

**Submission
No 4**

MANAGING INFORMATION RELATED TO DONOR CONCEPTION

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Submission to the NSW Parliament's Legislative Assembly Committee on Law and Safety Inquiry into Managing Information Related to Donor Conception.

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Aspects pertaining to the practice of donor conception within New South Wales at present, in the past and in the future will be discussed particularly in relation to the child's ability to access information on their donor (biological father/mother). When analysing the practice and its outcomes the most important factor to consider is the child as clearly they are the most vulnerable. In addressing this aspect the voices of those most affected must be heard and that is the voices of the donor conceived offspring themselves. They are the ones left to live with the consequences of other people's actions and decisions everyday, decisions that were made on their behalf and ones which they were not a party to nor had any control over. These decisions have the potential to adversely affect their psychological and physical well-being. Current and previous models implemented which have in some instances caused pain and trauma to offspring have resulted from the paternalism of the medical big business fertility industry catering to the desires of adults while at times neglecting the needs and welfare of the children they are creating. While considerable progress has been made in this regard, in particular access to donor information by offspring, this ability to access such information is restricted to those conceived after NH&MRC guidelines governing this aspect came into effect in 2005. These guidelines recognised that such information is vitally important to the welfare of the child but their implementation has meant that those conceived prior to this date are not being afforded the same rights as those conceived later.

The donor conceived can suffer from kinship separation, the deprivation of contact with half of their biological family and the associated deprivation of culture and heritage. Their identity formation can be severely hampered by not having those that they are descended from in their daily lives. These are the questions of who do you look like, whom do you take after in terms of likes, dislikes, and behaviour. Things that most children get to experience when growing up which is used as a foundation for identity formation. These aforementioned effects have been well documented in the adoption community which can experience similar problems resulting from familial deprivation.

Effects that we as a society have acknowledged and taken steps to try and correct but have yet to acknowledge and correct for the donor conceived. In addition, donor conceived people are being deprived of a familial health history which is vitally important for accurate and quick diagnosis as well as impinging on a person's autonomy to be able to take appropriate lifestyle choices to avoid health problems (ie type-2 diabetes, heart disease, familial linked cancers etc). In effect the question of whether or not to provide access to information that may assist in ameliorating some of these problems is not just about a donor conceived person's welfare now but also their future welfare and potential burdens on a health system which could be avoided.

The consequences of these practices are not only restricted to the current generation of offspring but have the potential to be felt in and passed on to future generations that will be born to donor conceived people. As such there is a duty of care to a far greater proportion of the population than just the figures of donor conceived people would lead one to believe.

Damian Adams is an adult donor offspring who was conceived during the early stages of the practice. He is a published medical research scientist with numerous articles in peer reviewed journals and in particular has published on the subject of accessing donor information by offspring in Australia. He has also presented at conferences on the subject of the ethical practice of donor conception. He is currently undertaking a PhD researching the welfare outcomes of donor conceived people. As a father himself, he has a unique insight into the ramifications that have and are currently being made on behalf of the Donated Generation.

The terms of reference for the inquiry will be addressed hereafter.

Terms of Reference

That the Committee inquire into and report on the management of information related to donor conception in NSW, with particular regard to:

- a) whether people conceived by donor conception prior to January 2010 should have access to donor conception information, including information that identifies their donor and donor conceived siblings.
- b) which agency should manage donor conception information and provide services related to the release of this information.
- c) what counselling or support services and public education measures are necessary to support people who are seeking access to donor conception information.
- d) any other relevant matter.

The terms of reference will be addressed by way of response to the specific questions posed by the committee.

Question 1: Should donor-conceived adults have retrospective access to donors' identifying details?

Both NSW legislation and national guidelines (NHMRC) acknowledge that knowledge of a donor's identifying details may be vitally important to the welfare of the donor conceived person. This is evident through the implementation of legislation and guidelines which now allows donor conceived people to access this information. Specifically, NHMRC guidelines state: "Persons conceived using ART procedures are entitled to know their genetic parents."¹

By creating divisions in the Donated Generation whereby some people are afforded the right to know who their progenitors are but others are not, discrimination is being implemented. This discrimination is age based and while it does not contravene the Commonwealth Age Discrimination Act due to legislative exemptions, it does contravene the spirit of the act which are described in the Objects of the Act, in particular (with specific sections underlined):

"The objects of this Act are:

- (a) to eliminate, as far as possible, discrimination against persons on the ground of age in the areas of work, education, access to premises, the provision of goods, services and facilities, accommodation, the disposal of land, the administration of Commonwealth laws and programs and requests for information; and
- (b) to ensure, as far as practicable, that everyone has the same rights to equality before the law, regardless of age, as the rest of the community; and
- (d) to promote recognition and acceptance within the community of the principle that people of all ages have the same fundamental rights."²

¹ National Health and Medical Research Council, *Ethical Guidelines on the use of Assisted Reproductive Technology in Clinical Practice and Research* (Australian Government: National Health and Medical Research Council, 2004).

² *Age Discrimination Act 2004* (Cwlth) s 3.

Not only has the right to knowledge about a donor conceived person's progenitor been enshrined in NSW legislation and Commonwealth Guidelines as mentioned previously, but has also been enshrined in the United Nations Conventions of the Rights (UNCRC) of the Child,³ which is the most widely and rapidly ratified convention with 192 countries as signatories including Australia. It has several articles germane to the issue of donor conceived rights:

Article 2 deals with discrimination and in particular references birth status as not being grounds for discrimination. Currently in Australia and NSW, the only people who are being systematically deprived of knowledge of their progenitors are donor conceived people and the reason for this is based on their birth status and agreements that were entered into by others, not themselves.

Article 3 describes the preservation of a child's best interests irrespective of court, institution or government involvement, such that these bodies cannot adversely affect the welfare of the child. Reports and accounts suggest that depriving a child of their origins including their genetic parents can potentially adversely affect the welfare of the child.⁴

Article 7 specifies that every child has a right to know and be cared for by their parents. From the UNICEF implementation handbook the original intent for this is described as meaning biological parents.⁵

Article 8 states that every child has a right to a name, identity, family relations and nationality. All of which can be adversely affected through donor conception. It also specifies the responsibility of the state to speedily re-establish these if removed which has not happened anywhere in Australia, although it has been proposed and recommended by the Victorian Law Reform Committee in their recent inquiry.⁶

Article 13 deals with the right to information affecting the child so that the child can maintain their autonomy. The information deprived through donor conception seriously diminishes this component.

Both the UNCRC and Commonwealth Age Discrimination Acts provide frameworks for acknowledging the right of donor conceived people to access identifying information on their donor retrospectively. Nor has privacy (in this instance privacy is referring to the

³ United Nations (1989). Convention on the Rights of the Child. United Nations.

⁴ Turner AJ, Coyle A. (2000). What does it mean to be a donor offspring? The identity experiences of adults conceived by donor insemination and the implications for counselling and therapy. *Hum Reprod.* 15(9):2041-51; Senate Legal and Constitutional Affairs Reference Committee. (2011). *Donor Conception Practices in Australia*; Victorian Law Reform Committee. (2012). *Inquiry into Access by Donor Conceived People to Information about the Donors*; Lorbach C, "Thoughts and Experiences of Donor Offspring" in Lorbach C. (2003). *Experiences of Donor Conception: Parents, Offspring and Donors Through the Years* (Jessica Kingsley Publishers, London), p 181 (Barry), pp 168-169 (Bill), p 172 (Christine), p 180 (Joanna), pp 186-187 (Lynne), p 160 (Priscilla); McWhinnie A. (2006). *Who am I? Experiences of Donor Conception* (Idreos Education Trust, Warwickshire, UK) pp 30-45 (Jamieson L), pp 1-13 (Rose J), pp 14-29 (Whipp C).

⁵ Hodgkin R, Newell P. (2007). *UNICEF Implementation Handbook for the Convention on the Rights of the Child* (3rd Ed).

⁶ Victorian Law Reform Committee. (2012). *Inquiry into Access by Donor Conceived People to Information about Donors*.

privacy of the donor), ever been absolute in Australia.⁷ Additionally a precedent has been set in Australia with the granting of retrospective access to identifying information for adoptees whom may experience similar issues as donor conceived people.⁸ By applying one rule for adoptees and another for donor conceived people another level of discrimination is being enshrined based on the mode of conception, contravening Article 2 of the UNCRC.

The granting of retrospective access to adoptees has not created undue stress or harm to those relinquishing parents identified. Those who wish to claim that donors on the other hand will be harmed by identification fail to acknowledge the evidence from the adoption field and are using scaremongering to hamper sociological and legislative change that can improve the welfare outcomes of donor conceived people.

Claims that the release of a donor's identifying information will breach doctor/patient confidentiality are poorly constructed as a donor is typically not a patient of the doctor or clinic receiving the gametes. They are providing gametes in exchange for monetary compensation (termed "reimbursements") and are therefore gamete providers and not patients. Additionally, Rees a law academic has investigated the agreements/contracts that donors and recipient parents entered into (as presented as evidence to the Victorian Inquiry into donor conception) and argues that these agreements fail to meet the requirements of contractual law and therefore not contracts at all.⁹ These agreements prescribe that identifying information will not be shared or given to either the donor or recipient parents. What they fail to prescribe is any information disclosure to the offspring themselves. Therefore allowing donor conceived people retrospective access to a donors identifying information does *not* breach the agreements that these parties entered into.

