

CHAPTER 5

Risk of consanguinity and limits on donations

5.1 This chapter considers the risk of consanguinity for donor conceived people and what limits should be placed on the number of donations that can be made, specifically:

- the risks of consanguine relationships and, in particular, the impact on the ability of donor conceived people to have meaningful relationships with donors and half-siblings; and
- whether limits should be established on the number of donations a donor can make, including:
 - variations between limits in different jurisdictions;
 - the enforcement of limits between jurisdictions;
 - how any limits should be expressed; and
 - what is an appropriate limit.

Risk of consanguine relationships

5.2 Donor conceived people highlighted the risks of inadvertently forming consanguine relationships due to their lack of access to donor information. 'Consanguinity' in this context refers to a partnership or marriage between two individuals from the same family. It is widely accepted that consanguine relationships can increase the risks of serious genetic disease in any resultant children. Given the significant stigma that attaches to consanguinity (more commonly referred to as 'incest'), the inadvertent formation of such a relationship could also lead to serious social and personal consequences for a couple and their children.

5.3 Further, consanguinity may have adverse legal consequences. For example, the *Marriage Act 1961* (Cth) specifies that a marriage is void where it is between a person and their whole- or half-blood brother or sister.¹

5.4 The risk of inadvertent formation of consanguine relationships may be enhanced where a donor has made, for example, multiple donations of sperm. Dr Sonia Allan noted that the risk of consanguine relationships may be more acute in states and territories with small populations, or in closely knit communities which may draw from a similar pool of donors from the same clinic.²

1 Subsection 23(2) of *Marriage Act 1961* (Cth).

2 *Submission 30*, p. 12; see, also, VARTA, 'Legal Consequences of being a donor', <http://www.varta.org.au/legal-consequences-of-being-a-donor/w1/i1003431/>, accessed 1 February 2011.

5.5 However, the statistical probability of entering into consanguine relationships may not be high.³ As Dr Martyn Stafford-Bell of the Canberra Fertility Centre advised:

...there is no adjective which accurately describes just how tiny this chance really is. If you consider for a moment the number of people at any one time aged between, say, 20 and 38 in the community who are donor conceived as a percentage of the total number of people of that age group in the community, you can see just how tiny it is, and the chance of two of those people meeting [is] even tinier, and the chance of them both coming from the same donor even more remote...⁴

5.6 For many donor conceived people though, knowing that they are donor conceived makes them more cautious about entering into relationships. As Ms Elizabeth Marquardt from the Centre for Marriage and Families, Institute for American Values, explained:

...[forming a consanguineous relationship]...is a real fear among donor conceived persons. In our study...donor conceived persons were far more likely, even than those who were adopted, to say that they have worried that they could be unknowingly attracted to someone who is their sibling or that their children could date someone who is the child of one of their siblings.⁵

5.7 Mr Richard Egan representing FamilyVoice Australia also noted:

[i]t is not just the issue of consanguineous relationships, which are statistically unlikely; it is the psychological impact on the child who, for a fellow, will be wondering about every girl he sees, 'Is she my half-sister?' You do not know where your siblings are.⁶

Impact on ability to have meaningful genetic relationships

5.8 Several submissions noted that it is important to limit the number of families a donor assists, not only to prevent the risk of consanguinity, but also to limit the number of half-siblings a donor conceived person could have. The Victorian Infertility Counsellors Group noted that it is not unusual for donor conceived people to discover that they have up to twenty genetic half-siblings and this can be daunting in terms of making sense of their identity and what 'family' means for them.⁷

5.9 Mr Damian Adams described the issues he faces as a donor conceived person, who is not able to find out if he has any half-siblings because he does not know the identity of his donor:

3 See, for example, DES Action Australia NSW, *Submission 18*, p. [3].

4 *Committee Hansard*, 29 October 2010, p. 2.

5 *Committee Hansard*, 2 November 2010, p. 23.

6 *Committee Hansard*, 29 October 2010, p. 16.

7 *Submission 68*, p. 6.

