SUBMISSION TO THE QUEENSLAND PARLIAMENT INQUIRY INTO MATTERS RELATING TO DONOR CONCEPTION INFORMATION

Ian Smith

Former Sperm Donor - Prince Henry's Hospital Melbourne 1986/87.

PhD Candidate – Latrobe University Law School

[redacted]

I am pleased to be able to respond to the call for submissions to this Inquiry. This is a very complex area – mixing legal, medical and social issues. Past practice in this area, in all States and Territories in Australia, has in my view failed to adequately take into account the significant human impact of decisions and practices regarding donor-based Assisted Reproductive Technology.

I am not from Queensland, nor were my sperm donations made in the State, thus I cannot provide commentary specifically relating to Queensland. However, I believe that I can offer useful comment, based on several, interconnected, perspectives. These are:

- my own experience as a sperm donor (in Victoria, in the mind 1980's)
- my subsequent volunteer work both in connecting and engaging with donor conceived (DC) people and former sperm and egg donors, and in working for change in policy and practice regarding people affected by donor ART
- my current research work as a PhD candidate - this work examining the socio-political dynamics that lead to the world-first retrospective changes to the laws In Victoria regulating access to information about sperm and egg donors.

My submission concentrates on these matters particularly as they relate to sperm donation/sperm donors. This is not to ignore the place in the donor conception triad of egg donors. However, my primary experience – personal, connecting with donors, and my research – is with sperm donors.

I would be happy to appear before the Inquiry, if that would be of value.

****

My submission begins by giving, by way of context, some brief explanation of my own personal experience and involvement in donor ART – as a former sperm donor. My comments then cover the following matters – all of which are specified in the Terms of Reference for this Inquiry:

- Rights of donor-conceived persons, including to know their genetic origins and Rights of donor-conceived persons, including to know their genetic origins;
- Extent to which identifying information about donors should be given to donor-conceived persons, taking into consideration the right to privacy of donors;
- Access to historical clinical records and implications of retrospectivity;
- Access to support and counselling for donor-conceived persons and donors;
- Whether a register should be established and options to manage collection, storage, and disclosure of identifying and non-identifying information about donors, donor-conceived persons and relatives;
- Benefits, risks and implications on donor conception practices arising from any recommendations.
- Current governance/regulatory frameworks, including registers established interstate;
- Whether and how to collect and disclose identifying information about donors where a donation was made on the condition of anonymity, including matters relating to consent;
- whether any model should include information from private donor arrangements;

In addition, while this is not specified in the Terms of Reference for the Inquiry I would like to propose for consideration a “Donor Linking” repository that would enable donors to lodge information and materials about themselves and their families – these materials to be safely stored in order to enable them to passed on to DC Offspring, if the latter seek out their donor after she or is deceased. ;

Personal Experience of Involvement in Donor-based ART and Work with Donor Conceived People and Gamete Donors

I am the biological father of nine children. Two of my offspring live with me and seven I have never met. The latter are the result of my being a sperm donor in the program at the Prince Henry’s hospital in Melbourne in the mid 80’s.

At the time that I was a sperm donor I was then in my early 30’s. I saw no prospect of marriage and children at the time and responded to a call for donors. I was acting from altruistic intentions. I had some awareness of issues of infertility because I had a close friend who was in that circumstance and I wanted to help people who wished to have children but could not do so because of infertility issues. I saw that I could help and I felt good about doing so. It seemed very simple then.

Now I see that it is not simple at all. I'm married, I have (now adult) children and can see before me the whole process of the development of a person who is the sum of so many genetic and familial influences. At times I feel quite anguished that I have seven other children somewhere in the world who carry a part of me and my genetic and family background but over whose lives I have no direct influence at all. I have wondered if they are alive, if they are healthy, happy, well cared for and loved. For me that question, in relation to one of those donor-conceived people is beginning to emerge. A donor-conceived daughter connected with me – via the Victorian Reproductive Treatment Authority - in November 2020. Since that time we have been slowly exploring our deep – and complex – connection. For the other six of my donor-conceived offspring I wait and wonder if I will ever know more of them.

One thing is very clear for me. That is that the interests and wellbeing of the children – all of them – are paramount. Regardless of what the legal framework was at the time of my being a sperm donor, I believe that I do have responsibilities to the children born as a result of my sperm donations. At the least, those people have a right to know what my part of their genetic heritage is – more if they want more. To that end, I have registered with the Voluntary Register here in Victoria and I have made myself available to be contacted if and when and how my offspring may seek to do so. I have also been active in engaging with both donor conceived adults and former gamete donors. I have worked to encourage and enable connection and understanding between both and in doing so I have developed insight into the complex dynamics that are at play in this area of human life.