This information release should not only be confined to donors but should also incorporate access to information on a donor conceived person's half siblings conceived through other donations. Research shows that the vast majority of offspring believe that they should know the identity of their donors¹⁰ and also the identity of any half-siblings.¹¹

⁷ Allan S. (2011). Psycho-social, ethical and legal arguments for and against the retrospective release of Information about donors to donor-conceived individuals in Australia. *J Law Med* 19(2): 354-376.

⁸ Triseliotis J. (1993). Donor insemination and the child. *Politics Life Sci.* 12(2):195-7; Evan B Donaldson Adoption Institute (2009). Old Lessons for a New World: Applying Adoption Research and Experience to Assisted Reproductive Technologies.

Retrieved September 6, 2009 from: http://www.adoptioninstitute.org/policy/2009_02_oldlessons.php

⁹ Rees A. (2012). Keeping Mum about Dad: 'Contracts' to protect gamete donor anonymity. *J Law Med* 19: 758-68.

¹⁰ 86% Scheib, J. E., M. Riordan, and S. Rubin. (2005). Adolescents with open identity sperm donors: reports from 12-17 year olds. *Human Reproduction* 20(1): 239-52; 87% Mahlstedt P. P., K. Labounty, and W. T. Kennedy. (2009). The views of adult offspring of sperm donation: essential feedback for the development of ethical guidelines within the practice of assisted reproductive technology in the United States. *Fertility and Sterility* 93(7): 2236-46; 77% Jadvá, V., T. Freeman, W. Kramer, and S. Golombok. (2010). Experiences of offspring searching for and contacting their donor siblings and donor. *Reproductive Biomedicine Online* 20(4): 523-32.

¹¹ 89% Scheib, J. E., M. Riordan, and S. Rubin. (2005). Adolescents with open identity sperm donors: reports from 12-17 year olds. *Human Reproduction* 20(1): 239-52; 78% Jadvá, V., T. Freeman, W. Kramer,

The parity between the desire to know their progenitor and half-siblings exhibits the value that offspring put into all biological connections and not just with their genetic father/mother.

Retrospective access to identifying information on donors must be provided to all donor conceived people who request it as a matter of principle in following the rights that are currently given to those conceived using identifiable donors and to ensure that older donor conceived people are no longer discriminated against based on age or birth status.

Recommendation: Donor-conceived people should have retrospective access to information including identifying information.

Question 2: If retrospective access were granted what conditions should apply?

The current paradigm for accessing a donor's identifying information is such that a donor conceived person must be over 18 years of age. However, the risk of damage occurring to a donor conceived person's identity due to the release of information at this late stage of their development would suggest that the ability to access such information should be made available at an earlier stage.

Donor offspring suffer from issues of identity formation and loss which is associated with the loss of kinship.¹² Identity formation occurs throughout a lifetime, however a critical window is in adolescence.¹³ If one of the child's biological links is removed then the process can become clouded as they will lack the mirror that they would see in both progenitors that would normally raise them. When genealogy is unclear then a person may suffer from genetic bewilderment,¹⁴ whereby a person's place in the world remains unclear to them and this genetic void may cause psychological harm.¹⁵ Late discovery of their mode of conception which frequently occurs for many varied reasons changes a person's perceptions of identity and family, thereby introducing distrust, confusion, and possibly anger between themselves and those that deceived them.¹⁶ If these factors are to be considered, then the current practice of only allowing donor offspring access to identifying information once they reach the age of 18 may cause irreparable damage as the vital identity construct window has passed. And as such it would be prudent to recommend that the age at which an offspring is able to access such information should be substantially lowered. This is supported by reports that less damage occurs when a

and S. Golombok. (2010). Experiences of offspring searching for and contacting their donor siblings and donor. *Reproductive Biomedicine Online* 20(4): 523-32.

¹² Weigert AJ, Hastings R. (1977). Identity loss, family, and social change. *AJS*. 82(6):1171-85.

¹³ Erikson, E. (1968). *Identity: Youth in Crisis* (p. 94). New York: W.W. Norton.

¹⁴ Sants HJ. (1964). Genealogical bewilderment in children with substitute parents. *Br J Med Psychol*. 37:133-41.

¹⁵ Cooper SL and Glazer ES. (1994). *Beyond Infertility: The New Paths to Parenthood*. (p. 351). Lanham, Maryland: Lexington Books.

¹⁶ McWhinnie A. (2000). Families from assisted conception: ethical and psychological issues. *Hum Fertil (Camb)*. 3(1):13-19; Turner AJ, Coyle A. (2000). What does it mean to be a donor offspring? The identity experiences of adults conceived by donor insemination and the implications for counselling and therapy. *Hum Reprod*. 15(9):2041-51.

child is told of their conception at an early age,¹⁷ and that it is certainly more beneficial to occur before the identity construct window of adolescence occurs.¹⁸ So not only should a child be told of their conception at an early age, but they should have access to the identity of their progenitor from a much early time point than what is currently allowed to ensure that the welfare of the child is appropriately protected. If access is to be granted before 18 years then counseling should be mandatory to those seeking information to ensure they fully understand what they are seeking.

The Victorian Law Reform Committee in their inquiry into donor conception recommended that contact vetoes be implemented as part of their recommendation that retrospective access be granted. This would mirror the model used in adoption and would also provide donors with peace of mind such that offspring could not unduly impose themselves on the donors lives.

To assume that all donors who were originally granted anonymity would always wish to remain anonymous is unfounded as research shows that some do change their views and perspectives on their donation and anonymity over time.¹⁹ Additionally, the Victorian voluntary register shows that there are more donors registered than donor conceived people.²⁰ This highlights that a significant number of donors do wish to have their identities revealed to their progeny and that the granting of retrospective access to information will also assist many donors in their search for their offspring.

Recommendation: That donor conceived people have retrospective access to information before 18 years of age and that for those seeking information before turning 18 they must receive counselling. That contact vetoes could be implemented to prevent unwanted intrusion in a donor's life.

Question 3: What other issues would be raised by granting retrospective access? For example, how would the process of applying for information be managed? Would counselling and support services be required?

VARTA in Victoria have been successfully managing information sharing and linking for some time. It would therefore be pertinent to use their previous model as a basis for any NSW model as the current model is too fragmented with 3 separate agencies being problematic. Counselling and support should be available to those that need it if they so desire. Crawshaw and Marshall report from the experience in running a DNA based linking service in the United Kingdom called UK DonorLink is that they found that

¹⁷ Hewitt, G. (2002). Missing links: Identity issues of donor-conceived people. *J Fert Counsel* 9(3), 14-20; Jadva V, Freeman T, Kramer W, Golombok S. (2009). The experiences of adolescents and adults conceived by sperm donation: comparisons by age of disclosure and family type. *Hum Reprod.* 24(8):1909-19.

¹⁸ Kirkman M. (2003) Parents' contributions to the narrative identity of offspring of donor-assisted conception. *Soc Sci Med.* 57(11):2229-42.

¹⁹ Daniels, K., E. Blyth, M. Crawshaw, and R. Curson. (2005). Short communication: previous semen donors and their views regarding the sharing of information with offspring. *Human Reproduction* 20(6): 1670-5.

²⁰ Victorian Assisted Reproductive Treatment Authority (2012). *Annual Report*. Victoria: Victorian Assisted Reproductive Treatment Authority.

having the support services and counselling with the appropriately qualified people was essential for the successful implementation of their system.²¹

At the 2011 ANZICA Donor Linking Symposium held in Melbourne, I heard that previously a letterbox system of information sharing was available in the Victorian model. It was the opinion of the users of that system that the removal of the letterbox was a retrograde step to efficient information sharing and therefore should be implemented in any NSW system.

The Ministry of Health is ill equipped to handle this process.

Recommendation: That a dedicated standalone body be created to deal with all issues and information requests, and that counselling and support services be available for each member of the triad (donors, parents and offspring) who require it.

Question 4: Which agency is best placed to manage the register of donor conception information (donor register)? Is the current management of the register adequate?

In Victoria, records are currently being held by the Births Death and Marriages Department. In my experience in communicating with those people in the Victorian donor conceived community; the donors, recipient parents and offspring, is that having BDM manage these records it is not working nearly as well as previously when they were held by a specialised agency such as VARTA. It is my opinion that expertise in the field of donor conception or related fields such as adoption is a requirement for appropriate and successful management of databases/registers of this type.

The current management of the register by the Health Ministry is unsatisfactory as they do not have the expertise in managing registers of this type nor do they understand the complexities required in successful linking programs.

Recommendation: That the current management is inadequate and that a standalone dedicated body be created to manage the register.

Question 5: Should a standalone body be established to manage the register? What other areas could it have responsibility for?

Yes a standalone body should be responsible for the management and maintenance of such a register. For streamlining of the process for the users of such registers this body should also have responsibility for counselling and public education, and promotion of the register. Typically the current ethos in streamlining governmental bodies is to separate such functions into specific departments which might make more economical sense for the government. However, this approach fails to acknowledge that it becomes confusing and unworkable for the end users, the people that require the services. In essence it needs to become more user friendly by providing a one stop service to the end user, where they can go for counselling and advice, for access to recorded information

²¹ Crawshaw M, Marshall L. (2008). Practice experiences of running UK DonorLink, a voluntary information exchange register for adults related through donor conception. *Hum Fertil (Camb)*. 11(4):231-7.

and to access DNA services if required. Otherwise too many people who require services may fall through the cracks because it becomes too difficult to locate and find what they need.

Recommendation: That the standalone body be responsible for record keeping, running of the register, counselling and support, education and providing access to DNA services.

Question 6: Should counselling and support services be offered to those seeking donor conception information from the donor register?

Yes, counselling and support should be available to those who require it. Not everyone seeking information will require support services. There are various levels of information that might be requested, non-identifying, health, identifying of donor or siblings or perhaps they may request to meet with their donor or siblings. Each of these has differing levels of complexities and not all require counselling. Support and counselling should be there if and when people require it.