[p]ersonally I am deeply traumatised that there could even be one half-sibling that I have never known and will never get to know, let alone the fact that there could easily be dozens. While never being able to know your own family is emotional enough, the fact that there may be numerous half-siblings is deeply disturbing on a level akin to being manufactured to appease the masses. We are human beings with biological and social families yet the ability to produce so many siblings is actually dehumanizing. Therefore it is suggested that the limit to donations should be capped to 3 families and or a total of 6 offspring...to also reduce the psychological burden on offspring of having so many siblings out there that they will never know.⁸

5.10 Miss Narelle Grech, a donor conceived person who knows that she has eight half-siblings but has not been able to identify them, provided an insight into her personal experience:

[a]s for my DC [donor conceived] siblings I often wonder about them, whether we have met or I have walked past them in the street. Do they know they are DC? Will their parents ever tell them? Will I ever have the chance to meet any of them? Recently, with the wonder of Facebook, I was pointed to a friend of a friend whom they said reminded them of me. To anyone else they might laugh and go along their day. For me it meant looking at this person's profile and analysing everything about them. Looking for physical similarities and comparing interests, ages and so on. I think there might be something in this link, but what am I to do? Do I approach this person and potentially open up a Pandora's box for them? Don't they deserve to know the truth about their own identity if they are DC? And what about me? Shouldn't I be able to know my own siblings?⁹

5.11 Ms Elizabeth Marquardt of the Centre for Marriage and Families, Institute for American Values, observed:

[b]y not having limits, we are asking people to struggle with making sense of their own identities amid kinship networks in a way that no-one in human history has ever had to do before.¹⁰

5.12 Mr Richard Egan of FamilyVoice Australia commented:

...[t]here is not just the possibility of mistakenly entering into a romantic or sexual relationship with one of them, but also, if you decide to reconnect all the pieces of the jigsaw puzzle of your family—we know how hard that is for adopted children where there are only two families involved—and we are allowing five different families to have children from the same father, try connecting that. It is more than a life's project to try to bring that

8 *Submission 38*, p. [7].

9 *Submission 107*, p. 3.

10 *Committee Hansard*, 2 November 2010, p. 23.

together. It just seems unjust to me to be imposing that fracturing of family on children.¹¹

5.13 Some donor conceived people, who have been able to locate their donor and their half-siblings, described it as a relief.¹² Often, parents of donor conceived people who have chosen to inform their child that they are donor conceived, have been supportive of their search for their donor and half-siblings.¹³ Miss Lauren Burns described meeting her donor and his children:

[h]e has a name and it is Ben. I was most fortunate in that I found myself in the capable hands of the counsellors at the ITA [Infertility Treatment Authority – now VARTA], who were wonderful in helping Ben and I forge our fragile connection. We exchanged letters and photographs and talked on the phone. In November 2009 I went to visit him for the first time and met his teenage children, my half siblings, two girls and a boy. I was very nervous prior to the meeting, but when I arrived I felt at ease. We all share many characteristics, both in appearance and temperament, and even mannerisms.

The overwhelming feeling I took from this meeting was relief. Relief that I had found a small chink in the imposing wall of legal structures designed to separate me from truth. Most of all, relief that I finally had answers to questions about the source of my personality and interests and no longer faced an uncertain future of missing knowledge concerning my biological heritage and identity.¹⁴

Variation between jurisdictions on limits

5.14 In formal settings today (that is, clinics), there are generally limits to the number of families that may receive gametes from a single donor. In Western Australia, a maximum of five families may receive gametes from a single donor unless there are exceptional circumstances.¹⁵ In New South Wales, donated gametes cannot be used if this is likely to result in offspring of the donor being born to more than five women (including the donor, or a current or former spouse of the donor).¹⁶ In Victoria, a donor's gametes cannot be used if it would result in more than ten women having children who are genetic siblings.¹⁷ However, although Victoria has a limit of ten women for each donor, some 'rural clinics impose a smaller limit of five

11 *Committee Hansard*, 29 October 2010, p. 16.

12 *Submission 40*, p. 4.

13 See, for example, *Submission 1 (name withheld)*, p. 1; Mr Callum Lorbach, *Submission 3*; *Submission 29 (name withheld)*, p. 2; Mrs Glenda and Mr Robert Davis, *Submission 35*.

14 *Submission 40*, p. 4. See also Miss Lauren Burns, *Committee Hansard*, 3 November 2010, p. 4.

15 Paragraph 8.1, *Human Reproductive Technology Directions (WA)*, Western Australian Government Gazette, 30 November 2004, p. 5434.

