware that they can contact MIVF for this service), we have enjoyed success in either linking donors and donor offspring or providing donor offspring with current and relevant information about their donor whilst maintaining the confidentiality of the donor.

Melbourne IVF also provides support to donor parents who may wish to make contact with their donor to provide them with information about their donor conceived child or to ask the donor for information without providing identifying information about themselves.

MIVF does not provide assistance to donor conceived individuals wanting to make contact with donor-conceived siblings. MIVF will only provide non-identifying information in accordance with the National Health and Medical Research Council's (NHMRC) ethical guidelines. Currently there is no process for donor conceived individuals to make contact with donor conceived siblings unless both have provided information on the voluntary register.

Summary of Recommendations:

1. Melbourne IVF (MIVF) understands and supports the rights of the donor conceived individual to access information about their genetic background.
2. The rights of the donor conceived child to information about their genetic background should never over-ride the donor's rights to privacy and control over the release of their personal information.
3. Donor information should be made available to those born before 1987 only with the donor's consent (as is currently the case with those born between 1987 and 1998). Donor conceived individuals should not be given access to information about their donor without the donor first providing their consent to the information being provided and the type of information provided. MIVF feels a strong obligation to protect the privacy of our donors and respect the circumstances under which the donations were made.
4. Any exchange of information between donor conceived half siblings should be driven by the donor conceived individuals and continue to rely on these donor conceived individuals placing information about themselves on the voluntary register. However, for these registers to more effectively link donor conceived siblings, a community education program should be implemented and management of the information provided on the voluntary register should be improved.
5. Donor linking should be undertaken by a centralised service that has access to the registers and information held by the clinics. This centralised service should include a comprehensive donor linking counselling service and work in much the same way as The Infertility Treatment Authority (ITA) previously functioned where there is a clear process where a third party takes responsibility for accessing information and then approaching the party from whom information has been requested. Any approach for information from a donor needs to acknowledge the potential emotional impact of the request, the need for confidentiality and that the donor will possibly have a family who may have no knowledge of the donation having occurred. All parties should feel in control of how, when and where information will be released.

- 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 that the donation was made;**

Consent:

The main issue in providing all donor-conceived individuals access to identifying information about their donors is that donors who donated prior to 1997 have not given consent to their identifying information being released. Donors who donated pre 1988 presumed that this donation would be anonymous and have not provided consent to the release of any identifying information. Those who donated between 1988 and 1997 donated believing that they would be contacted to provide consent prior to any identifying information being released. The context in which these donors donated therefore must be respected and consent **MUST** first be obtained from donors in a confidential and respectful way before any identifying information is released.

Accessing accurate contact details:

Melbourne IVF and the Royal Women's Hospital main issue in contacting donors when requested by donor conceived individuals is accessing current contact information as we have often not had any contact from the donor since they donated. We have relied largely on the electoral role to access current contact details and the lack of readily accessible information to accurately identify a donor, has meant it has at times been a laborious and delicate task to locate a donor as there may be more than one person with the same name.

Psychological impact on donors, donor-conceived individuals and recipients.

Any approach by a third party for information from a donor needs to acknowledge the potential emotional impact of the request, the need for confidentiality and that the donor will possibly have a family who may have no knowledge of the donation having occurred. Donors may be ill-prepared for contact and as such if contact is not made in a discreet and careful manner, this could cause considerable distress for a donor and indeed any family they may have.

The impact on donor recipients should also be carefully considered. Those who utilised donor gametes prior to 1988 did so believing that this donation was anonymous. Whilst some recipients may welcome access to information for their children, this may also cause considerable distress for others who may still not have come to terms with their use of donor gametes or informed their children of their donor origins.

Providing donor conceived individuals access to information about their donor conceived half siblings is a complex and highly sensitive issue, particularly given that many donor conceived individuals (particularly those born before the introduction of the registers) may have not been informed of their donor conceived origins. MIVF would strongly recommend that any exchange of information between donor

conceived half siblings should be driven by the donor conceived individuals. The exchange of information between donor conceived half siblings should continue to rely on donor conceived individuals placing information about themselves on the voluntary register. However, for these registers to more effectively link donor conceived half siblings, a community education program should be implemented and management of the information provided on the voluntary register should be improved.

The legal, practical and other issues are discussed in further detail in the sections below.

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;

Sections 5 & 6 of the National Health & Medical Research Council's (NHMRC) Ethical Guidelines are relevant to the debate about whether all donor offspring should have equal access to information about their genetic background.

5.1 Respect all participants

Assisted reproductive technology (ART) procedures must be conducted in a way that is respectful of all involved. Clinical decisions must respect, primarily, the interests and welfare of the persons who may be born, as well as the long-term health and psychosocial welfare of all participants, including gamete donors.

6. 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.

6.1 Persons conceived using ART procedures are entitled to know their genetic parents. Clinics must not use donated gametes in reproductive procedures unless the donor has consented to the release of identifying information about himself or herself to the persons conceived using his or her gametes.

6.13 Respect the privacy of all persons involved in ART procedures. People have a right to privacy. Clinics must not release identifying information to another person without the consent of the person.