Such counselling and support should be available to all members of the triad (donors, recipients and offspring). While counselling is provided to those when they initially seek treatment or donate, there is no follow up support for them later on and many are left feeling alone and have to fend for themselves with their changing situation and emotions over time. VARTA has found through their “Time to Tell” campaign that many recipient parents have needed additional support in the process of informing their children of their conception, showing that follow up support in other jurisdictions such as NSW is required.

Recommendation: That counselling and support be made available to those who wish to receive it but that it is not mandatory.

Question 7: Are there other types of support that could be offered?

Not all records are available for each person who is donor conceived or who donated gametes. This may be through the destruction or loss of records, or perhaps even through incomplete record keeping. Subsequently there will be many people who wish to use the service but who may not be able to be linked up with others due to the poor records. The only way to determine links in these instances is through DNA testing. This is a complex process with different types of analysis required depending on the relationship being investigated. For a more thorough discussion of DNA tests and their pros and cons please read the section titled “Dealing with the Current Paradigm” in my article “Accessing donor conception information in Australia: A call for retrospective access” published in the *Journal of Law and Medicine* (attached).²² A similar system is currently being implemented successfully in the UK called UK DonorLink.

Recommendation: That DNA testing services be made available to those who

²² Adams D, Lorbach C. (2012). Accessing donor conception information in Australia: a call for retrospective access. *J Law Med.* 19(4):707-21.

have incomplete or destroyed records.

Question 8: How would support services be funded? By the government, the individual seeking the service, or by ART clinics?

Support services should be partially funded by the patients seeking ART treatment through the clinics and also subsidised by the government. Adding an ART support services levy to each cycle of ART being undertaken will assist in the funding of each program. For the thousands of dollars that each treatment costs the patient, the addition of a few extra dollars to fund these programs would not be a substantial burden. It is unconscionable to make donor conceived people pay for programs to assist them with fixing the problems that are not of their making and result directly from the actions of others. Forcing donors to pay to put their names on registers may also scare some away that may otherwise be willing to have their details passed on to offspring and therefore should also not fund the service.

Recommendation: That services be funded by placing a levy on ART services paid for by recipient people and also subsidised by the government.

Question 9: How would such support be provided? By referral to the Department of Family and Community Services (as with adoption) or by a standalone body (as has been recommended in Victoria)?

Due to the commonality between the experiences of adoptees and the donor conceived, the support services provided in the adoption community would be a good foundation for support to the donor conceived community. A standalone body is the preferred model, however, the expertise and counselling provided to adoptees could either be mirrored or the counselling by these experts could be subcontracted.

Recommendation: That a standalone body be created but that services and expertise in the adoption community should be utilised, mirrored or subcontracted.

Question 10: How long should ART clinics be required to retain records?

In NSW medical records are required to be kept for 7 years.²³ In donor conception practice this would mean that the child would only be 7 years of age when the records could be destroyed if they are deemed to be medical records by the medical practitioner. As donor conceived people are only able to seek identifying information once they reach 18 years of age, provided the donor is willing to be identified and provided that the child knows of their conception status, then their records may have already been destroyed. For some donor conceived people, they do not search for information until having a family of their own, which in our current society is typically around 30-40 years of age. To ensure that every opportunity is available to these people to seek information if they so choose,

²³ Health Practitioner Regulation (NSW) Regulation 2010 - PART 4. Accessed December 30, 2012; <http://www.mcnsww.org.au/page/resources/legislation/medical-records-legislation/>

then the records must be kept for at least 50 years. This is in agreement with the NSW ART Act 2007 which also stipulates that records be kept for a minimum of 50 years.

Another factor to consider is that for some people in the adoption community that the search may be instigated by the adoptees own children when they reach a mature age to understand the implications of the adoption and search for their own family origins. There is no reason to assume that the children of donor conceived people who may have otherwise been satisfied with their conception and not have sought identifying information on the progenitor, may not wish to seek out such information as it has the potential to also impact on their welfare and sense of place in the world. This would suggest that an indefinite period of record may be the optimal choice.

Recommendation: That records be kept for a minimum of 50 years and preferably indefinitely.

Question 11: What should happen to records if a clinic closes?

This is not merely a question of what should happen to records when a clinic closes but what should happen to records as matter of due process. There must be a level of redundancy built into the record keeping and storage procedure. This then avoids the possibility of the permanent loss or destruction of vital information if the records are deliberately destroyed or accidentally due to fire, flood or other catastrophe. As such duplication of records is required so that not only must a clinic keep accurate records but that a copy of these records are stored in a central repository held by the standalone body responsible for the support services.

Recommendation: That records be duplicated with a copy kept in a central repository.

Question 12: How can we ensure the integrity of records? For example, ensuring that they are not destroyed or tampered with.

See answer to question 11.

Recommendation: Duplication of records to build in a level of redundancy is required to prevent record loss/destruction and or tampering.

Accessing donor conception information in Australia: A call for retrospective access

Damian Adams and Caroline Lorbach*

Donor conception practices in Australia have left thousands of donor-conceived people, their families and gamete donors bereft of information. The lack of a nationally timeline-consistent approach to information access has driven these people to seek support and information from self-help groups, online communities and even their own DNA. This article examines the historical perspective of information access and how progress is being made through lobbying and public awareness. To determine the current status of information availability, fertility clinics around Australia were surveyed. It is argued that current practices continue to fail donor-conceived people, their families and gamete donors, and that until all donor offspring are afforded the right to know their genetic family history, they will continue to suffer discrimination, and potentially risk psychological and physical trauma.

INTRODUCTION

There are reports that donor conception was being performed by individual medical practitioners in Australia before 1946,¹ during a time when donor anonymity was strictly adhered to. Despite secrecy being encouraged for many years, over time views have changed. Today, some jurisdictions have removed anonymous donations legislatively,² and all jurisdictions are required to adhere to the National Health and Medical Research Council's (NHMRC) Guidelines on assisted reproductive technologies.³ Since 2005 these guidelines have recognised the importance of information exchange, and have required clinics to only use donors who agree to disclose identifying information about themselves to any resultant offspring. This reflects a more open attitude toward donor conception, and an increased focus on educating recipient parents about the need for information and disclosure to their child about their method of conception.⁴ Subsequently, increasing numbers of parents have been requesting information before their child reaches maturity. Research reveals that parental motivation for this trend is a desire to enable the child to develop a clearer sense of identity and to satisfy their curiosity.⁵ The views of adult and teenage offspring regarding information provide a clearer picture of those needs. While parents may still influence their teenagers' beliefs, teenagers' views are significant

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¹ Unknown Author, "Childlessness in SA. Use of Artificial Insemination", *The Advertiser* (Adelaide) (25 July 1946).

² *Assisted Reproductive Treatment Regulations 2010* (SA), reg 8(4)(c); *Human Reproductive Technology Act 1991* (WA), s 49; *Assisted Reproductive Treatment Act 2008* (Vic), s 59(a)-(b); *Assisted Reproductive Technology Act 2007* (NSW), s 37.

³ National Health and Medical Research Council, *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* (Australian Government, National Health and Medical Research Council, 2004) (NHMRC Guidelines).

⁴ For example, see Johnson L and Kane H, "Regulation of Donor Conception and the 'Time to Tell' Campaign" (2007) 15 JLM 117.

⁵ Freeman T, Jadv V, Kramer W and Golombok S, "Gamete Donation: Parents' Experiences of Searching for Their Child's Donor Siblings and Donor" (2009) 24(3) Hum Reprod 505.

as those years are a critical window for identity formation.⁶ Studies of adolescent offspring show that the majority believe they have a right to know the identity of their donor,⁷ and half-siblings,⁸ a health history,⁹ they are curious about non-identifying characteristics (such as nationality, vocation),¹⁰ and would even like to meet their donor.¹¹ Additionally, many donors over time address and reframe their thoughts and emotions on the subject,¹² with a significant number changing their minds about being anonymous,¹³ and in one of the longest running voluntary registers in the world (Victoria), the number of donors registered is three times greater than the number of offspring registered.¹⁴ This illustrates that some donors also desire access to information, a situation that has been typically overlooked.

This article examines the experiences of recipient parents, donor-conceived people and donors (the “triad”) who have sought information about each other in the context of assisted reproduction that utilises donated gametes. While many of the triad do not seek information, their perspectives are not examined here. That is not to discount their position; rather the focus is on those who are seeking information but are denied access. The scope of this article is restricted to donor-conceived people, their families and donors who were involved in donor conception under anonymous conditions (noting that where gametes were donated after 2005¹⁵ throughout Australia, after 1998 in Victoria¹⁶ (or after 1984 with the donor’s consent),¹⁷ and after 2004 in Western Australia,¹⁸ identifying donor information is available). It is these people who are experiencing the greatest difficulty in accessing information. While all parties have importance, the primary focus of this article is on offspring, as they are the only non-consenting party to agreements concerning donor anonymity.

The article begins with a brief history that recounts the experience of members of the triad seeking information and describes a survey the authors conducted of clinics in Australia to assess what information is available to those parties requesting information from them. It then discusses support groups such as the Donor Conception Support Group (DCSG)¹⁹ and TangledWebs²⁰ that are available

⁶ Erikson E, *Identity: Youth in Crisis* (WW Norton, New York, 1968) p 94.