16 Subsection 27(1) of the *Assisted Reproductive Technology Act 2007* (NSW).

17 Section 29 of the *Assisted Reproductive Treatment Act 2008* (Vic).

families for a donor' to take account of 'the potential for meeting related families and future contact with [the relevant] donor'.¹⁸

5.15 In Queensland, South Australia, Tasmania, the Northern Territory and the Australian Capital Territory, the NHMRC Guidelines provide that 'clinics must take all reasonable steps to reduce the numbers of genetic relatives created through donor gamete programs' to protect donor conceived people, and donors, from having too many genetic siblings or too many offspring, respectively.¹⁹ In particular, the NHMRC Guidelines state:

[g]ametes from one donor should be used in a limited number of families. In deciding the number of families, clinicians should take account of:

- the number of genetic relatives that the persons conceived...will have;
- the risk of a person conceived with donor gametes inadvertently having a sexual relationship with a close genetic relative (with particular reference to the population and ethnic group in which the donation will be used);
- the consent of the donor for the number of families to be created; and
- whether the donor has already donated gametes at another clinic.²⁰

Enforcement of limits

5.16 A number of submissions noted that the inconsistent approaches between the states and territories regarding registration of donors mean that there is no way of accurately knowing or controlling the number of families a particular donor assists.²¹

5.17 Several submissions also reported that the current state or clinic based data management arrangements mean that there is no way for clinics to ensure they comply with limits on donations. For example, SMC Australia referred to an example where:

[a] member was informed by the donor co-ordinator of their Queensland clinic that sperm imported from the US would only be imported for use by that clinic. Through their own networks, the member later found that sperm from the same donor had also been imported by a clinic in [NSW] and used by a number of families in that [s]tate. Neither clinic seemed to have knowledge that the situation had occurred.²²

18 VARTA, 'Legal Consequences of being a donor', <http://www.varta.org.au/legal-consequences-of-being-a-donor/w1/i1003431/>, accessed 1 February 2011.

19 NHMRC Guideline 6.3.

20 NHMRC Guideline 6.3. In South Australia, there is a legislative requirement for fertility clinics to abide by the NHMRC Guidelines: paragraph 8(2)(a) of the *Assisted Reproductive Treatment Regulations 2010* (SA).

21 See, for example, *Submission 93 (name withheld)*, p. 5; SMC Australia, *Submission 99*, p. 10; Ms Kate Dobby, *Submission 103*, p. 4; Fertility First, *Submission 104*, p. 3.

22 SMC Australia, *Submission 99*, p. 4.

5.18 Dr Damien Riggs, a researcher in the field of sperm donation, pointed out that donors may be donating in multiple states:

[a] man should not be able to donate sperm in one state that can be used for 10 families and then go to another state and do that. There could be a huge number of children born from that, because his sperm can be used for 10 families but, obviously, those families could have three children each. So there are a very large number of potential children from one man's donated sperm.²³

5.19 According to some, the variations between jurisdictions regarding limits also make it possible to circumvent limits by transferring gametes and embryos to other jurisdictions.²⁴ SMC Australia indicated that they are aware of circumstances where a donor has reached their limit through donations to clinics and has then gone on to make additional private donations.²⁵

5.20 Mrs Fiona Hearne of SMC Australia advised the committee that, even though there are limits, there are occasions where clinics do not abide by them:

[t]here are 13 families. I was told when I started the treatment that it would be limited to 10. I recently spoke to the clinical director of the clinic I used and he said, 'I will tell you how that happened', and I said, 'I know how it happened. You guys have stuffed up', which was totally true. They were keeping a record but they were not keeping an exact lid on it: 'This person is using this donor, but we actually have another clinic and this person is also using that donor'. So my daughter is one of 17. The donor has three children of his own, so she is one of 20.²⁶

5.21 SMC Australia also noted that there has been a lot of confusion among clinics about how the limits apply, with one NSW clinic taking the view that the limit applies only to women in NSW, while another clinic is of the opinion that the limit applies to women world-wide.²⁷

How should any limits be expressed?

5.22 It is possible to set a limit on donations in a number of different ways – for example, by reference to the number of children born, the number of women assisted, or the number of families assisted.

5.23 A number of submissions considered that a limit should be placed on the number of families assisted, rather than the number of women, because this would

23 *Committee Hansard*, 2 November 2010, p. 37.

24 See, for example, Ms Karen Boyd, *Submission 16*, p. 1; *Submission 93 (name withheld)*, p. 5; Ms Kate Dobby, *Submission 103*, p. 1.

25 *Submission 99*, p. 10.

26 *Committee Hansard*, 2 November 2010, p. 49.

27 *Submission 99*, p. 10.

take into consideration lesbian couples where both women choose to use the same donor to ensure that their children are genetically related.²⁸ In relation to this point, Dr Riggs made the following observations:

...as far as I know...if a lesbian couple accesses some donor sperm in a clinic, they count as one of the donor's 10 families, where one woman carries the child. However, if the other woman wants to then carry a child, she is classed as a separate family and must use a separate lot of sperm. I think that is probably a nonsense in the sense that both women are the parents of the children, so the children are not likely to have any relationship as adults that is inappropriate because they know they are brother and sister or brother and brother et cetera...We are in a sense wasting some of our available donor resources because we are mandating that if both women in a lesbian couple decide to get pregnant they must use different donor sperm, which to me does not make any sense.²⁹

5.24 Similarly, some submissions suggested that the limit should not be expressed in terms of children, because this could lead 'to the possibility that some women may be artificially prevented from completing their family with one donor',³⁰ and may need to use a different donor, with the result that their children would then have different biological fathers.