6.13.1 If the consent form does not include permission for release of identifying information 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.

The NHMRC guidelines provide a framework for allowing access to donor conceived individuals in a way that is respectful of all parties involved. The guidelines clearly recognise the rights of the donor conceived child to information about their genetic

background but indicates that these rights must be tempered with respect for the privacy and psychosocial wellbeing of the donor; that exchange of information should be voluntary and only with the consent of all parties. Melbourne IVF does not believe that the rights of the donor conceived child should over-ride the rights of the donor to confidentiality and control over their information.

A comprehensive donor linking counselling service plays an integral role in preparing and supporting the donor, recipients and donor offspring through this process and finding outcomes for the benefit of all parties involved. A sensitively managed linkage program based on a donor providing consent to the release of their information, can have greater success in linking donors and offspring than legislative changes requiring the mandatory release of information.

It has been Melbourne IVF's experience that donors may initially be reluctant to respond to contact from the Clinic. However, once they speak with a counsellor and understand why the donor conceived individual wishes to make contact with them, that the release of any information is voluntary and the options available to them (eg can provide information only with out identifying themselves) most donors agree to participate.

- 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;**

Melbourne IVF and the Royal Women's Hospital have always maintained information regarding donors and donor treatments. As such, Melbourne IVF and the Royal Women's Hospital would be able to provide information about donors who donated prior to 1988 relevant to the donor at the time of donation. Obviously further investigation would be required to gain contemporary information about donors based on the information provided by clinics.

Again the main issue in providing donor information is that we do not have the authority to release information either to a donor conceived child or a third party seeking information about a donor on behalf of a donor conceived individual, without the donor's consent.

A further issue would be managing a request for donor information where a donor is deceased and therefore unable to provide consent.

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

Options for implementing any changes to current arrangements include:

- Equal access for all donor conceived individuals to information about their donors in line with post 1997 donor conceived individuals; or

- Pre 1988 donor conceived individuals be given access to information about their donors in line with those born 1987 – 1997. This would mean that this group has access to information only with the permission of the donor.

MIVF does not support equal access for all donor conceived individuals as this does not protect the rights of the donor or respect the agreement that Melbourne IVF entered into with the donor at the time they donated.

MIVF supports the second option (that donor information is only released with the donor's consent) as long as this process is undertaken in a sensitive and respectful way that acknowledges the context in which donors consented to donation and adequately supports all parties through the donor linking process to ensure a successful outcome for all.

Assisted Reproductive Treatment clinics are able to provide donor linkage services to their patients without a change to legislation in the way Melbourne IVF currently does. However, this may limit the access to information for donor conceived individuals and their donors, as it relies on private clinics to undertake what is essentially a free service and would be dependent on the clinics being able to carry out their own investigation to locate a donor. Clinics would require greater access to information to assist in locating donors and would need to be adequately funded to provide such a service. A comprehensive community education program would also need to be established to raise awareness of the availability of donor linking services for those born before 1988.

A second and more appropriate option for providing donor linkage for those born before 1988 is that donor linkage is provided by a central service that has access to the registers and information held by the clinics. This centralised service should work in much the same way as The Infertility Treatment Authority (ITA) previously functioned where they would provide outreach to donors on behalf of donor conceived individuals, supporting both parties to make contact or share information in a way that is most comfortable for all parties.

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

Any request from a donor conceived person for information regarding their donor has implications for more than just the person requesting the information. There is a myriad of relationships where gamete donation has occurred with a minimum of 3 parties directly involved in the family formation ie the donor, the recipient parents and donor conceived individuals. If the donor has donated to more than one family and/or created their own family, there are then connections either genetic or social to all these individuals.

Despite this challenging framework in which donor linking can often occur, it is MIVF's experience through our donor linking service for those born prior to 1988 that the vast majority of contacts made have been reported by both donors and donor conceived individuals as having a positive outcome.

Donor (and family where they have one):

When assisting pre 1988 offspring to find their donors, MIVF works closely with both the donor and donor offspring to assist them in identifying their goals and preparing them for either meeting or exchanging information. It has been MIVF's experience that many of these pre 1988 donors are more than willing to be involved in assisting offspring learn about their genetic origins.

Some donors have wished to involve their families in this while others have been clear this is information they have never shared with family and do not wish to do so. Where a donor is not comfortable having their identity revealed, only non-identifying information has been provided by the donor as identifying information was felt to be too intrusive for the donors existing family.

A common response in MIVF's small sample of donor linkage cases for those born pre 1988, is that donors have often been wondering about offspring, but had felt they had no right to know. Some expressed a real desire to cooperate with the offspring and to assist them and derived great satisfaction from knowing that their donation had been successful. Some have gone on to form good relationships and strong bonds and expressed surprise and delight at discovering commonalities.

Donor Conceived Person:

In MIVF's experience, offspring wanting to make contact with their donor or seeking current information about their donor are typically seeking information about their donor's health, family details, why they donated and a profile of interests and talents that may help the offspring understand more about themselves.