⁷ Scheib JE, Riordan M and Rubin S, “Adolescents with Open Identity Sperm Donors: Reports From 12-17 Year Olds” (2005) 20(1) *Hum Reprod* 239 (86%); Mahlstedt PP, Labounty K and Kennedy WT, “The Views of Adult Offspring of Sperm Donation: Essential Feedback for the Development of Ethical Guidelines Within the Practice of Assisted Reproductive Technology in the United States” (2009) 93(7) *Fertil Steril* 2236 (87%); Jadv V, Freeman T, Kramer W and Golombok S, “Experiences of Offspring Searching for and Contacting Their Donor Siblings and Donor” (2010) 20(4) *Reprod Biomed Online* 523 (77%). The high percentages reported in the aforementioned studies represent a significant proportion of offspring who feel that they need identifying information on their donor for their wellbeing, thereby supporting the concept of donor-identity disclosure.

⁸ Scheib, Riordan and Rubin, n 7 (89%); Jadv, Freeman, Kramer and Golombok, n 7 (78%).

⁹ Hewitt G, “Missing Links: Identity Issues of Donor-conceived People” (2002) 9(3) *J Fert Counsel* 14.

¹⁰ Scheib, Riordan and Rubin, n 7 (96.6% want a picture of their donor, 89.7% would like other non-identifying information such as vocation, marital status, children).

¹¹ Mahlstedt, Labounty and Kennedy, n 7 (62%).

¹² Crawshaw M, Blyth E and Daniels K, “Past Semen Donors’ Views About the Use of a Voluntary Contact Register” (2007) 14(4) *Reprod Biomed Online* 411.

¹³ Daniels K, Blyth E, Crawshaw M and Curson R, “Short Communication: Previous Semen Donors and Their Views Regarding the Sharing of Information with Offspring” (2005) 20(6) *Hum Reprod* 1670.

¹⁴ Infertility Treatment Authority, *Annual Report* (Infertility Treatment Authority, Victoria, 2009) p 20.

¹⁵ NHMRC Guidelines, n 3.

¹⁶ *Assisted Reproductive Treatment Act 2008* (Vic), s 59(a)-(b).

¹⁷ *Assisted Reproductive Treatment Act 2008* (Vic), s 59(b)(ii).

¹⁸ *Human Reproductive Technology Act 1991* (WA), s 49.

¹⁹ The DCSG is a self-funded organisation run by volunteers that has been in existence since 1993. Membership is made up of people considering or using donor sperm, egg or embryo, those who already have children conceived on donor programs, adult donor offspring and donors, as well as social workers, clinic staff, researchers and other interested people. This support group is discussed further below.

²⁰ TangledWebs is an action group challenging donor conception practices in Australia and internationally. Members have personal and/or professional experience that relates to donor conception or adoption. TangledWebs provides an alternative voice

to assist people. For those who are unable to access information directly, other avenues available to them in their quest for information are investigated. Finally, the ongoing lobbying of governments and policy-makers to review legislation to enable equal and therefore retrospective access to information for all those requesting it, rather than just those conceived under identity-release conditions, is discussed.

REQUESTING INFORMATION

The request for information by members of the triad has changed over time. This section briefly shows how things were historically and what the situation is today. It is restricted to the ability to access information directly from clinics as this is where the vast majority go to get information.

In the past, infertility specialists recommended to parents that they should not disclose to their children the truth about the child's conception as secrecy was deemed to be in the best interests of all parties involved.²¹ Some parents were required to sign consent forms with clauses such as:

We understand that the identity of the donor of the semen will not be disclosed to us nor will we directly or indirectly seek his identity.²²

It was also not unusual for doctors to use sperm from more than one man to confuse paternity, thereby placing a further barrier to identification of a child's biological parent.²³ This resulted in a belief that members of the triad could not and should not seek information about each other. Once a pregnancy/birth was achieved, this was typically the end of the relationship with the clinic. Anecdotally, parents were never told that they could come back if they required further information or aid if issues arose in regard to donor information:

The clinics had no policies for what do to about requests like this and most had no idea how they should deal with the requests. The reactions parents were met with when requesting information from clinics varied from antagonistic to puzzlement through to a complete lack of understanding as to why a parent would want this information.²⁴

Those parents and offspring who did try to access information found that it was not easy, as the following experiences from the late 1990s show:

The clinic said that the records for our eldest child no longer existed ... This process took three or four years ... We have now established that there are records.²⁵

[T]he scant facts held by our clinic are difficult to obtain and even worse, inconsistent. We have been given different eye colour and nationality with two separate inquiries for the donor.²⁶

In more recent times, clinics have been creating protocols to deal with requests for information access. However, it has been evident to the DCSG over many years that their responses can vary considerably. There is no standardised consensus between clinics, nor do the NHMRC Guidelines

to assisted reproductive technologies through greater recognition of the complex lifelong issues that affect the person created through donor conception. The group's concern is entirely focused on the welfare of donor-conceived offspring. This support group is also discussed further below.

²¹ Daniels K, "Donor Gametes: Anonymous or Identified?" (2007) 21(1) Best Pract Res Clin Obstet Gynaecol 113; Turner AJ and Coyle A, "What Does It Mean to be a Donor Offspring? The Identity Experiences of Adults Conceived by Donor Insemination and the Implications for Counselling and Therapy" (2000) 15(9) Hum Reprod 2041. Also, it was the experience of the DCSG when it was formed in 1993 that the majority of parents within the group had been advised by their fertility specialist not to tell their children about their conception.

²² Author Lorbach's own records from fertility clinic attended in 1991 and other records shown to author by other recipient parents.

²³ Letter dated 8 January 2002 from a doctor to a member of the Donor Conception Support Group.

²⁴ Senate Legal and Constitutional Affairs References Committee, *Donor Conception Practices in Australia* (2011) (Senate Report), Submission 122 (Donor Conception Support Group of Australia) p 54.

²⁵ Lorbach C, *Experiences of Donor Conception: Parents, Offspring and Donors Through the Years* (Jessica Kingsley Publishers, London, 2003) pp 143-144 (Leonie).

²⁶ Recipient parent, email communication with DCSG (19 April 1999).

provide instruction as to the amount of personal and non-identifying information that is collected, how it should be stored, for how long and how it can or cannot be accessed by the person(s) to whom this information may be of importance.

The lack of standards or consensus among clinics regarding information was evident in a survey the authors conducted to ascertain what, if any, information was available to offspring through the clinic system. The aim was to develop a better understanding of how clinics are able to assist donor offspring and to gather information that could be provided to offspring who came to the DCSG and TangledWebs for help. Surveys were sent to 59 clinics (not all satellite clinics were sent surveys as some are not actually treatment centres) with pre-paid self-addressed envelopes for return. Perhaps telling in itself is that, of the 59 surveys that were sent, only 12 were returned (20% response rate) and not all of those were completed. Unfortunately, due to the poor response rate, the results may not accurately reflect what information access services Australian clinics provide. Nonetheless, the results of the responses that were provided are presented in Appendix 1 (below), and discussion of these is warranted as they do provide some insight into those clinics that did respond.

Of the 12 clinics that responded, the availability of identifying and non-identifying donor information varied from 67 to 92%,²⁷ while the ability or willingness to facilitate contact between half-siblings occurred in only a third of clinics that responded.²⁸

Responses from some clinics also indicated that not all of those completing the survey were knowledgeable regarding the regulations and legislation governing the industry that they work in, with one clinic not acknowledging that they must retain records,²⁹ and one clinic stating that all people requesting information get referred to the State register.³⁰ However, the register is only for those involved after 1993. Nor did the responses suggest that all were aware of the differences in the ability to access information according to the era in which the conception occurred: two clinics did not report a difference in available information.³¹ These results create cause for concern as does the high non-return rate (80%). The reasons for the lack of response are unclear; however, in the authors' view, they mirror the experience of the DCSG, TangledWebs and others who have attempted to access information: that is, the response can vary depending on to whom one talks and when. This can lead to confusion and anxiety:

I got really different information depending on who I talked to.³²

I am searching in vain for information about my donor ... Tasmania has no voluntary register ... I think this situation is discriminatory ... I have no idea if I have latent hereditary diseases ... or whether I am forming a relationship with my half-sibling not to mention the lingering sense that a part of my identity is incomplete.³³

The search for information in an environment that has not, historically, required information release, and has not provided a consistent framework within which information may be exchanged, may be frustrating. When requests for information fail, some requesters may feel dissatisfaction and despair. In an attempt to deal with their emotions and to further aid them in their search, some members of the triad have turned to support networks.

SUPPORT AND NETWORKING

As indicated, members of the triad have few places to go in seeking to access information and support. In most States their only avenue is to return to clinic-provided counsellors, but as the above discussion

²⁷ See App 1, Question 4.

²⁸ See App 1, Question 8.

²⁹ See App 1, Question 3.

³⁰ See App 1, Question 5.

³¹ See App 1, Question 10.

³² Rose WA, "How do I ...?", *Australian Donor Conception Forum* (13 April 2007), <http://www.austliandonorconceptionforum.org/index.php?topic=73.0> viewed 2 October 2011.