What would be an appropriate limit?

5.25 Of those who supported a limit being expressed by reference to the number of families assisted, the preferred number of families was either one,³¹ five³² or ten families.³³

5.26 Mrs Leonie Hewitt, Ms Michelle Cefai and Mrs Caroline Lorbach, all of the DCSG, supported a limit of no more than five families using a single donor, noting that if a donor only wants to donate to one family, that should be respected.³⁴ Dr Sonia Allan observed that setting a limit was a difficult proposition, but she supported a limit of 'no more than three [families] and preferably less...dependent

28 See, for example, Ms Zoe Brillante, *Submission 6*, p. 1; Rainbow Families Council, *Submission 73*, p. 3; Fertility First, *Submission 104*, p. 2.

29 *Committee Hansard*, 2 November 2010, p. 37.

30 Fertility Society of Australia, *Submission 109*, p.13. See, also, SMC Australia, *Submission 99*, p. 10.

31 See, for example, Mr Michael and Mrs Laureen Dempsey, *Submission 27*, p. 2; Mrs Myfanwy Cummerford, *Submission 63*, p. [1]; Miss Narelle Grech, *Submission 107*, p. 6; Ms Kylie Dempsey, *Submission 114*, p. [3].

32 See, for example, the Canberra Fertility Centre, *Submission 48*, p. [6].

33 See, for example, Monash IVF, *Submission 120*, p. 5.

34 Mrs Leonie Hewitt and Ms Michelle Cefai, DCSG, *Committee Hansard*, 2 November 2010, p. 7, and Mrs Caroline Lorbach, DCSG, *Committee Hansard*, 2 November 2010, p. 17.

upon the number of children within a family'.³⁵ Mr Richard Egan of FamilyVoice Australia stated that, if donor conception is to continue, his organisation supported only one family using a single donor.³⁶

5.27 Some submissions supported the limit only applying to donations in Australia, while others supported the limit applying world-wide. The Canberra Fertility Centre suggested that a limit of five families world-wide would be unnecessarily restrictive and that the limit should be five families in Australia.³⁷ However, one submission suggested that the donation limit should be set at an international level in order to have any meaningful effect on reducing the risk of consanguinity.³⁸

5.28 Another factor raised was the impact that any limit could have on the number of families able to access donor treatment, taking into account the low rate of sperm donation in Australia relative to demand. For example, Monash IVF considered that limiting the number of donors to less than ten families would severely limit the number of people able to access donor treatment.³⁹

5.29 Some submissions noted that a limit should be set according to evidence-based research, 'rather than whim or assumption'.⁴⁰

5.30 Finally, some submissions argued that the only real way to limit the risk of consanguinity is to remove anonymity regarding donor conception, such as through the establishment of a national register or by requiring that a donor's identity be recorded on the donor conceived child's birth certificate.⁴¹ By way of example, Ms Louise Jamieson and International Donor Offspring Alliance argued that it is 'absurd' to use donation limitation as the means to address the danger of consanguinity.⁴²

35 *Committee Hansard*, 3 November 2010, p. 24.

36 *Committee Hansard*, 29 October 2010, p. 16.

37 *Submission 48*, p. [6].

38 *Submission 72 (name withheld)*, p. [4].

39 *Submission 120*, p. 6.

40 See, for example, Repromed, *Submission 49*, p. 4; Fertility First, *Submission 104*, p. 2; Fertility Society of Australia, *Submission 106*, p. 13. Similarly, in her article, 'Prospective application of a five-step regulatory assessment model to a proposed federal sperm donor registry in Australia: Is it in the public interest?', *Journal of Law and Medicine*, February 2010, 17(4), pp 608-16, at p. 610, Ms Neroli Sawyer indicated that the various limits which exist in different jurisdictions in Australia regarding the use of sperm donors do not appear to be evidence-based with reference to the risk of consanguinity

41 See, for example, Ms Kimberley Springfield, *Submission 52*, p. [3]; Ms Louise Jamieson and International Donor Offspring Alliance, *Submission 115*, p. 4; DCSG, *Submission 122*, p. 110.

42 *Submission 115*, p. 4.