It would be accurate to say, that these young adults are hoping to fulfil a deep desire for the answer to the perplexing questions about who they are genetically. Donor conceived offspring are primarily seeking information as it relates directly to their genetic heritage. They are not seeking a substitute parent or change in roles and responsibilities of the donor.

Those requesting information from a donor are often anxious about being rejected but accepting that their donor may not be found, or may chose not to cooperate. They have also been very respectful of the rights of the donor. They are aware that the donor donated when the expectations for providing information were very different from what they are now. When a donor has not been prepared to cooperate, the offspring have generally been understanding and accepting of this. Melbourne IVF provides support to the donor conceived individual to deal with their reactions to the donor's refusal.

Recipients:

The parent(s) of a donor conceived individual should also be considered when looking at the impact of any changes to the current arrangements. As discussed previously, whilst some parents may fully support their child's search for information about their genetic background, this may cause distress and anxiety for other parents who have struggled with their decision to use donor gametes or are worried about the impact of their child potentially meeting their donor and what this might mean for their relationship. Recipients should therefore be given access to any supports available to donors and donor conceived individuals. Additionally, any attempt to contact a donor conceived child born before 1997 should be made via the recipient parent(s) wherever possible.

Future Donor programs:

There would not need to be any change to Melbourne IVF's current donor programs, as under current legislation all donor conceived individuals have access to information about their donors once they turn 18 years of age and many recipients are accessing this information prior to their children reaching 18 years of age. Donors are carefully counselled by Melbourne IVF counsellors about donor conceived individuals' rights to access information about their donor and of the significance of the biological connection they will have with any individuals conceived using the gametes as per the NHMRC Guidelines.

f. The impacts of the transfer of the donor registers currently held by the Infertility Treatment Authority to the Registrar of Births, Deaths and Marriages;

The Infertility Treatment Authority (ITA) was responsible for management of the voluntary and central registers until 1st January 2010. In addition to the provision of information from the registers, the ITA also provided a donor linkage counselling service to individuals accessing the registers and those whose information was being sought.

In conjunction with this service, the ITA provided a comprehensive counselling service for donors, donor recipients and donor conceived offspring. This service provided counselling to support parents to tell their children of their donor origins, for assisting a donor conceived individual through the process of first learning they are donor conceived to thinking about contacting their donor, to assisting them to make contact with their donor and then to managing the outcome of this contact. ITA would also provide support to a donor who was considering accessing information from the registers or who received a request for contact from a donor conceived child or their parents.

The ITA also provided a 'Letter Box Drop' service where donors and recipients could send each other information and or requests for information without identifying themselves.

Since 1st January 2010, the donor registers are managed by Births Deaths & Marriages (BDM). BDM's role is purely information provision. The donor linkage counselling is provided by Adoption & Family Record Services (AFRS). This service provides one information session to individuals seeking information from the registers (this is mandatory for those accessing the central register). It does not provide counselling support to the individual whose information is being requested. Melbourne IVF is concerned about this reduction in counselling support to those accessing the registers or having information accessed about them and so offers this service to all past MIVF patients and donors. Melbourne IVF is also concerned that there is a split between the provision of information from the registers and linkage support.

An integral part to a donor conceived individual's right to information about their origins is ensuring that this information is provided in a supportive and comprehensive way that maximises successful outcomes for all parties involved. There should be a clear process where a third party takes responsibility for accessing information and

then approaching the party from whom information has been requested. Counselling should assist all parties to clarify process and expectations. All parties should feel in control of how, when and where information will be released. MIVF recently received feedback from a donor who had received notification from Births Deaths & Marriages that he had five donor conceived offspring. He described feeling shocked that he had received this information in the mail without any preparation for receiving such information or subsequent follow up. He felt ill-prepared for receiving this letter.

The counselling process should be conducted by counsellors with expert knowledge of the issues involved, and in a timely manner that allows adjustment to and careful consideration of all the issues involved including the individual family's requirements. Any program undertaking this sensitive counselling must be well resourced and offer flexibility to cater for individual need and ongoing support. It has been observed that some offspring will be presenting at a critical life stage where they are rapidly becoming adults and establishing their identity. It is no surprise then that seeking information regarding their donor is a vital part of this journey.

It is strongly recommended that counselling be available to both the individual seeking information from the registers and the individual who the information is being sought and that this counselling support be provided in an integrated way and tailored to individual needs as was the case when ITA was managing the registers. MIVF is concerned that due to legislative and resourcing constraints, the current counselling service offered by AFRS is a tokenistic gesture and not one that adds real value to the donor linking process.

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

A person has the right-

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

Given this, any changes to donor conceived individual's access to donor information would only be appropriate if this is undertaken with the donor's consent and that this consent is obtained through a sensitive and confidential process. This would preserve the rights to privacy of the donor as it would give donors the choice to give permission for identifying information to be provided and choice about the level of information provided.

<p>This submission has been compiled following consultation with Melbourne IVF Counsellors, nurses and Melbourne IVF Fertility Specialists and represents the considered opinion of those who have considerable experience in treating many forms of infertility including donor sperm, egg and embryo treatments.</p>
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