³³ Email correspondence to the DCSG, copy of letter sent to Philip Ruddock, Federal Attorney-General (28 January 2007).

illustrates, this may prove fruitless and frustrating. In all but two States of Australia³⁴ there are no government agencies that offer them support. To fill this void, self-created groups and networks have formed not only to assist in information searches but also to provide emotional support. This is particularly important for those who fall under the paradigm of the past in which parents were encouraged by clinicians not tell their children about their conception. These parties particularly may feel a sense of isolation.³⁵ The majority of offspring from the anonymity period, even if they were told about their conception from a young age, will grow up without ever knowing or interacting with other donor-conceived people. It is only now that this is changing and they are able to, and do, interact with other offspring and donor-conception families through self-created networks. The first group to provide support in Australia was the Donor Conception Support Group, which was established in 1993 by a small group of families with the following ethos:

We feel that Donor Gamete families need an ongoing support system. Conceiving a child using donated gametes is only the first step. Parents, donor conceived people, donors and their family need help with accessing information and dealing with issues throughout their lives.³⁶

The membership of the DCSG peaked at just over 800 in 2011.³⁷ Given the secrecy that was originally encouraged and the fact that the majority of parents did not disclose the conception to their child,³⁸ and with many still maintaining secrecy even though they initially intended to tell,³⁹ the number seeking support is lower than the number of actual donor-conceived births.⁴⁰ Additionally, it will always be the case that there will be members of the triad who simply do not feel a need for support. Nevertheless, with respect to the support the DCSG does provide, its experience has been that those seeking support need help in several areas, particularly in how to tell, whether it is telling the child, family or friends. Members of the triad also request help in accessing information about one another which necessitates discussions with them about the historical and current situation regarding legislation and guidelines in Australia. The DCSG provides individual support in person, by phone and email. The group also provides more general support with its website, newsletters, social events, media interviews, information seminars, publications and lobbying.

³⁴ In Victoria, the Victorian Assisted Reproductive Technology Authority, <http://www.varta.org.au>; in Western Australia, the Reproductive Technology Council, <http://www rtc.org.au>. South Australia used to have the South Australian Council for Reproductive Technologies but this was dissolved with the passage of the *Reproductive Technology (Clinical Practices) (Miscellaneous) Amendment Act 2009* (SA).

³⁵ Benward J, *Talking With Children About Sperm Donation* (American Fertility Association, New York, 2010) p 3; Leiblum SR and Hamkins SE, "To Tell or Not to Tell: Attitudes of Reproductive Endocrinologists Concerning Disclosure to Offspring of Conception via Assisted Insemination by Donor" (1992) 13(4) *J Psychosom Obstet Gynaecol* 267.

³⁶ Donor Conception Support Group, <http://www.dcs.org.au> viewed 5 October 2011.

³⁷ Actual numbers would be much larger as the majority of memberships are family memberships.

³⁸ Golombok S, Brewaeys A, Cook R, Giavazzi MT, Guerra D, Mantovani A, van Hall E, Crosignani PG and Dexeus A, "Children: The European Study of Assisted Reproduction Families: Family Functioning and Child Development" (1996) 11 *Hum Reprod* 2324; Golombok S, MacCallum F, Goodman E and Rutter M, "Families with Children Conceived by Donor Insemination: A Follow-up at Age Twelve" (2002) 73 *Child Development* 9528; Broderick P and Walker I, "Donor Gametes and Embryos: Who Wants to Know What About Whom, and Why?" (2001) 20(1) *Politics Life Sci* 29; Brewaeys A, Golombok S, Naaktgeboren N, de Bruyn JK and van Hall EV, "Donor Insemination: Dutch Parents' Opinions About Confidentiality and Donor Anonymity and the Emotional Adjustment of Their Children" (1997) 12 *Hum Reprod* 1591; Rumball A and Adair V, "Telling the Story: Parents' Scripts for Donor Offspring" (1999) 14(5) *Hum Reprod* 1392; Lycett E, Daniels K, Curson R and Golombok S, "School-aged Children of Donor Insemination: A Study of Parents' Disclosure Patterns" (2005) 20 *Hum Reprod* 810.

³⁹ Blyth E and Ryll I, "Why Wouldn't You Tell? Telling Donor-conceived Children About Their Conception" (2005) 15(1) *Health Ethics Today* 4.

⁴⁰ While it is unknown exactly how many donor-conceived people there are in Australia, it is estimated to be between 20,000 and 60,000: see Senate Report, n 24, p 3. The number of births resulting from assisted reproductive technology was not recorded on a nationwide basis until 2002: see Dean JH and Sullivan EA, *Assisted Conception Australia and New Zealand 2000 and 2001* (AIHW, Canberra, 2003) p 7; Bryant J, Sullivan EA and Dean JH, *Assisted Reproductive Technology in Australia and New Zealand 2002* (AIHW, Canberra, 2004) p 18. In addition, one cannot account for the number of donor-conceived individuals born as a result of private arrangements or with the assistance of a local general practitioner.

There is also evidence that some offspring have been deeply traumatised through the donor-conception process.⁴¹ The TangledWebs group was formed in 2002 for those (not just offspring) who are unhappy with the process and outcomes. It focuses upon the welfare of the child, stating:

The interests and welfare of potential and actual children born as a result of the use of DC must be the over-riding consideration in all decisions concerning the use of such technologies and in the subsequent lives of the children so created. The interests of such children must override those of gamete donors and of social and genetic parents.⁴²

TangledWebs is actively involved in lobbying, working with the media, and also providing an online forum for members to interact in a safe environment without fear of having their views dismissed.

In a similar vein, an international online community for offspring, People Conceived Via Artificial Insemination (PCVAI), was created specifically because of the isolation that some offspring encounter and to allow them to discuss issues freely. Membership is restricted to offspring only:

We want our members to feel comfortable expressing strong opinions and feelings that may be unacceptable to their parents, friends, or the general public. Often donor insemination children/adults feel isolated without access to others who have lived their experiences.⁴³

The theme emerging from the experiences of TangledWebs and PCVAI, which are either predominantly or expressly composed of offspring, is that many feel unable to discuss their thoughts and emotions with their immediate family, partly perhaps through a fear of hurting the feelings of their parents.⁴⁴ Networking with other offspring who have been through similar life experiences is validating and reassuring, allowing them to process and work through their issues.

In addition, many forums provide online support for people who wish to become parents, some with specific sections devoted to donor conception.⁴⁵ As these forums are primarily concerned with the “getting a child” phase rather than accessing information post-natally, they are not relevant to this discussion. There are, however, other options for people seeking support, some of which are international, eg the United States-based Donor Sibling Registry Forum;⁴⁶ a similar but smaller forum created specifically for Australians is the Australian Donor Conception Forum.⁴⁷

The variety of groups shows that support is a significant need for people affected by donor conception. However, the support received is typically untrained, although it may be experientially rich. Given that some offspring and recipient parents have developed a distrust of the clinics,⁴⁸ they

⁴¹ Turner and Coyle, n 21; Lorbach C, “Thoughts and Experiences of Donor Offspring” in Lorbach, n 25, p 181 (Barry), pp 168-169 (Bill), p 172 (Christine), p 180 (Joanna), pp 186-187 (Lynne), p 160 (Priscilla); McWhinnie A, *Who am I? Experiences of Donor Conception* (Idreos Education Trust, Warwickshire, UK, 2006) pp 30-45 (Jamieson L), pp 1-13 (Rose J), pp 14-29 (Whipp C).

⁴² TangledWebs Incorp, <http://www.tangledwebsorg.wordpress.com> viewed 5 October 2011.

⁴³ *People Conceived Via Artificial Insemination*, <http://www.groups.yahoo.com/group/pcvai> viewed 5 October 2011.

⁴⁴ Greenawalt L, “DI is Wrong and I’m Not An Ungrateful Little Brat!!”, *Confessions of a Cryokid* (6 March 2008), <http://www.cryokidconfessions.blogspot.com/2008/03/di-is-wrong-and-im-not-ungrateful.html> viewed 5 October 2011; Ellis T, *Grief That Cannot be Mourned* (TangledWebs UK), <http://www.tangledwebs.org.uk/tw/WhyWrong/Problems> viewed 5 October 2011; Marquardt E, in Miller C, “Donated Generation”, *The New Atlantis* (2008), <http://www.thenewatlantis.com/publications/donated-generation> viewed 5 October 2011.

⁴⁵ See *BubHub*, <http://www.bubhub.com.au/community/forums> viewed 5 October 2011; *Single Mother Forum*, <http://www.singlemotherforum.com/index.php?sid=beb47dc7a91b8fc2ab5646e7c991ad63> viewed 5 October 2011; *Fertility Community*, <http://www.forums.fertilitycommunity.com> viewed 5 October 2011.

⁴⁶ *Donor Sibling Registry Forum*, <http://www.health.groups.yahoo.com/group/DonorSiblingRegistry> viewed 5 October 2011.

⁴⁷ *Australian Donor Conception Forum*, <http://www.australiandonorconceptionforum.org/index.php> viewed 5 October 2011.

⁴⁸ Human Fertilisation and Embryology Authority, *Ethics and Law Horizon Scanning Seminar Report* (Human Fertilisation and Embryology Authority, London, 2010) p 12; Maxey K, in Stryker J, *Regulation or Free Markets? An Uncomfortable Question for Sperm Banks* (Science Progress, 7 November 2007), <http://www.scienceprogress.org/2007/11/regulation-or-free-markets> viewed 6 October 2011; Senate Report, n 24, Submission 76 (Lorbach C), p 8; also see *Fertile Thoughts*, <http://www.fertilethoughts.com/forums/ivf-high-tech/507004-anyone-move-frozen-embryos-one-clinic-another.html> viewed 6 October 2011.

may be more comfortable seeking advice from people who have already travelled the same path and are independent of these clinics. It is often through these support networks that members of the triad become aware of other avenues they may be able to pursue in trying to find out information.

DEALING WITH THE CURRENT PARADIGM

The current paradigm in Australia is an inconsistent one that leaves many people who wish to access information frustrated. Some offspring from the anonymity period, without retrospective access to identifying information, are putting their faith and hopes into other avenues. This section discusses some of those avenues and their limitations and benefits.