A key thing apparent to me in my reflection on my own experience, and my experience of meeting many gamete donors and donor conceived people, is that that there is a very complicated human aspect to what I fear many in the medical profession have often, in the past and to a significant degree still now, viewed as simply a clinical process. It is not simply a clinical process. It is a very complex social issue - as well as a medico-legal issue. Governments, world-wide, are now left with the task of attending to the mess left from previous actions in this field. I say that it is imperative that Governments act decisively – with full regard to the impact on the people who are involved here: the donor conceived people, the gamete donors, and the families of all of those people. It is those people whose interests and welfare are paramount.

Much of the current focus in discussion of ART is about enabling people who want to have babies to do so. The risk there is that insufficient attention is given to the impact on the people being born from that ART. The babies grow up to be adults. I say that the rights of the donor-conceived people should be the predominant point of attention in any instance of consideration of ART policy, law and practice.

Responses to the Inquiry Terms of Reference

Rights of donor-conceived persons, including to know their genetic origins; and the extent to which identifying information about donors should be given to donor-conceived persons, taking into consideration the right to privacy of donors.

I strongly support the principle that donor conceived people should have, as a basic human right, access to information about their genetic heritage and thus to information regarding their gamete donors. I say that this principle should be at the base of any Government policy and action. I say too that, while giving primacy to that right to know, there is a need for careful and sensitive approaches to the gamete donors – some of whom made those donations on the basis of anonymity and some of whom either wish to preserve that status, or have hesitations about a change to that regime.

In my submission to the 2012 Victorian Parliamentary Law Reform Inquiry I argued the case for changes to be made which would remove donor anonymity –even where this had been promised as a condition of the gamete donation (as, for example, was the case for me when I was a sperm donor in 1986/7). In making that submission I observed that one set of human rights has, inevitably, to give way to some degree, in a circumstance such as this. Both sets of rights cannot be fully maintained. The right of sperm and egg donors to retain anonymity is, in my strong view, ultimately inferior to the rights of donor conceived people to know their biological origins. The rights of the donor conceived are, in this instance, the more important and should be accorded priority. That said, the rights of former gamete donors must be treated with respect and care. It is not simply a matter of telling former donors the promises made to them are without meaning and are to be voided, regardless of their views and feelings.

The promises made to people like me were, in my view, wrong. I believe that many of clinicians and scientists, especially in the early days of donor ART, had been so excited by the scientific possibilities of what could be done that they largely ignored the social and emotional impact of what they were doing. Those impacts fall on both the donors and the donor conceived people. The promises, of anonymity-for-ever, that were made should not have been made – but they were. Donors such as me acted on the basis of those promises. Some, indeed I believe the majority, of past sperm donors, are willing to forgo that promise of anonymity made many years ago. Some actively seek to surmount that anonymity and to proactively connect with their donor-conceived offspring. Equally, there are some for whom the removal of the anonymity that they were promised when becoming a donor is a profound betrayal of undertakings made to them, and an invasion of their privacy and the privacy of their families. Some former donors speak of the unfairness of "changing the rules after the game has begun", another I spoke to in the course of my current research recounted the profound betrayal he felt had been perpetrated by the retrospective law reforms which removed his anonymity. The views of these people are valid and should be heard and considered. Equally, there is evidence of a large portion of the donor community who are willing, some even eager, to relinquish their promised anonymity and those views mesh and support the argument from many donor-conceived people who seek the right to know biological identity and heritage.

One pointer to the willingness of many former donors to not only be non-anonymised, but actively making themselves available for connection with their donor-conceived offspring, can be seen in the numbers of former sperm donors signing up to the Voluntary Register in Victoria – thus pro-actively letting go of their right to anonymity. Equally, there is evidence that some donors are very anxious about removal of their anonymity. From my own work engaging with former sperm donors, I know personally of men who sit at both ends of that spectrum. There are men who feel passionately that they should be known and who want to be known to their DC offspring, – and others for whom the prospect of removal of anonymity is profoundly troubling. The report on consultation with former donors conducted in Victoria 2012 provides a good representation of points across that spectrum.

