

**Submission
No 17**

**MANAGING INFORMATION RELATED TO DONOR
CONCEPTION**

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Mr John Barilaro, Chair,
Committee on Law and Safety,
Legislative Assembly,
NSW Parliament.
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Dear Sir,

Inquiry into Managing Information Related to Donor Conception

Further to my previous submission dated December 21, 2011, which I made to the Inquiry into the Inclusion of Donor Details on the Register of Births. Thank you for the opportunity to comment on this related Inquiry. Whilst I have given my professional background information previously I now do so again as it adds an important historical context to my submission to this current Inquiry.

Background

I am a psychologist (endorsed health psychology) and family therapist and have worked in the areas of infertility and assisted reproduction for more than twenty five years. For nine of those years (1992-2001) I worked as the clinic Infertility Counsellor at the then City West IVF (now IVF Australia, Western Sydney). I have also worked as a Couple Therapist at Relationships Australia, and in addition I set up the CJD Counselling Service in NSW, which was funded to counsel people (and their families) who had been treated with human pituitary hormones and were at increased risk of iatrogenic CJD. Since 2001 I have worked exclusively in private practice in Glebe, with about 50% of my work being related to infertility and assisted reproduction, particularly third party reproduction, including altruistic surrogacy and counselling of current donor gamete recipients and donors.

As an illustration of my professional expertise, I list here a sample of the papers/presentations which I have given at professional conferences and seminars over the years:

- Secrets in Families, Fertility Society of Australia, Conference, Adelaide, 1992
- Ethical Considerations in ART – A Baby at any price? Psycho-Social Implications. International Meeting of Consumers and Physicians (IFIPA), Sydney 1996
- Patient Satisfaction with ART & Counselling, Fertility Society of Australia Conference, Adelaide 1997
- Third Party Reproduction – Donor gametes, Surrogacy. Family Planning Association, Ashfield 1999
- Assisted Reproduction: Processes, Meanings, Dilemmas, National Family Law Conference, Sydney 2000
- Assisted Reproduction and possible long term family issues. Family Court Judges' Conference, Sydney 2001
- Information Provision, Coping Styles & ART Treatment Outcome, World Congress on Fertility & Sterility, Melbourne, November 2001
- A Voluntary Contact Register: Stakeholders, Values, Processes, Dilemmas. Fertility Society of Australia Annual Conference, Perth 2003

Professional Experience with Donor Sperm, Oocyte and Embryo Treatment

During my 9 years employment as Counsellor at City West IVF (now IVF Australia, Westmead) I conducted implications and decision making counselling sessions with gamete and embryo donors and recipients. Some of these cases involved the use of anonymous donation, mostly for sperm donor treatment, and others involved the use of known gamete donation, mostly for oocytes. In 1999 on behalf of the Australia and New Zealand Infertility Counsellors Association (ANZICA) NSW, I organized a professional workshop on "Donor Offspring Issues" which was attended by infertility counsellors from a number of Australian states and New Zealand.

During 2001-2002 I was employed one day a week as a Project Officer, Reproductive Medicine, at the Royal Hospital for Women, Randwick where my work involved the consolidation of all records of sperm and oocyte donors, recipients and offspring of donation since treatment started there in 1978. This required the development of a Voluntary Contact Register data base to facilitate record keeping, and counselling of patients, donor offspring and donors seeking information or contact. In collaboration with hospital staff I also reviewed and developed protocols for contact with all parties to a gamete/embryo donation conception as well as worked on developing processes for and searching for past sperm donors, connected to inquiries from donor recipient parents and donor offspring.

Over the years I have attended a number of conference presentations and seminars related to donor issues, the most recent of which was the Donor Linking Symposium organised by ANZICA,

the Donor Conception Support Group and the Victorian Assisted Reproduction Treatment Authority and held on December 3, 2011.