In some States there are voluntary registers that can store personal details and assist in providing matches. The most commonly used register is based on available records to create a “paper trail”, whereby people are matched through donor codes, blood grouping, time of treatment/donation and so forth. Examples of these have been successful and ongoing in Victoria, and more recently in Western Australia. The other type of register, which is not currently in use in Australia but is being implemented in the United Kingdom (UK DonorLink),⁴⁹ uses DNA profiling to create matches even when no records exist, and as such could complement the paper trail register.

Both registers involve a voluntary aspect in that both parties (eg, donor and donor-conceived; or donor-conceived siblings) must be willing to have their details stored on the register and their identities revealed to matches. This is meant to overcome issues of privacy that were either explicit or implied under the anonymity paradigm.⁵⁰ However, requiring *both* parties to place their name *actively* on the register results in fewer instances of information exchange. In addition, the paper trail register is hampered by poor record-keeping. Through anecdotal evidence, a significant number of records have either been destroyed or misplaced; for those that do have records, some contain a paucity of information, making matching extremely difficult.

For many families, the lack of registers in various jurisdictions and poor record-keeping have led to the establishment of online registers where offspring, families and donors can voluntarily enter their information without the oversight of clinicians or legislators, to facilitate matches of their own. The most popular online registers currently are the Donor Sibling Registry (DSR)⁵¹ and the AMFOR Registry,⁵² both of which are international, while one created specifically for Australians is the Australian Donor Conception Registry.⁵³

DNA registers have the potential to circumvent poor or missing records. The current system employed by UK DonorLink, and used by the majority of DNA testing laboratories to determine half-sibship to match offspring from the one putative donor, relies on the same markers as paternity testing. These are commonly referred to as the CODIS markers.⁵⁴ Unlike paternity testing which is

⁴⁹ Crawshaw M and Marshall L, “Practice Experiences of Running UK DonorLink, a Voluntary Information Exchange Register for Adults Related Through Donor Conception” (2008) 11(4) Hum Fert (Camb) 231.

⁵⁰ Noting that a “right to privacy” is, if recognised at law, not absolute: see Allan S, “Psycho-social, Ethical and Legal Arguments For and Against the Retrospective Release of Information about Donors to Donor-conceived Individuals in Australia” (2011) 19 JLM 354; and in some jurisdictions has been challenged, and overturned, in the context of assisted reproductive technology: see *Johnson v Superior Court* 80 Cal App 4th 1050 at 1056-1057 (2000). Nonetheless, some argue that breach of privacy is a valid concern: see Senate Report, n 24, Submission 20 (Office of the Information Commissioner (Qld) p 2; Submission 151 (Office of the Privacy Commissioner (Commonwealth)), p 8.

⁵¹ Donor Sibling Registry (an international register with almost 33,000 registrants and over 8,000 matches, registration requires a membership fee), <https://www.donorsiblingregistry.com> viewed 26 September 2011.

⁵² AMFOR (Americans for Open Records) Donor Offspring/Parent Registry (an international register with over 1,600 registrants, free to register), <http://www.amfor.net/DonorOffspring> viewed 26 September 2011.

⁵³ Australian Donor Conception Registry (a Yahoo group for Australians to register with over 40 registrants, free to register), <http://www.health.groups.yahoo.com/group/AustralianDonorConceptionRegistry> viewed 26 September 2011.

⁵⁴ CODIS or Combined DNA Index System was originally funded by the FBI as a means of identifying suspects. It has since also been used as a means to identify unidentified human remains and to establish the likelihood of two people being related. It uses short tandem repeat (STR) loci/markers which are highly variable within a given population. Typically a half-sibship analysis will involve 13 markers.

conclusive because it is easy to exclude non-biological relationships, sibship testing is more complex and can only report a probability of two offspring being related.⁵⁵ This gives offspring the possibility of finding or confirming a relationship with their biological kin. However, while CODIS DNA registers provide a source of hope for those who have no records, they can also be a source of false hope. While some results show that the relationship is clear cut (either being related or not), many results are simply inconclusive. There is also the possibility that some true half-siblings will be falsely excluded,⁵⁶ and conversely some non-half-siblings falsely included. To some degree this has been borne out in practice in the United Kingdom with CODIS testing indicating that two women were possible siblings. While they were advised that the results were not definitive, they did form a relationship and were disappointed with news that the link may not be supported by subsequent evidence.⁵⁷ This type of DNA matching is clearly problematic as it can only determine probabilities.

In recent times there has been progress in improving DNA analysis for determining relationships through what is called genetic genealogy. These DNA tests use different regions of DNA for analysis and some implement larger numbers of markers.⁵⁸ For male offspring their Y-chromosome DNA (Y-DNA) traces their paternal line (sperm donor), as it typically passes down father to son unchanged and therefore is a useful genealogical tool as it is linked with surnames and geographic ancestry.⁵⁹ Some male offspring have already identified their genetic fathers,⁶⁰ not necessarily because their genetic father is listed on the database but because another close male relative has tested or a matching surname may be linked to a possible name the offspring has acquired from information such as student records (students were often recruited for donations).⁶¹ Tracing the maternal line (egg donor) through this method is also possible through testing mitochondrial DNA (mtDNA), as it is only inherited from the mother. However, tracing maternity through this method is more difficult due to the practice of women changing their surname and because it is harder to differentiate between close and distant relatives when compared to Y-DNA.⁶² Using mtDNA or Y-DNA for these analyses is an acceptable and accurate method for inferring maternal genealogy,⁶³ and paternal genealogy which may also provide evidence as to a person's historical geographic origins.⁶⁴ While some of this information may

⁵⁵ The probability of two people being half-siblings is based on a Sibship Index (SI), also known as a Likelihood Ratio (LR) which works on an inclusion principle rather than the paternity test's exclusion principle. See Wenk RE, Traver M and Chiafari FA, "Determination of Sibship in Any Two Persons" (1996) 36(3) *Transfusion* 259.

⁵⁶ Allen RW, Fu J, Reid TM and Baird M, "Considerations for the Interpretation of STR Results in Cases of Questioned Half-sibship" (2007) 47(3) *Transfusion* 515. The typical cut-off for determining relatedness in half-siblings falsely eliminates 10% of real half-siblings and is therefore problematic for this type of analysis: see Pu CE and Linacre A, "Increasing the Confidence in Half-sibship Determination Based Upon 15 STR Loci" (2008) 15(6) *J Forensic Leg Med* 373.

⁵⁷ Personal communication with author Adams.

⁵⁸ The CODIS test typically use 13 markers, while some autosomal DNA tests use approximately 1 million markers. When analysing half-sibship relationships this increase provides a far greater level of confidence.

⁵⁹ Gill P, Brenner C, Brinkmann B, Budowle B, Carracedo A, Jobling MA, de Knijff P, Kayser M, Krawczak M, Mayr WR, Morling N, Olaisen B, Pascali V, Prinz M, Roewer L, Schneider PM, Sajantila A and Tyler-Smith C, "DNA Commission of the International Society of Forensic Genetics: Recommendations on Forensic Analysis using Y-Chromosome STRs" (2001) 124(1) *Forensic Sci Int* 50.

⁶⁰ Motluk A, "Anonymous Sperm Donor Traced on Internet" (2005) 2524 *New Scientist* 6; Lehmann-Haupt R, *Are Sperm Donors Really Anonymous Anymore? DNA Testing Makes Them Easy to Trace* (Slate, 1 March 2010), <http://www.slate.com/id/2243743> viewed 22 September 2011.

⁶¹ Levine AD, "Self-regulation, Compensation, and the Ethical Recruitment of Oocyte Donors" (2010) 40(2) *Hastings Cent Rep* 25; Paul S, Harbottle S and Stewart JA, "Recruitment of Sperm Donors: The Newcastle-Upon-Tyne Experience 1994-2003" (2006) 21(1) *Hum Reprod* 150; New South Wales Law Reform Commission, *Artificial Conception: Human Artificial Insemination, Report 49* (1986) at [5.4].

⁶² Mitochondrial DNA mutates at a slower rate than Y-chromosome DNA, meaning that even more distant relatives are also likely to match the offspring.

⁶³ Hudson RR, "Gene Genealogies and the Coalescent Process" (1991) 7 *Oxf Surv Evol Biol* 1.

⁶⁴ Barbujani G and Bertorelle G, "Genetics and the Population History of Europe" (2001) 98(1) *Proc Natl Acad Sci* 22.

not pertain directly to the donor, in the absence of this information, an historical place of origin provides a person with roots, a heritage, and a place of belonging which can be extremely important for many people.

Another method for determining relationships can be achieved through autosomal DNA testing such as FamilyTreeDNA's Family Finder test, and 23andMe's Relative Finder test. These tests have not only allowed some offspring to find out the identity of their donor, but they have also been able to match cousins, uncles and aunts.⁶⁵ It is the authors' opinion that these newer genetic genealogy tests provide greater information and level of certainty than the CODIS testing achieves and therefore should be the default DNA tests to be used in support of paper-trail registers.

Similarly, donors can use the same technologies to track down their progeny even if that child is unaware of their method of conception. While such news from "outside" the current family structure could have negative consequences, evidence suggests that such concerns are relatively unfounded as, when presented with this opportunity, donors are unlikely to push for identification of their offspring (noting the Victorian registers show only 0.2% of donors make this request).⁶⁶

A few testing companies, such as 23andMe, also include a genetic health analysis determining the increased likelihood of developing a condition or disease based on DNA that is linked with such conditions or diseases. While these are only risk ratios, which may not be straightforward,⁶⁷ and therefore are not definitive predictors for developing that disease or condition, for offspring devoid of half their family health history, knowledge of such a health history and increased risks is seen as vital in assisting clinical diagnosis and prevention.⁶⁸ Patients may not always be inclined to do something about these findings,⁶⁹ and treatments often lag behind diagnostic research,⁷⁰ but by having information, offspring gain autonomy over their health that may otherwise be lacking.

