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Submission to the Inquiry into Access by Donor Conceived People to Information About Donors

I am a donor conceived person and I have previously told my story to the Committee in my submission for the interim report. I have personal knowledge of the harmful effect of the current secrecy provisions in the ART Act. For no other reason than the fact that I was born before 1988, for five years I was unable to have knowledge of half of my biological identity because of this legislation. As it happened, my biological father was happy to have contact. He just needed to be asked. In his very first letter to me he gave me his full name, address, telephone number, family tree, and photographs of himself and his three children (my half brothers and sisters). About two months later I met him and his children and we have been in regular contact ever since. We weren't able to connect via the Voluntary Register because he simply hadn't heard of it. Why would he know about it? The existence of the Voluntary Register isn't advertised in print media, on the radio or on TV.

So I experienced five years of frustration and lost five years of contact with my biological family, for no reason, except the rigidity of the current legislation, which prevents any flow of information from donor-conceived person to donor, or vice-versa. In some cases the lack of openness can have life-threatening consequences. Narelle Grech was the first

other donor-conceived person I ever met, and meeting her changed my life. Recently, after going to hospital with acute abdominal pain, she was diagnosed with stage IV bowel cancer. Bowel cancer runs in families, but there is no history on her mother's side of the family. If her biological father does have bowel cancer in his medical history he doesn't have any way of transmitting this information to Narelle. Even if he contacted the clinic where he donated, they would not be compelled to pass the information on. Narelle has eight half siblings, and the rigid embargo on communication means she can't pass on this important information. Perhaps one of them will go on to develop bowel cancer, unaware they have a family medical history of the disease. Even though Narelle has been searching unsuccessfully for her biological father for thirteen years, and her cancer may not be curable, there has been no compassion shown for her situation by bureaucrats holding her records.

- 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; and**

- 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;**

Much has been made of the existence of so-called 'contracts' that supposedly gave donors an iron clad, watertight, legal guarantee that their identity will not be released to their children. The Committee received an example of a statement and consent form, from the Royal Women's hospital, which was included in the interim report. I believe the Committee made an oversight in not noticing that what this statement and consent form or 'contract' actually says is;

I understand that the identity of any recipient shall not be disclosed to me, nor shall you voluntarily reveal my identity to any recipient.

In other words, there is no mention of any guarantee that the donor's identity will not be released to either his donor-conceived child, or a third party, such as the Victorian donor registers.

I have tabled three donor statement and consent forms from Prince Henry's hospital, the Royal Women's hospital and Queen Victoria Hospital (Monash). All of these are similar, and all say only that the identity of the donor shall not be released to the recipient (woman undergoing insemination).

I suggest to the committee that in light of the known existence of a number of donor statement and consent forms that do not preclude the identity of the donor being released to either the donor-conceived person or a third party (e.g. donor register), the existence of such contracts is a **myth** that has been perpetuated by clinics and the Fertility Society of Australia (FSA), who are the main opponents of reform (the overwhelming number of submissions received by both the VPLRC interim report and the recent inquiry into donor conception conducted by the Legal and Constitutional Affairs Senate Committee were supportive of removing secrecy provisions. The main opponents were some, but not all clinics, and the FSA).

In the absence of any evidence as to the existence of contracts forbidding the release of the donor's identity to his children, I suggest that the burden of proof should be on clinics to prove the existence of these contracts, rather than the onus being on us, the donor-conceived people, to prove that they don't exist. In any case, even if such a contract does exist, how could the donor-conceived person, who wasn't conceived at the time the contract was signed, be considered in any way a party to, or bound by such a contract?

The other question the Committee must consider is the question of retroactive legislation. The government does have the power to pass retroactive legislation allowing the release of identifying and non-identifying information about donors to donor-conceived individuals. However, the passing of retroactive legislation is not commonly done.