There is a very difficult balancing act to be undertaken here – meeting the paramount principle of the right of donor conceived people to know their genetic identify while taking into account the significant impact on gamete donors of any change in policy and practice regarding access to information about donors by their genetic offspring. As I've argued above, I believe that on balance the scales should tip to the side of donor conceived people having the right, if they wish to, to know of their genetic heritage. However, that brings with it significant impacts for the donors for whom promised anonymity will be removed – in some cases against their will. The more militant in the DC community say to such men, "Tough, get over it". I do not think that is it that simple. I support the principle that DC people should be able to discover their genetic identity if they wish to do so. I argue too that this must be achieved while respecting the views of those donors who are hesitant about the removal of their anonymity. In parallel too significant measures should be put in place to engage, support and explain to gamete donors why this change in practice is to be made and how and why it would be implemented.

In Victoria the retrospective removal of donor anonymity occurred in two legislative tranches. The first (2013) enabled retrospective removal of donor anonymity regardless of date of the gamete donation. However, identification of donors required the approval of the donor. This legislation aimed to make a compromise between the desire of DC people to identify their donors and the reticence of some donors to relinquish their anonymity. The later tranche of legislation (2016) removed the requirement of donors to agree to their DC being provided with information identifying their donor/bio-parent. Donors were/are though able to lodge a veto which proscribes any contact with the donor. Information published by the Victorian Reproductive Treatment Authority (VARTA) show that in the early stages of the identity release regime - 2018/19 - of the 94 cases where applications were lodged by donor-conceived seeking identifying information about donors, 1/3rd of those resulted in the donors implementing contact vetoes. To my knowledge, there have been no instances of contact vetos being breached.

My professional work has been in the area of facilitating organisational change and mediation of workplace conflict. That work has led me to the strongly held view that change is a long term task – and one best achieved through cooperation rather than coercion. In my experience, coercion breeds anger and resistance. Conversely engagement, conversation, collaboration generally yields sustainable results. I am concerned that, in some instances the effect of forcing release of a donor's identity regardless of the donor's wishes, will be that some donor-conceived people will achieve a pyrrhic victory – obtaining the identify of their donor but, because the donor has been forced to relinquish anonymity, being blocked from obtaining any further information or cooperation from the donor. I know this to have been the case in some instances in Victoria. Mindful of these dynamics, I argue for consideration of an approach that would, while encouraging relinquishment of anonymity, would not force this on donors in the face of opposition. In such cases, I would propose that donors should be actively encouraged to allow themselves to be identified to their DC offspring (if that is the desire of the latter), but that they not be forced to relinquish anonymity. Further, I argue that by force of law, donors who do wish to retain anonymity should be required to provide certain information, (about ancestry and health information for example), to their donor offspring while retaining the right to preserve their anonymity if that is their wish. I believe that this softer and more conciliatory approach has the potential to lead to fuller and further contact between a donor-conceived person and their biological parent at some future time, when the donor may have had more time to consider and come to terms with the knowledge of their DC offspring's existence and the desire of the latter to know more of and about their donor/bio-parent.

Making change in a complex and sensitive area such as this is hard. In addition to the measures above, I advocate proactive publicity and community education regarding any changes that are to be considered in this area of policy and practice, and active engagement with both donor conceived people and former sperm and egg donors about any changes to policy and practice. There is a need for advice, counselling, support to enable all those impacted – the donors, the donor conceived people, and their families – to make their way through these complex matters, (and I address the issue of counselling further below). The work undertaken by VARTA, which followed the changes in Victorian donor-conception legislation which came into effect in 2017, provides an excellent model of practice in this regard.

Access to historical clinical records and related matters.

Records regarding donor conception are critical to connecting donor conceived people with their donors, and vice versa. In Victoria it is the case that some records are well preserved, in others, records have been lost or destroyed. The impact of the latter for donor conceived people is monumental. For example, for a donor conceived person for whom there is no donor code or extant and accessible they quickly reach a dead end. Anecdotal evidence suggests that the same applies in other States – that is, that the records of gamete donations are frequently incomplete and/or hard to locate. Retention and preservation of donor conception records is thus imperative, as is enabling access to such records for the purpose of searching and donor/donor conceived linking.

