

**Submission to the South Australian Government Review of the Assisted Reproductive Treatment Act – 1988**

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I commend the South Australian Government for undertaking this Review. This is very complex area – mixing legal, medical and social issues. Past practice in this area has, in my view, failed to adequately take into account the significant human impact of decisions and practices regarding donor-based ART.

I have noted the specific terms of reference for this Review, and the invitation to respond to these specific points. I am not from South Australia and I have no direct connection to donor based ART in the State. There are thus many points of the Review on which I cannot offer useful direct comment. However, I believe that I can offer useful comment more generally, based on my own experience as a sperm donor and my experiences – both in connecting and engaging with both donor conceived people and former sperm and egg donors, and in working for change in policy and practice regarding people affected by donor ART in Victoria.

My submission begins by giving, by way of context, some brief explanation of my own personal experience and involvement in donor ART. My comments then cover these matters – all of which I see to be of importance to the matters under consideration by this Review:

- The Principle of the Right to Know One's Genetic Identity
- Pro-Active Communication and Engagement with Former Sperm and Egg Donors About Any Changes to Policy and Practice.
- Records: Keeping, Preserving, Accessing, Linking and Connecting – Donors and Donor Conceived People, DNA Testing – DNA Databanks
- Proposing a Concept: a "Donor Linking" Collection - Repository for Material Donors Wish Pass on to their DC Offspring
- State-to State and National Coordination

## **1. 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, have 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 wonder if they are alive, if they are healthy, happy, well cared for and loved.

One thing is very clear for me. That is that the interests and well being 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 my offspring 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 there is a very complicated human aspect to what I fear many in the medical profession have often, in the past and perhaps still now, viewed as simply a clinical process. It is not that, it is a very complex social issue - as well as a medico-legal issue. Governments 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.

## **2. The Principle of the Right to Know One's Genetic Identity**

The consultation document refers to the requirement in the Act that the welfare of any child born as a consequence of ART is treated as of paramount importance. I strongly support that principle. An extension of that principle is 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 this 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 change 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 donor).

In making that submission I observed that one set of human rights has, inevitably, to give way in this circumstance. Both sets of rights cannot be fully maintained. In my view it must be the right to anonymity, of gamete donors such as me, which has to give way. Our right 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. That said, the rights of former donors must be treated with respect and care. I argue that if that is the position to be adopted in policy and practice there must be put in place significant measures to engage, support and explain to gamete donors why this change is to be made and how and why it would be implemented. 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 account the significant impact on gamete donors of any change in policy and practice regarding access to information about donors by their genetic offspring.

## **3. Pro-Active Communication and Engagement with Donor Conceived People Former Sperm and Egg Donors About Any Changes to Policy and Practice.**

Making change in a complex and sensitive area such as this is hard. My professional work is in the area of organisational change facilitation 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 advocate pro-active 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.

The work undertaken by the Victorian Reproductive Treatment Authority (VARTA) provides an excellent model of practice in this regard.

#### **4. Records, Searching, DNA Testing.**

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.

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.

In Victoria, VANISH (a small NFP group which focussed on meeting the needs of people effected by adoption, and more latterly those effected by donor conception) has considerable expertise in kind of searching for family information and connecting people separated from their family of genetic origin. I would advocate that the South Australian Government give priority to establishing a similar search and investigation capability, with Government funding and thus available to donor conceived people at no cost to them.

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 provides a good model.

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.

Again Victoria provides some potential guidance. The legislation which is to come into effect in 2017 will enable VARTA to undertake DNA testing where required as part of the process of establishing donor/donor conceived person linking. A logical progression from that is to collate the records of such testing and to progressively build a database of these records. Ideally such a data base would be a national undertaking.

#### **5. Proposing a Concept: a “Donor Linking” Collection - Repository for Material Donors Wish Pass on to their DC Offspring**

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 information to be provided and lodged and curated in a variety of formats (e.g. documents, photographs, videos, audio recordings) - 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, I understand that VARTA is considering expanding the current Voluntary Register to fulfil this kind of function. I encourage consideration of such a concept in South Australia.

#### **6. State-to State and National Coordination in Dealing with Donor/Donor Conceived**

Current practice in this regard is very fragmented across Australia. The 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 recent legislative action in Victoria and NSW, this Review in South Australia, and the beginnings of attention to these matters in Tasmania is encouraging.

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 COAG Health Council would seem an obvious avenue for discussion on these topics. I encourage the South Australian Government to consider raising these matters in that forum.

**Ian Smith. April 15, 2015**