The most obvious precedent is the case of the Adoption Act (1984). Twenty-seven years ago law reformers in Victoria were considering almost the exact same conundrum facing the VPLRC today. Adoptees were agitating for changes to remove secrecy provisions in closed adoptions and there were many heart-breaking stories about the harm caused by the current state of the law. In 1984 Victoria decided to give all adoptees dating back to 1928 the right to information about their biological family, despite a promise given to relinquishing parents that they would remain anonymous, and concern from some members of society that changing the law would affect the privacy of relinquishing parents who wished to remain anonymous.

Recently in NSW a **retrospective** law introduced in 2008 gave lesbian partners of women who conceive through artificial insemination legal parenting status. This has huge implications. For example, in one case, a sperm donor listed on his daughter's birth certificate, who has had regular contact and contributed to the cost of her upbringing and education, and was considered her father in all except legal terms, is fighting through the courts not to be expunged from his daughter birth certificate¹. Surely a law permitting retrospective re-engineering of legal parentage and birth certificates is more controversial than a law allowing people such as myself the legal right to know the identity of our biological father?

In both adoption and donor conception the arguments based on balancing rights and interests are very similar. In adoption it was decided that possible injustice to one party (some birth parents) was acceptable in correcting a manifest injustice to others (adopted people, birth parents who wished to release their information and parents who wanted their children to have information about their identity). In exactly the same way, in considering the balance of rights and interests of all parties, the possible injustice to one party (some donors) is acceptable in correcting a manifest injustice to others (donor-conceived people, donors who wish to release their information and parents of donor-conceived people who want their children to have information about their identity).

Today it is no longer controversial to allow all adoptees access to their records, and all Australian states and several other countries have followed Victoria's lead. The VPLRC has a successful legislative model from Adoption law reform to use as a template for how to reform the law governing donor-conceived people's right to access information about their biological identity.

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;

Any records that have been lost should not prevent people obtaining information where their records do exist.

¹ <http://www.theage.com.au/national/sperm-donor-could-lose-his-status-20110802-1i9wq.html#ixzz1UhLSbMF5>

d. the options for implementing any changes to the current arrangements, including nonlegislative options;

Legislative change is required because any other options, including non-legislative options, do not protect records and do not resolve the murky legal status of what action may be taken to contact donors, leading to discrimination against donor-conceived people and other poor outcomes such as future destruction of records.

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

Many donor-conceived people are currently suffering. I know a few of their stories and they are heart-breaking. Many donors wonder about the children that were conceived with their sperm and wonder if they are healthy, happy and loved, and would like the opportunity to answer any questions the donor-conceived person may have. Other donors may feel nervous about changes, but what they need is the counselling that was never provided when they signed up for the original donor programme, and the chance to explore what this might mean for themselves and their family before they make a decision.

The Committee should recognise that this is not about forcing people into relationships that are unwanted, it is about dismantling an antiquated and inhumane system that denies people knowledge of their biological identity. Donors who do not want contact will be free to assert this right. If it is considered necessary, the Committee could include a provision into new legislation giving donors the right to a contact veto.

The right to know who we are should not be compromised by the wishes of either party, even if they do not want to be contacted. Everyone involved are adults and should be treated as such. Those not wanting contact can simply make their wishes known, as do adults in other spheres of life. Not wanting contact is insufficient reason for either party to be denied information about the other.

Victoria has the chance to once more be a world leader on an issue of social progress in righting an injustice. The world is watching. Establishing reciprocal information access rights for donor conceived people and donors will most likely be copied by other jurisdictions in the near future, as was the case in adoption law reform.

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 key to ensuring the success of awarding donor-conceived Victorians the same rights as adoptees is recognising the sensitivity of information that may be released by having appropriate counselling/mediation services in place.
- This structure was previously in place via the integrated 'one-stop shop' Infertility Treatment Authority (ITA), which enjoyed very high levels of satisfaction amongst service users
- Many of these essential counselling/intermediary services have been lost as a direct result of the transfer of the donor registers from the Infertility Treatment Authority to the Registrar of Births Deaths and Marriages and the subsequent splintering of the functions of the ITA between three bureaucracies (BDM now hold the donor registers, FIND provides counselling and VARTA do public education)
- These counselling/intermediary services need to be restored into the previously successful integrated model in order for any planned reform of information management to succeed in practice. It is recommended that authority over the donor registers and services in relation to applications to the registers (e.g. counselling) be returned to VARTA who have the staff and the expertise to do a first class job, as was previously achieved at the ITA
- The previous integrated ITA service model also had the benefit of being very cost effective. It was administered by a pro rata: 0.4 Donor Registers Officer and 1.2 Donor Linking Counsellors. In contrast, splintering the functions between three bureaucracies is much more expensive.