Searching for information about donor conception and former donors, in order to make connections between donor conceived people and their donors, is an important and complex process. That process is made harder with the paucity of older DC records and the often limited access to those records (where they exist). Work in Victoria, in response to several tranches of legislative change in this area, provides a good model of practice. One element of that practice is the work of VANISH (a small NFP group which focusses on meeting the needs of people effected by adoption, and more latterly those effected by donor conception) is salient. VANISH has considerable expertise in searching for family information and connecting people separated from their family of genetic origin. I would advocate that the Queensland Government give priority to establishing a search and investigation capability, similar to that of VANISH. I would further advocate Government funding of such a service - thus making available to donor conceived people the capacity to search for their donors at no, or little, cost to the DC people.

In the same vein, I advocate enhanced practice for locating and verifying records and working to redress gaps which exist in donor records. It is of vital importance that legislated requirements are put into place which can both discover and protect collations of donor records – including records held in private hands by clinicians (and potentially by the families of clinicians who have died). Once again, the precedent set by legislation in Victoria, and the work done by VARTA in this regard, provides a good model for practice.

Despite best efforts to locate and preserve records it is inevitable that there will be gaps. In the absence of adequate records, DNA testing provides virtually the only means of verifying family genetic connections. I understand that the science around DNA testing is complex and I make no claim to understand that science. Thus I do not propose any particular approach to DNA testing, record keeping and matching. I do though strongly advocate the establishment of a suitable form of Government supported, and funded, DNA testing and record keeping for donor-conceived people and donors. In this context I note that the 2011 *Senate Legal and Constitutional Affairs References Committee on Donor Conception Practices in Australia* recommended (Recommendation 12 7.76) that any voluntary registers incorporate a DNA databank in order to enable donors and donor conceived individuals to have their details placed on the register for possible matching, in circumstances where records relating to their identities have been destroyed.

Once again Victoria provides some potential guidance. The legislation which is to come into effect in that State in 2017 enabled VARTA to undertake DNA testing where required as part of the process of establishing donor/donor conceived person linking. I understand that VARTA has initiated such testing in some instances – particularly where doubt existed as to the veracity of the records on which donor/DC offspring matches were being made. I argue that DNA testing, now readily available and at relatively low cost, should be offer, as a matter or course, to donors and DC offspring where matches have been made on the basis of clinic records. This would remove the possibility of false matches being made, as has happened in at least one notable instance in Victoria, and would remove any degree of uncertainty that may exist - on the part of either the DC person and/or the donor/the donor's family.

A logical progression from the collection and matching of DNA records would be to collate those records and to progressively build a database of DNA records, with tight provisions for ensuring security and confidentiality of such records. Ideally a donor conception DNA database would be a national undertaking. My comment below, relating to State-to State and national coordination of practice, is pertinent to consideration of this idea.

Implications of retrospectivity in opening up records and potentially removing donor-anonymity.

Retrospective action was a central argument from the proponents of DC law reform in the case of Victoria. I expect that will so too from those seeking similar law reform in Queensland. There is a strong basis for action to enable all DC people – regardless of when they were conceived – to be able to access records which will enable them to know their biological identity and heritage. In the case of the Victorian law reforms the argument was that, because of multiple tranches of legislation, DC people conceived at different times had different degrees of access to information about their conception. The argument there, and I expect it to be the same in Queensland, was that retrospective action was need to make information access the same for all DC people – regardless of when they were conceived.

However, retrospective change such as this is a very significant step. Such action sits uneasily with the principle that law should be able to be known to all, so that people can rely on the law as it is at the time that they act. In the case of the debate over the law reforms in Victoria that argument was put by, amongst, others, one of the clinicians prominent in the development of donor-ART in that State:

> "… clinicians recruiting donors prior to 1998 had assured donors that identifying information about them would NOT *[sic]* be released … I respectfully request the Inquiry not to RETROSPECTIVELY *[sic]* remove anonymity prior to 1998 … "
>
> Dr Gab Kovacs, Director Donor Insemination Clinic, Prince Henry's Hospital 1978 – 1998[2] [1]

Conversely, advocates of retrospectivity asserted that the right of DC people to know their genetic identity was paramount, and that this justified retrospective action:

> "… any stance in regard to maintaining privacy is on shaky ground and does not stand up to scrutiny. Legislation allowing ALL [*sic*] offspring access to identifying information on their donors and half-siblings must be implemented and done so retrospectively "
>
> Damian Adams, donor-conceived person[1] [1] [2]

The key argument for retrospective action in this case is that it is necessary in order to make access by donor conceived people equable – regardless of the date of the sperm or egg donation that led to their conception. The counter argument is that retrospectively changing the rules around access to donor identity is unfair to the donors who donated with the promise of perpetual anonymity. Once again the contest between two sets of rights arises.