In the context of my professional background as a psychologist (endorsed health psychology), family therapist and infertility counsellor; and experience (more than 30 years psychologist & relationship counsellor, 27 years infertility counsellor) I make this submission in response to the questions raised by the Terms of Reference of this Inquiry:

Question 1. *Should donor-conceived adults have retrospective access to donor's identifying details?*

I do not believe that donor-conceived adults should have retrospective access to donor identifying details for the following reasons. I believe that if this were to occur it would place the rights of donor offspring higher than the rights of donors, which is inequitable. Whilst donor offspring did not consent to the anonymity of the donors from whom they were conceived, their parents did so, on their own behalf as recipients, and by implication on behalf of their potential child who then becomes the donor offspring.

Whilst the view of some parents and donor offspring may have changed over time regarding openness and access to information this does not mean that the views of all parents, donor offspring, and donors will have changed. Thus, I also believe that donor-conceived offspring should not have access to retrospective donor identifying information about donor siblings. It would be extremely intrusive and potentially psychologically damaging if a donor offspring were to contact a donor half sibling if that person did not wish contact, and particularly if they were unaware that they were donor conceived. To my knowledge there are many donor conceived offspring who are unaware that they are donor conceived, and I believe that their rights should be given equal value to the rights of those donor conceived offspring who are aware and who are seeking contact.

As I have worked in infertility counselling for more than twenty five years I am very aware as to how the values of stakeholders have changed over the years, and this includes the values of the parents of donor conceived offspring. At the time of assisted reproductive treatment when they were attempting to conceive their much longed for children using donor gametes (mostly anonymous donor sperm) patients were not uncommonly uninterested in the rights or needs of their future children and were often resistant to the clinic requirement that they undergo implications counselling before they had donor treatment.

There is an underlying unspoken assumption that it is essential that donor offspring know that they are donor conceived for there to be psychological health and wellbeing in their families and in their relationships. To my understanding there is no evidence from research that donor offspring who are unaware of their donor history are less psychologically healthy or have less healthy relationships with their parents. However research has only been conducted up to the

age of 18 years for donor offspring, because given that donor offspring have not always been informed of their donor history, it is not possible to obtain their consent to further research.

Though I am recommending against retrospective access to donor information it does not mean that I am unsupportive of the current system whereby donor offspring have access to identifying information at the age of 18 years. In fact I was one of those who have worked over the years to change the system. An illustration of this is my first presentation at a Fertility Society Conference in 1992 was entitled, "*Secrets in Families*" where I discussed the potential communication and relationship problems which could occur because of the use anonymous donor gametes, and in 1999 I organised an ANZICA seminar on "*Donor Offspring Issues*."

Whilst I have always counselled recipients and donors as to the benefits of openness it does not mean that I believe that those who do not agree with or act in this way are necessarily being incompetent parents or necessarily psychologically damaging donor offspring, and there is no research evidence of this. I have also occasional experience where information about donor conception has been used in a damaging way to deleteriously affect relationships in families.

I do however support the establishment of a Voluntary Contact Register through which donor conceived offspring and donors can seek contact, and in such a register information availability and contact would depend equally on the wishes of all parties to donor conception. This proposed Voluntary Contact Register would be a repository for all historical information (prior to January 2010) from ART clinics and privately treating medical practitioners. The establishment of such a Register would ensure that this sensitive data would not be lost and would be available for the very long term future.

Question 2. *If retrospective access were granted what conditions should apply?*

If retrospective access were to be granted then I believe that there should also be the possibility of a veto being placed on contact by any of the parties to the gamete donation, including donor offspring, donors, and recipient parents of children under the age of 18 years. Again I support the establishment of a Voluntary Contact Register from which non identifying information can be available about donor genetic and medical history, number of genetic half siblings, and contact could be initiated if all parties were in agreement.

An important consideration here is that even if there is identifying information about a donor, it may not be possible to locate that donor. They may have changed their name, have a very common name, changed their address, just be unlocateable or important information may have already been destroyed. I say this from my experience in the establishment of the Voluntary Contact Register at the Royal Hospital for Women, and my significant unsuccessful attempts to locate and contact sperm donors where offspring had requested information or contact.