The people the committee should be listening to are the social workers and counsellors who have years of experience dealing with donor-conceived people, donors, their families, and bringing the two together through donor-linking. Helen Kane is a social worker with many years of experience in the adoption and donor conception fields and previously worked at the Infertility Treatment Authority. All quotations come from her submission to the Victorian Law Reform Committee interim report.

"I believe that it is important that all donor-conceived people possess the right to seek information which identifies their donor. That does not mean the automatic release of that information without the involvement of the donor."

Helen was involved with the implementation of the 1984 Adoption Act in Victoria. *"It was retrospective, and was a clear and positive success, as long as it was accompanied with good counselling and linking services, which acknowledged the needs of all the people concerned."*

She provides a model for how donor conception information management might be reformed, based upon the adoption precedent. *"The first step was extensive publicity about the changes, and dissemination of information about how this translated into action. What was essential was a practice of involving all the parties as required, and moving at their pace. This included exchange of non-identifying information, which helped decision making about proceeding to closer contact, or not. But it was the people themselves who made those decisions, not an agency or a law which denied them the right to even consider this. Social workers provided the counselling and outreach/mediation services to support this process."*

In summary, *"It is essential that counselling be an integral part of any service which manages such requests (for identifying information)."*

I believe the key term of reference for the current inquiry is (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.

In the course of this transfer many essential services have been lost. The most crucial include the loss of all counselling services for persons born prior to the 1988 enactment of legislation as well as other parties affected, such as partners, parents and children of donors and donor-conceived people. Furthermore, if the person under outreach declines to give their consent the applicant receives no support or explanation as to the reason. BDM communicates with the parties via letter only.

Frustratingly, the wording of the ART Act prevents exchange of information between Births, Deaths and Marriages who hold the information contained within the donor registers, and FIND who provide the counselling services for people making applications to the donor registers, meaning the counsellors at FIND can no longer give people counselling specific to their circumstances, or act as an intermediary to exchange non-identifying information between donor and donor-conceived person (with their consent) to help develop a sense of trust. In addition, no intermediary service is provided to forward letters between parties so that they can communicate together without releasing their private details, as was previously offered by the ITA.

This means that **the person who has been contacted as a result of an application to the donor registers currently has no information upon to make their decision whether to give consent to release information.** Clearly this would be an even more unsatisfactory situation for pre-1988 donors who may not be expecting a request for information and unsure of what the consequences of agreeing to any such request would mean for themselves and their family.

A donor-conceived person unaware they are donor-conceived as their parent has not informed them, can be contacted as a result from an application by their donor; and discover their origins by a letter from the Registry with no specialised counselling or support provided.

Previously the Infertility Treatment Authority (ITA) was able to provide an integrated comprehensive service to donor-conceived people, their parents and donors, their partners and children. This was provided from first point of enquiry, to application, to counselling to mediating and facilitating a successful arrangement comfortable to both parties, to assistance and support to navigate exchange of information and occasionally to facilitate a meeting between parties. This integrated service was also a very cost effective service. It was administered by a pro rata: 0.4 Donor Registers Officer and 1.2 Donor Linking Counsellors.

Currently there is inadequate support for people considering making an application to the Registers. I recognise that the decision to move the donor register from the ITA/VARTA to BDM was made under the previous government. Considering the large weight of evidence that this was a mistake and that services and levels of satisfaction have dropped steeply, and costs have increased (due to fracturing services across three bureaucracies) I urge the Committee to reinstate authority and management of the donor registers to VARTA.

I look forward to progress on this issue in the near future and would like the Committee to know that I am happy to appear at any public hearings to provide more information regarding this inquiry. Thank you for reading this submission.