



9th August 2011

Mr Clem Newton-Brown MP
Chair
Parliament of Victoria
Law Reform Committee
Parliament House
Spring Street
East Melbourne, 3002

Dear Mr Newton-Brown,

**RE: INQUIRY INTO ACCESS BY DONOR-CONCEIVED PEOPLE TO INFORMATION
ABOUT DONORS**

Thank you for the opportunity to contribute to this inquiry and address the Terms of Reference (ToR). Our work in the Public Health Genetics group at the Murdoch Childrens Research Institute (MCRI), involves conducting research to determine the health and wellbeing of offspring born from ART. It is from this perspective and our access to current literature that we would like to comment in relation to ToR e) and f) that are relevant to our field.

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

Donors

- The donors who donated prior to 1998 (predominantly male sperm donors) are likely to feel exposed and vulnerable. Many of them will have kept their donation secret as was common in this era due to limited awareness of potential issues and few resources or supports available for them to even contemplate disclosure.
- Many donors will fear invasions of their privacy and disruption to their family lives however, changes to adoption act in 1984 provoked similar concerns amongst adoptees and birth parents but in reality there were very few or no cases of abuse and all parties were found to be extremely respectful of each other.
- Should changes occur, donors will require access to expert counselling and resources so that they can be as prepared as possible should they be contacted or chose to contact their biological offspring.

Donor – conceived persons

- In the pre-1988 era, the parent recipients, who were only heterosexual couples during this period in Victoria, commonly maintained secrecy about their treatment. Consequently, it is likely that some of the couples from this period have not disclosed donor conception to their offspring. Furthermore, disclosure was not encouraged because of the lack of capacity for offspring to access to information about their donor, should they wish to pursue this.
- At the MCRI, we are currently conducting a study of mothers and IVF-conceived young adults born in 1982-1992, to determine their health and wellbeing. Currently we have interviewed 656 mothers with adult offspring and 7% have not disclosed IVF conception to their sons or daughters. There are a higher proportion of mothers who conceived with donor gametes in the non-disclosing group and the mothers who conceived with donor gametes were also significantly less likely to participate in the study at all, possibly because they have not disclosed. Overall, however, the proportion of non-disclosing parents appears fairly small.
- If access to identifying information for the pre -1998 and 1988 periods is made available, couples who have not disclosed use of donor gametes to their offspring are likely to feel vulnerable and may feel compelled to disclose. A recent study by Daniels et. al. (2011)ⁱⁱ provides some insight into how difficult it is for parents to disclose when their offspring are of an older age. Many did, however, also express considerable relief at making the decision to do so. Parents described having suffered a great burden of stress and sometimes personal conflict through maintaining secrecy for a long period of time and many wished that they had told earlier. Fear of rejection by their offspring was a commonly expressed anxiety experienced by fathers yet interestingly very few parents expressed concern about their offspring wanting to find their donor. So in effect, provided that there is considerable support for parents who find themselves in this position, such as expert counselling and appropriate resources, there may actually be positive outcomes for parents who feel compelled to disclose at a later age.
- The outcomes for offspring who learn of their conception from donor gametes at a later age tend to be less positive initially, particularly as sometimes this knowledge was imparted incidentally. Studies by Jadva et. al (2009)ⁱⁱⁱ and Beeson et. al. (2011)^{iv} of donor conceived offspring, report feelings of shock, confusion and betrayal to be experienced initially, when disclosure occurs at a later age. However, these feelings generally diminished with time and often there was a sense of relief as they had previously suspected that there was a 'secret' or that they 'didn't quite fit in.' A more important source of resentment for the offspring once they knew of their donor conception was their lack of access to information about their donor. They felt curious about the identity of their donor and their medical background, yet offspring in heterosexual families found it less comfortable to express their curiosity than offspring within single parent or lesbian families. In particular, social fathers were reported to be insensitive to or unaware of their offspring's curiosity. In view of these findings, donor conceived offspring who learn of their donor conception at a later age, have the potential for positive outcomes with their families and are likely to benefit significantly if their quest for information about their donor and half siblings is made easier to obtain. We believe that positive outcomes will be best facilitated if donor-conceived persons and their parents can access expert counselling.
- From a public health point of view, the screening of donors in the early decades lacked rigor, and now, with the growth in genetic technology, it is important that donor-conceived people can learn more of their true genetic origins openly.

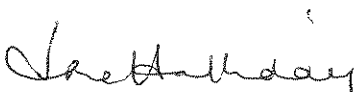
Overall, we believe that the positive outcomes associated with openness for both parents, donor-conceived offspring and donors will outweigh any negative outcomes.

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;*

- Whilst we agree that the intention of de-stigmatising infertility and donor conception through transferring the Central and Voluntary Registers from the Infertility Treatment Authority to the Registry of Births, Deaths and Marriages, we are concerned about the loss of expertise and access to specialised counselling services for the concerned parties. As stated above, we believe that the provision of expert support and suitable resources is integral to the responsible and successful introduction of significant change such as has been suggested.

Please let me know if you require any further information or clarification in relation to this submission.

Yours sincerely,



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Head, Public Health Genetics



Ms Cate Wilson
Research Officer, Public Health Genetics

ⁱ Carp W, Does Opening Adoption Records Have an Adverse Social Impact? Some lessons from the U.S., Great Britain, and Australia, 1953-2001, *Adoption Quarterly*, 2007;10(3-4):29-52

ⁱⁱ Daniels KR, Grace VM, Gillett WR, Factors associated with parents decisions to tell their adult offspring about the offspring's donor conception, *Human Reproduction Advance Access* published July 28, 2011, p1-8

ⁱⁱⁱ Jadvá V, Freeman T, Kramer W, Golombok S. The experiences of adolescent and adults conceived by sperm donation: comparisons by age of disclosure and family type. *Human Reproduction* 2009; 24:1909-1919

^{iv} Beeson DR, Jennings PK, Kramer W, Offspring searching for their sperm donors: how family type shapes the process. *Human Reproduction Advance Access*, published July 27, 2011, p1-10