Question 3. *What other issues would be raised by granting retrospective access? For example, how would the process of applying for information be managed? Would counselling and support services be required?*

Following an application to the organisation holding the ART Central Register, a search for information could be initiated. I believe it to be essential for there to be counselling and support services for all parties affected by a request for information. This would include donor offspring, donor half siblings, donors and members of their family, including their children, and parents of donor offspring. Counselling and support services could be provided through a number of entities such as the NSW Department of Health, the NSW Benevolent Society or perhaps assisted reproductive clinics. This counselling would then be based on the established ANZICA Guidelines for Professional Standards of Practice: Donor Linking Counselling.

Question 4. *Which agency is best placed to manage the register of donor conception information (donor register)? Is the current management of the register adequate?*

I believe that the information on the ART Central Register is best maintained by the Registry of Births, Deaths and Marriages, because they already have established record keeping processes, particularly for the maintenance of records for the long term future, and access and availability protocols. I do not believe that current management of the ART Central register is adequate, though it has not been really tested because of the short period of operation, and age of offspring. This however is not a criticism of the NSW Department of Health but a comment on the current guidelines under which the Register was established.

I believe that in addition to the ART Central Register there should be established an ART Voluntary Contact Register for information prior to January 2010, whether or not a decision is made to allow retrospective access to information. I believe that it is important for this information to be maintained by a government body and not only by the ART clinics which is the current situation. Again this is not to criticise the ART clinics but there is no guarantee that the information will be available in more than fifty years time, when it would be if held by a government body. The long term availability of donor conception and surrogacy birth data should be entrusted to BDM which is already doing so for other personal data.

I have no concern regarding privacy of information held by BDM. They have much information that is private, this is what they do, and I am sure BDM have very clear established guidelines regarding privacy. If however a decision were to be made to maintain the Register at the NSW Department of Health or separate agency (similar to VARTA) I believe that they would also have the capacity to manage applications for information within proscribed guidelines.

Question 5. *Should a standalone body be established to manage the register? What other areas could it have responsibility for?*

I do not have a strong view with regard to this question, and believe that all three options are viable options, though as stated above I believe that the BDM is the most appropriate option.

Question 6. *Should counselling and support services be offered to those seeking donor conception information from the donor register?*

Question 7. *Are there other types of support that could be offered?*

I believe that counselling and support services should be available for donor offspring seeking donor conception information, and also for those recipients or donors who are wishing to inform their family members of the past gamete donation.

It is interesting that in the discussion paper for this Inquiry that the needs of gamete donors are somehow implicitly seen as less valid or noteworthy. Thus an illustration from the Discussion Paper related to this question, *“The Committee is of the opinion that some level of counselling may be beneficial for people who are seeking to access donor conception information, and to parents wishing to tell their children about their conception.”* Whilst this does not specifically say that it is donor offspring seeking *“donor conception information”* it is by implication relating to donor offspring, and from my experience it is mostly donor offspring seeking information.

There is no clear mention of the valid needs of donors, donors for whom the rules have been changed significantly since they made the sperm donation many years ago. From my understanding there was little if any pre donation counselling of sperm donors in the past (over 20 years ago) which in my view was disrespectful of the needs of the donors. It continues this disrespect not to acknowledge them as equal parties at this stage.

This counselling and support would again fit within the ANZICA Guidelines for Donor Linking Counselling. I believe that counselling and support is important not only for when there is link found and possible contact, but also if there is no retrospective access to information, or there is no information to be found. Despite the best intentions of all involved it is not always possible to find information, or the information may be significantly different from the imagining or belief of the donor offspring, and in such a situation it can be very difficult for donor offspring and their parents.

There is a need for letterboxing, as is undertaken by VARTA and also in my experience has been undertaken by individual clinics. There is also a need for education and information, and support services, which could be done through a specifically established organisation such as VARTA or through a funded service at an organisation such as the NSW Benevolent Society.

