
Guest editorial

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DONOR CONCEPTION, SECRECY AND THE SEARCH FOR INFORMATION

Donor conception has historically been shrouded in secrecy. Such secrecy has been underpinned by social views and legal issues concerning the adults involved in the process – the donor, the recipient parent(s), and, at times, the doctor. However, there is increasing recognition of the need to focus upon donor-conceived people's interests and rights to have identifying and non-identifying information about their donors. This editorial examines issues raised in relation to information release, while also introducing some of the arguments presented by other authors in this Special Issue of the JLM. It also considers recent Australian federal and State government inquiries that have favoured information release and the former Victorian Infertility Treatment Authority's service model to support people in the process of information access and release. While there has been a clear shift to favouring openness and honesty, legislative action is still required to ensure the balancing and realisation of people's interests.

We dance round in a ring and suppose
But the secret sits in the middle and knows.

Robert Frost, "The Secret Sits",
The Poetry of Robert Frost (Lathem EC, ed) (New York, 1969) p 362.

INTRODUCTION

The progress of assisted reproductive technology throughout history has been both celebrated and derided. It has been a practice that, while assisting people to have children, has been cloaked in a veil of secrecy. Such secrecy reflects religious, moral and social views of the past, which were focused upon protecting the adults involved (the recipient parents, donor and doctors) and failed to consider the impact that secrecy may have upon some donor-conceived people. In recent times, little has changed. While some jurisdictions have passed laws that prohibit anonymous donations, and provide access to information for some donor-conceived people, for many people donor conception is still a clandestine practice. For those who do not have access to information, calls to lift the veil of secrecy have been steadily increasing.¹ What is the basis for such calls? What are the psycho-social, ethical and legal arguments for and against release of information? How may competing interests be balanced? How, if the call for information is heeded, should release of information take place? These are some of the questions considered in this editorial and in the articles commissioned for this Special Issue of the *Journal of Law and Medicine*.²

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¹ See eg *Pratten v British Columbia (Attorney General)* 2011 BCSC 656; Senate Legal and Constitutional Affairs References Committee, *Donor Conception Practices in Australia* (2011) (Senate Report); Victorian Law Reform Committee, *Inquiry into Access by Donor Conceived People to Information about the Donors* (March 2012); 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.

² The articles were commissioned to explore psycho-social, ethical and legal issues the current author had raised in an article concerning the retrospective release of information to donor-conceived people and in light of the Senate Legal and Constitutional

To “set the scene”, this editorial first considers the history of artificial insemination, highlighting early reactions to assisted reproductive technology that reinforced it being very much a clandestine practice. It illustrates how acceptance of artificial insemination, including artificial insemination by donor and other assisted reproductive technologies, has changed over time, and then questions the continuance of secrecy that surrounds the practice. It argues that what has been overlooked historically is the impact of secrecy upon some donor-conceived people. The above-mentioned call by the now adult offspring for information about their donors is examined in light of psycho-social, ethical and legal arguments that are raised for and against release. Laws in a number of jurisdictions that require non-anonymous donations are highlighted, as are the practical realities of those who search for information. The editorial then considers two recent Australian government committee reports that conclude that the release of information to donor-conceived people about their donors is required. A brief introduction to the model used in Victoria by the former Infertility Treatment Authority for facilitating and supporting such release is also given. These issues are further explored in the articles included in this Special Issue. The editorial concludes with a question: do the recent recommendations of the Australian inquiries indicate a future of openness and honesty? This last question is introduced, but left open – the answer will be seen in what Australian legislatures do in response to these calls, and whether or not other jurisdictions elsewhere in the world follow.

A LONG HISTORY OF RESEARCH, PRACTICE AND SECRECY

The use of artificial insemination to achieve pregnancy has reportedly existed for centuries.³ So, too, has the secrecy that has surrounded such practice. Bateman Noveas⁴ notes that “the historical origins of assisted conception are clearly tainted by doubts about the morality of the acts involved [including masturbation and instrumental substitution for sexual intercourse] and their legitimacy as medical treatment”.⁵ This is clearly illustrated by the strong disapproval that met early experimentation at the turn of the 19th century in impregnating a woman with her husband’s sperm using “instrumental insemination”.⁶ The practice was publicly condemned as “offensive to natural law”.⁷ It was said that it “could constitute a real social peril”, and that “it was of import to the dignity of marriage that such procedures not be transferred from the domain of Science to the domain of Practice”.⁸ Around this time, Dr J Marion Sims, who conducted 55 inseminations of six women using their husband’s sperm, allegedly repudiated his own work as immoral.⁹

Affairs References Committee Report, and ongoing inquiries in Victoria and New South Wales, Australia, into information release to donor-conceived people: see Allan, n 1; Senate Report, n 1; Victorian Law Reform Committee, n 1; New South Wales Committee on Law and Safety Inquiry into Inclusion of Donor Details on the Register of Births (2012) (ongoing).