On balance I believe that the argument for retrospective action to open donor records is strong. I support that course of action, with the proviso that there should be a nuanced and mediated approach to the release of identifying information about donors- as is set out in point a) above.

Access to support and counselling for donor-conceived people and donors.

The experience of donor linking in Victoria is once again instructive. Pro-active and comprehensive counselling has been a key element of the donor linking work carried out by VARTA, although I understand that there has been some reduction in the emphasis on counselling over the past several years.

---

[1] [2] Submission No, DCP 40, Victorian Parliament Law Reform Committee, 3/9/2011, pp1-2 https://www.parliament.vic.gov.au/images/stories/committees/lawrefrom/iadcpiad/submissions/DCP40_-_Prof_Gab_Kovacs.pdf

[2] Submission No, DCP 4, Victorian Parliament Law Reform Committee, 30/7/2010, p. 5 , https://www.parliament.vic.gov.au/images/stories/committees/lawrefrom/iadcpiad/submissions/DCP4_Damian_Adams.pd

In my experience – both direct and by observation of others in the DC community – counselling is of most value when driven and guided client demand. That is counselling on the impact of, for example discovery of DC status by a DC person or a donor discovering the existence of DC offspring who may wish to connect, should be available and encouraged, but not forced. The DC people and their donors are adults an can make their own decisions on if, when and how to avail themselves of counselling and related advice and support.

Such counselling services should be provided at no cost to DC people, donors, and recipient parents.

Benefits, risks and implications on donor conception practices arising from any recommendations.

It is frequently asserted that changes to policy and practice regarding donor identification –in particular retrospective action to identify donors – will impact the future willingness of sperm and egg donors to donate. The impact, it is further asserted, would be that fewer donors may be available for those people wishing to access donor ART services. Such assertions come – I say – from a perspective slanted towards the need of ART clinics to enable those who wish to have babies via ART, and the needs and desires of potential parents via donor ART. My response to such assertions is that is the case then so be it. The wellbeing of the donor-conceived people should be the first priority.

Whether any model should include information from private donor arrangements.

Private donation arrangements are becoming increasingly common. There are particular complexities in capturing and including information regarding private donor arrangements – chief amounts these ensuring the veracity of information supplied by either/or donors or recipients. Notwithstanding this and other potential problems, I would advocate a model which includes information from private donation arrangements, where the parties to those arrangements wish to submit and store such information. The key benefit in doing this is that it has the potential to enable information seeking and donor/DC linking in the future, if any of the parties to the donor arrangement wish to do so.

Current governance/regulatory frameworks, including registers established interstate.

The fact of regulation of ART, including donor conception, being a State/Territory responsibility has resulted in widely varying, and poorly coordinated, policy and practice in this area. Current practice in State-to State and national coordination in dealing with donor conception – records and donor/DC linking in particular - is very fragmented across Australia. The 2010 Senate report cited previously made a number of recommendations for action – with an underlying thread of achieving greater cohesion in donor conception policy and practice across the States and Territories. Such cooperation is still not much apparent, although the legislative action in Victoria, Western Australia and NSW, the work currently on foot in South Australia, and the review work that is now underway in the ACT, as well as this current Inquiry in Queensland provides reason for optimism.

I argue that that there is both scope and a need for much better collaboration and cooperation on these matters between the State and Territory Governments – potentially too at a Commonwealth Government level. The national Health Ministers' Meeting would seem an obvious avenue for discussion on these topics. I encourage the Queensland Government to consider raising these matters in that forum.

Proposing a Concept: a "Donor Linking" Collection - Repository for Material Donors Wish Pass on to their DC Offspring.

In addition to my response to the Terms of Reference above I would like to put forward for consideration the establishment of a donor linking collection/repository in Queensland.

An issue for many gamete donors is that as we become older there is a greater risk that we may die before our donor offspring may seek to gain information from us. A donor linking collection – with provision for a variety of forms of information in a variety of formats (e.g. documents, photographs, videos, audio recordings) to be provided and lodged and curated - would serve a valuable purpose in this regard. This would be so for both donors and donor conceived people. Looking again to Victoria for examples of practice, the Victorian Reproductive Treatment Authority has implemented such a service . I encourage consideration of this concept in Queensland.

In conclusion, I again commend this Inquiry for examining this fraught area of public policy and practice. I hope that my submission is of value to your Inquiry.

Ian Smith. April 16, 2022.