Nonetheless, the above methods illustrate the consequences of the current situation which denies accurate access to information. Turning to genetic testing can be financially costly, and those searching for information are unsupported by the clinics or government departments. It is the opinion of the DCSG and TangledWebs that members of the triad should not have to resort to such measures to obtain information that should be made available to them. These organisations have therefore turned to appealing to governments and policy-makers to support their quest for retrospectivity which may help reduce some of the need for these other avenues.

LOBBYING

The final avenue to be discussed in terms of attempts to obtain information is the lobbying that has been undertaken by the DCSG and TangledWebs. These groups consider that offspring conceived under anonymity provisions suffer discrimination on four grounds:

- as a result of legislation and/or guidelines providing for only those born after certain dates to have access to information, offspring conceived prior to these dates are deprived of access to information when younger offspring do not have such barriers in place;
- their mode of conception denies them knowledge of their progenitors when those conceived naturally typically have access to information about their genetic heritage;
- the State in which they were conceived may have differing acknowledgments and ability to access information compared to other States; and

⁶⁵ Personal communication between several donor-conceived offspring with author Adams.

⁶⁶ Infertility Treatment Authority, *Annual Report* (ITA, Victoria, 2009) pp 18-19.

⁶⁷ Lenzer J and Brownlee S, "Knowing Me, Knowing You" (2008) 336(7649) *BMJ* 858.

⁶⁸ Hastrup JL, "Inaccuracy of Family Health Information: Implications for Prevention" (1985) 4(4) *Health Psychol* 389; Centers for Disease Control and Prevention (CDC), "Awareness of Family Health History as a Risk Factor for Disease – United States, 2004" (2004) 53(44) *Morb Mortal Wkly Rep* 1044; Burke W, "Genetic Testing" (2002) 347(23) *NEJM* 1867.

⁶⁹ Marteau TM and Lerman C, "Genetic Risk and Behavioural Change" (2001) 322(7293) *BMJ* 1056.

⁷⁰ Brower V, "Genomics and Health Care. How Genomics Medicine is Translated into Better Health Care Largely Depends on How Physicians Handle This Information" (2004) 5(2) *EMBO Rep* 131.

- other disenfranchised groups (such as adoptees) have gained retrospective access to information which identifies their genetic parents.

The DCSG and TangledWebs maintain that creating institutionalised change that will benefit information availability not only for the offspring but for all members of the triad requires grass roots redirection away from the current paradigm. To achieve this, individuals and these groups have been lobbying State and federal parliaments and parliamentarians for the past two decades. There is little evidence to suggest that lobbying by individuals has provided any meaningful progress in donor conception legislation or regulation in Australia. Progress in this regard has been achieved through groups such as the DCSG and to a lesser extent TangledWebs.

While the initial focus of the DCSG in the early 1990s was on parenting, it quickly became apparent to them that, while there was little formal regulation of clinics across Australia with regard to donor information release, parents and donor-conceived people were increasingly contacting the DCSG to ask how they could access such information. Legislation in South Australia⁷¹ at the time permitted access to non-identifying donor information, but also enshrined donor anonymity in law, making it the only State to do so. Victorian legislation⁷² was the first in the world to specify that parents and donors were able to access non-identifying information about each other and the donor was able to know if a birth had occurred as a result of his donation. Western Australia also allowed access to non-identifying information.⁷³ The rest of Australia was devoid of any regulation of donor-conception practices. While it is sometimes difficult to ascertain if any specific lobbying has led directly to changes in legislation, the lobbying described below certainly preceded legislative change and therefore can perhaps be viewed as providing some form of impetus.

In the first year of the DCSG's existence (1993), the group realised from corresponding with a number of clinics that the clinics seemed satisfied with using anonymous donors; however, a vote of the DCSG membership revealed that members were not. The DCSG believed that lobbying to achieve legislative change was the only answer.⁷⁴ Its first submission was made in 1994 to the New South Wales Law Reform Commission's *Review of the Adoption of Children Act 1965*. It voiced its opinion that donor conception should be treated in a like manner to adoption and that all donor-conceived people should have access to identifying information. This review concluded that donor conception lacked the information system that adoption deemed necessary for the welfare of adoptees, and that it continued to "promote deception and secrecy making this the most persuasive argument in favour of regulation".⁷⁵ It also made other comparisons between adoption and donor conception, including the fact that in both situations "children live with non-genetic social parents and may desire or need information about their genetic parent(s)".⁷⁶ However, the New South Wales Parliament chose not to act on these findings.

In 2000, the DCSG lobbying of the New South Wales Government to review the *Human Tissue Act 1983* (NSW) culminated in the enactment of the *Assisted Reproductive Technology Act 2007* (NSW). Legislation only gave rights of access to information to people conceived after enactment in 2010, not retrospectively as argued by the DCSG.

Over many years the DCSG regularly lobbied State and Territory governments to encourage the introduction of legislation to ban anonymous donation and provide donor-conceived people with the

⁷¹ *Reproductive Technology (Clinical Practices) Act 1988* (SA).

⁷² *Infertility (Medical Procedures) Act 1984* (Vic); *Infertility (Medical Procedures) Regulations 1988* (Vic).

⁷³ *Human Reproductive Technology Act 1991* (WA).

⁷⁴ West R, "Children Need an Identity", *The Age* (5 August 1993).

⁷⁵ New South Wales Law Reform Commission, *Review of the Adoption of Children Act 1965 (NSW)*, *Discussion Paper 34* (1994) at [10.1].

⁷⁶ New South Wales Law Reform Commission, n 75.

right to access donor and half-sibling information. State government responses were negative, with Queensland expressing the view in 2002 that it had no intention of legislating in this field.⁷⁷

In addition, the need for nationally consistent regulation and legislation was highlighted by donor members of the DCSG who had donated at multiple clinics in the one State and also in multiple States.⁷⁸ Initial approaches to Federal Parliament were met with the response that “legislation on ART is the responsibility of the States and Territories”.⁷⁹ It has caused distress to many members of the DCSG and TangledWebs that this is the case despite enactment of the *Prohibition of Human Cloning for Reproduction Act 2002* (Cth), and the *Research Involving Human Embryos Act 2002* (Cth) which deal to some extent with reproductive technologies. The NHMRC Guidelines on assisted reproductive technology have declared that “The RIHE Act acknowledges the importance of the application of ethical principles to research involving human embryos”.⁸⁰ In addition, the Federal Government acknowledged the importance of applying ethical principles by creating a licensing committee to oversee the application of the *Research Involving Human Embryos Act* and report to Federal Parliament.⁸¹ The disparity between legislating federally on research involving reproductive technologies, yet allowing human creation through the same technologies to be controlled by the States has created confusion and anxiety.⁸² While the issue of the extent to which the Federal Government has powers to create legislation in this area is extremely complex, generally triad members are unaware of these complexities and perceive an inequality when the Federal Government deals with these issues in some contexts, and not in others.

This reaction provided the impetus to lobbying of the then Commonwealth Attorney-General Philip Ruddock, following which the Standing Committee of Attorneys-General (SCAG) in 2009, in referring to a National Register of Donors, stated:

Ministers discussed the importance of all persons born as a result of artificial conception procedures having the means to access information concerning their genetic heritage and agreed to develop a discussion paper on a national model for registration of donors.⁸³

However, this discussion paper has not eventuated and has not been mentioned in any SCAG communiqué since.⁸⁴

The frustrations experienced by the DCSG did not stop the group from seeking to be heard by the Federal Parliament. In June 2009, the DCSG held a meeting with Senator Trish Crossin, who assisted the group in lobbying further for a federal inquiry. On Valentine’s Day, February 2010, every Member of Federal Parliament received a card showing two adults embracing, with thought bubbles saying “Is she my half-sister?”, “Is my donor father also his father?” This card was also an invitation to Members of Parliament for a meeting at Parliament House. This meeting was attended by approximately 30 parliamentarians with Members expressing concern that donor-conceived people were being treated differently to adoptees. It was the first example of bipartisan support for reform at the federal level.⁸⁵ At this meeting a petition with over 1,000 signatures asked for the Senate to initiate an inquiry into donor conception practices. Subsequently, in 2011 the Senate Legal and Constitutional Affairs References Committee conducted an inquiry into donor conception in Australia which can only be attributed to the work of the DCSG. The recommendations are yet to be acted on and more

⁷⁷ Correspondence from Wendy Edmond, Minister for Health, Queensland (13 June 2002). Edmond stated that there would be no Queensland legislation in this area because no donor-conception procedures were carried out in public hospitals.

⁷⁸ Senate Report, n 24, Submission 122 (Donor Conception Support Group of Australia) pp 98-110.

⁷⁹ Correspondence from Joan Sheedy, Senior Government Counsel, Human Rights Branch, Attorney-General’s Department (13 December 1996).

⁸⁰ NHMRC Guidelines, n 3, p 3.

⁸¹ Patterson K, *Research Involving Embryos Bill 2002* (Australian Parliament, Senate, *Hansard*, 12 November 2002).

⁸² Personal communication between individual members of the DCSG and TangledWebs and the authors.

⁸³ Standing Committee of Attorneys-General, *Communiqué; Summary of Decisions* (April 2009).

⁸⁴ See http://www.scag.gov.au/lawlink/SCAG/ll_scag.nsf/pages/scag_meetingoutcomes viewed 7 October 2011.