Question 8. *How would support services be funded? By the government, the individual seeking the service, or by ART clinics?*

Over the years I have counselled donor offspring, recipient parents, and gamete/sperm donors. This has mostly occurred through a clinic, or through my private work, where it has been paid for by the patient/client. However when I was employed by the Royal Hospital for Women to establish their Voluntary Contact Register it is my understanding that the work was funded by a special grant from the hospital Foundation. I have no strong opinion as to who should fund donor linking services, though I do believe that if there were to be government funding that it should be limited to specific issues and a limited number of sessions. Regarding the suggestion that this counselling could be undertaken under a Mental Health Plan, work which I currently undertake in my private psychological practice. From my understanding of the requirements for use of this service I do not believe this would be an option generally, but would be limited to those who have a diagnosed mental health illness.

Question 9. *How would such support be provided? By referral to the Department of Family and Community Services (as with adoption) or by a standalone body (as has been recommended in Victoria)?*

Donor conception information, or donor linking counselling could be undertaken following a request initiation through the body holding the ART Central Register, or an ART Voluntary Contact Register. The counselling and support services could be provided by NSW Department of Health, the NSW Benevolent Society, or a new body similar to VARTA.

Question 10. *How long should ART clinics be required to retain records?*

Question 11. *What should happen to records if a clinic closes?*

Question 12. *How can we ensure the integrity of records? For example, ensuring that they are not destroyed or tampered with?*

One reason why I believe that ART records should be kept by the Register of Births, Deaths and Marriages, is that they are already doing this for other important personal data, and it is my understanding that the records are kept forever. It should be the same for the ART Central Register and a ART Voluntary Contact Register. Given the rapid changes in genetic knowledge it is foreseeable in the future that either a donor, or donor's family member may wish to advise of genetic related health issues; or donor offspring, or their child/ren may wish to access genetic information. This extends the requirement for access to information about donor conception into the distant future as well as to the present, or even mid term future.

The Register of Births, Deaths and Marriages, already has in place limitations on access to personal data, such as birth and marriage data for a time limited period of many years. Though I do not support current retrospective access to information, which relates to as little as 3 years ago, I do support the establishment of protocols for retrospective access to donor conception data on a similar basis to the current protocols for information held by BDM for birth and marriage data.

Some final comments from 25 years of Infertility Counselling

The emotional needs of stakeholders to donor conception vary over time. Thus for example, the emotional needs of recipient parent/s can be overwhelming when they are hoping desperately for a baby. At this stage it is their emotional needs that are dominant and the needs of the yet to be conceived donor offspring are not really on the table, despite the best intentions of ART clinics and counsellors. This is not just from experience in the past where it was not common practice for donor access and information to be available, but even now I am counselling people who cannot consider the future while their emotions are so dominated by being unable to have a child, and the fear that it may not eventuate.

In my experience, once a child is born through donor treatment, the parent/s love that child more than their own emotional pain of their infertility, which gradually recedes over time, though it never disappears entirely. After a donor conception birth when they love and care for their so longed for child, the needs of the child, the donor offspring, become more pressing, and hence the need to do the best they can by this child. Over time as they love this child in their family, they may become more interested in helping their child gain access to information or contact with their donor. As I have said, from my experience and from research, this is not the situation in all families with donor conceived offspring and there are many donor conceived offspring who are unaware of their donor conception.

And past sperm donors, who donated 20 or more years ago, have their own sorting through and rearranging of emotions to process. From my knowledge, many of them were very young men who were not counselled at all about the implications of donating their sperm. They may have only realised the implications of having donor offspring when they had their own children, and they may not know how many donor offspring they have, and there could be many offspring. This could be quite scary for them. A decision made to donate in the enthusiasm and naiveté of youth may have ramifications twenty years on, and the needs of these donors should be respected as equal, though perhaps different from, the needs of other parties to a gamete or embryo donation conception, including the offspring of donation conception.

I thank the members of the Inquiry for the opportunity to submit my views and would be available to attend the Inquiry if it were to be requested.



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