⁸⁵ The authors were present at this meeting and this is the message that was presented to them and other members of the DCSG.

worryingly, in the views of the DCSG, TangledWebs and those donor-conceived people wishing for information, there has not been a response from the government.

While much of the DCSG's lobbying has focused on information access, the lack of support services is also another reason why it has felt that new legislation in various jurisdictions is necessary. In particular, it has called for help to give recognition to the needs of triad members, as shown by support services – such as those provided by the Victorian Assisted Reproductive Treatment Authority (VARTA), previously the Infertility Treatment Authority – nationwide.

Other groups have also played a significant role in lobbying. TangledWebs achieved a conscience vote on the Victorian *Assisted Reproductive Technology Act (Vic)* in 2008,⁸⁶ and was the prime mover in the current Victorian *Inquiry into Access by Donor-conceived People to Information about Donors*,⁸⁷ of which one of the terms of reference is:

[T]he 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,⁸⁸

It would appear that this is the first government inquiry in any jurisdiction worldwide to look at the possibility of retrospective access to identifying information on donors by donor-conceived people. TangledWebs was also the first group in the world to protest on the steps of a parliament for donor-conceived rights.⁸⁹

While there have been some successes in governments taking more seriously the importance of information exchange to members of the triad, and especially to the donor-conceived offspring, without certain legislative change, access to information remains only a hope and a need, without a remedy, and media and lobbying campaigns will continue.

CONCLUSION

In the authors' experience, a significant number of triad members feel the current systems regarding information and support have failed them in both the short and long term. This is particularly so for those conceived during the anonymity period. Members of the triad are turning to groups that their own members have created out of necessity to fill the void that some believe the clinics and governments should have filled. Perhaps it could be postulated that they are looking for a sense of community, although it cannot be said that these groups and networks would have still existed if appropriate support infrastructure and access to information was made available in the first instance.

This article has examined the history of secrecy surrounding donor conception, and the information (or lack thereof) available to those seeking details from clinics. It highlighted that there is a lack of uniformity and perhaps understanding of the legal requirements regarding information access. It is clear that those people searching for information have been frustrated in their search. Increasing numbers of offspring are therefore turning to alternative avenues, including voluntary registers and genetic genealogy. Inherent shortcomings in some of these avenues have driven members of the triad to lobby governments for legislative change, with mixed results.

⁸⁶ ABC News, *Conscience Vote Debate on Fertility Treatment Bill* (7 October 2008), <http://www.abc.net.au/news/2008-10-07/conscience-vote-debate-on-fertility-treatment-bill/533922> viewed 3 October 2011. While it is not widely acknowledged that the conscience vote was a result of lobbying by TangledWebs, the decision to do so and the change from non-party line voting occurred after TangledWebs lobbied for this change. For example, see Powell S, "Fertile Ground for Doubt", *The Australian* (16 February 2008), <http://www.theaustralian.com.au/news/health-science/fertile-ground-for-doubt/story-e6frg8y6-111115563210> viewed 3 October 2011 (author interviewed Myfanwy Walker, member of TangledWebs).

⁸⁷ Parliament of Victoria, Law Reform Committee, *Inquiry into Access by Donor Conceived People to Information about Donors* (2010-2011).

⁸⁸ Parliament of Victoria, Law Reform Committee, n 87.

⁸⁹ TangledWebs held a protest on the steps of the Victorian Parliament, Melbourne, on 22 October 2008. <http://www.t5sdaughter.blogspot.com/2008/10/first-dc-protest-parliament-house-steps.html> viewed 7 November 2011.

Years of searching, possible heartache and trauma, and an inordinate expenditure of time and money can simply be avoided by heeding the call of Allan,⁹⁰ and the DCSG and TangledWebs for the retrospective release of information. While retrospectivity is not without barriers, these can be overcome. It can also be argued that it is in the best interests of all parties involved, not just the offspring, that identifying information is provided.⁹¹ Unfortunately, retrospectivity will not solve the problem for all, as some have had their records destroyed. It will, however, provide thousands of Australians with the opportunity to find answers and information about their genetic heritage if they choose to do so, which may also benefit their own health and wellbeing. It is the authors' view that, in a country that values equality and the wellbeing of our children, it is the ethically correct thing to do.

APPENDIX 1 RESULTS OF SURVEY OF 59 AUSTRALIAN ASSISTED REPRODUCTIVE TECHNOLOGY CLINICS REGARDING RECORD-KEEPING AND PROVISION OF INFORMATION ABOUT DONORS

Questions 1 and 2: When the clinic commenced operation and do they still hold records from that date?

Eleven clinics responded to these questions. All stated they had records dating back to their opening. The mean year of opening was 1997, with the earliest opening in 1982 and the latest opening in 2007. The year of opening is pertinent to how an offspring fits into the timeline of being conceived before or after NHMRC Guidelines (2005), or in the case of Victoria (1998), and Western Australia (2004), and what information they may receive.

Question 3: How long does each clinic keep donor conception records?

Records were stored "indefinitely", "permanently" or "for life" in 67% of respondents while the remainder failed to answer the question. One Western Australian clinic stated that all records go to the Western Australia State Register. However, Western Australian requirements state that the licensee must hold all records indefinitely but send information from donor treatments performed after 2004 to the register.⁹²

Question 4: Clinics were asked to provide a YES/NO response to a range of donor information that they would provide to a donor-conceived person if requested.

The percentage of clinics stating they can provide the requested information relating to specific information was as follows:⁹³

Donor personal information	Availability (%)
Name	67
Last known address	67
Age at donation	83
Physical description	83
Education	92

⁹⁰ Allan, n 50.

⁹¹ Dennison M, "Revealing Your Sources: The Case for Non-anonymous Gamete Donation" (2008) 21(1) JL & Health 1.

⁹² Western Australia, *Western Australian Government Gazette No 201* (Perth, 2004) pp 5425-5426.

⁹³ Responses were positive or negative. However, analysis of the data is complex due to a quarter of the clinics opening after NHMRC Guidelines implementation. Such clinics have only operated under identifiable donor conditions and therefore should have all requested information freely available, which they did. Only a quarter of the clinics that responded have been in operation long enough to have mature age (18 years of age) offspring approaching them seeking information. Under anonymity provisions, those earlier clinics would not be willing to release personal information without a donor's consent. Yet two of the three clinics said that they would have such information available for the offspring, while the other stated that information was stored at another clinic from where their donor sperm was sourced.

Donor personal information	Availability (%)
Career	83
Religion	83
Interests/hobbies	83
Ethnic background	75
Country of birth	83
Half siblings	83
Reasons for donation	92
Familial medical history	83

Question 5: Would clinics facilitate contact with a donor if requested by a donor-conceived person and how contact with the donor would be made; whether this would be by letter to last known address, electoral roll search or any other means.

Of the 12 responses, nine stated that they would attempt to facilitate contact in a variety of ways by phone, email and letter. Seven responded that they would also use electoral roll searches if necessary. One clinic informed the authors that they keep in contact with their donors to ensure contact details are updated. One clinic stated that they referred everyone to the Western Australia State Register, which is only applicable for those conceived after 1993 as the register does not keep records prior to that date.⁹⁴

Question 6: How do clinics match records; are records digitised and matched through donor codes or matched through a paper trail and if the ability to match was dependent on year of donation/conception?

Four clinics stated that they used both digitised records and a paper trail while three used paper only and three used digitised records. There appeared to be no correlation between the age of the clinic and what type of matching technique they used. One clinic said they did not do matching as everything was done by their State Register.

Question 7: Do clinics charge a fee for accessing records and if so how much and what does it cover?

Of the nine clinics responding to this question, seven did not charge for this service. One stated that it was not usual to charge but it was at their discretion and another stated it would depend on the quantity of paperwork.

Question 8: Are clinics able to facilitate contact between half-siblings?

A third of clinics responding stated they would facilitate contact between half-siblings, one stating this would be "time dependent". One New South Wales and two Western Australian clinics stated this was the work of the Registers in their respective States. Registers in these States only make matches when both parties register; they are not proactive in contacting other parties. However, clinics are able to do this at their discretion.

Question 9: Do clinics have a policy for passing letters between parties?

Half of the clinics stated they were able to do this but some had qualifications. One would pass letters between parents/donor offspring and donors but not between half-siblings. Another stated they would do so provided they could screen the letters.

⁹⁴ Western Australian Reproductive Technology Council, *Questions and Answers about the Donation of Human Reproductive Material* (Western Australian Reproductive Technology Council, Department of Health, Western Australia, 2005) p 5.

Question 10: Is there a difference in information provided depending on when a donor donated or when an offspring was conceived?

Half of the clinics stated there was no difference in the information they would provide. Two of these clinics opened after NHMRC Guidelines implementation and therefore do not have to deal with varying paradigms. One Victorian clinic opened after Victorian anonymity was banned, while another imported donor sperm from Victoria. The remaining two should have varying degrees of what is available to offspring dependent on the year of the child's conception, yet did not report this. One clinic responded that if the donation occurred prior to 2004 and the donor had not agreed to be known then they would contact the donor and ask for permission to release information. Another clinic stated that recent donors have more information available and that if the donor was local there was more information than those sourced from interstate.

Question 11: Are there any other services that the clinic can provide in relation to information access?

Four clinics responded that they provide counselling; two clinics would facilitate meetings between donors and recipients with the aid of their counsellor. Another provides assistance for parents in how to tell children about their conception.

Question 12: Does the clinic hold records of clinics/medical practitioners who are no longer in practice?

Ten clinics responded that they did not hold records of clinics or practitioners no longer operating, one did not answer and one clinic said that they hold records of three other clinics which were amalgamated into a new company.