³ References to artificial insemination go back to Talmudic documents written more than three centuries ago which record rabbis discussing the status of a woman hypothetically impregnated by semen previously deposited in bath water: Kordimon S, *Artificial Insemination in the Talmud* (Harofe Haivrc, 1942-43, Hebrew) p 62; English translation, p 164, cited in Critser JK, “Therapeutic Insemination by Donor: A Review of Its Efficacy” (1995) 4 *Reproductive Medicine Review* 9. There is also very early reference to King Henry IV of Ceville – often referred to as “le-impotent” – and attempts to impregnate his wife in the 1400s using artificial insemination (the use of a donor is not indicated): Birkhead TR and Montgomerie R, “Three Centuries of Sperm Research” in Birkhead TR, Hosken DJ and Pitnik S (eds), *Sperm Biology an Evolutionary Perspective* (Academic Press, USA, 2009) p 11. The history of artificial insemination is not complete without recognising that there was much experimentation with it in farm animals: see Foote RH, *The History of Artificial Insemination: Selected Notes and Notables* (American Society of Animal Science, 2002).

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⁵ Bateman Noveas S, “The Medical Management of Donor Insemination” in Daniels K and Haimes E (eds), *Donor Insemination: International Social Science Perspectives* (Cambridge University Press, United Kingdom, 1998) p 110.

⁶ In particular, the work of John Hunter in the United Kingdom and MA Thouret in France.

⁷ Tribunal de Bordeaux, 1880, *Affaire Lejâtre*, cited in Bateman Noveas, n 5.

⁸ See n 7.

⁹ Weinberger AD, “Partial Solution to Legitimacy Problems Arising From the Use of Artificial Insemination” (1959-1960) 35 *Ind LJ* 144.

Given the disapproval of artificial insemination with the sperm of a woman's husband, it is not surprising that the early use of *donor sperm*¹⁰ also met with great disapproval. For example, in one of the earliest reported cases of donor insemination (1884), an American physician, Professor William Pancoast, used the sperm of one of his "best-looking" medical students to impregnate the wife of a sterile Quaker merchant.¹¹ The woman was anaesthetised with chloroform and not informed of the procedure, although reportedly the husband was told. It was only in 1909 (some 25 years later), after Dr Pancoast's death, that one of the medical students, who had been present, revealed the story.¹² Similarly, treatments conducted in the 1890s, by Dr Robert L Dickson,¹³ were not reported until some 40 years later.

During this period, the Vatican condemned such practices as gravely immoral, stating that they "infringe the child's right to be born of a father and mother known to him and bound to each other by marriage" and "betray the spouses' right to become a father and a mother only through each other".¹⁴ In addition to objections regarding masturbation and instrumental substitution for sexual intercourse, there were also objections concerning adultery. To this end, Bateman Novaes observes the significance of using fresh sperm to maintaining secrecy:

The conditions under which the three principal participants in DI (the woman to be inseminated, the man providing the sperm, and the physician) were being brought together emphasized the moral premises of this arrangement: even if the offer of treatment might ultimately be justifiable in terms of its positive results, it was nevertheless not perceived as morally appropriate or legally expedient for the infertile couple to be acquainted with the sperm donor. The physician therefore beyond his/her technical role as inseminator, had to intervene as a mediator: someone who makes it possible for semen transfer to take place, without requiring the two parties to meet.

Stigma about male infertility was also apparent. As such, "the secrecy surrounding the procedure and anonymity of the semen provider became the central organising principles of the practice, and in one sense served as the most obvious justification for the physician's presence in this situation".¹⁵ Notably, views bound up in morality, religion and natural law that criticised instrumental insemination did not stop research or practice, but rather reinforced the secrecy surrounding donor conception for over a century.

The history of artificial insemination by donor was significantly tainted during World War II by doctors in Nazi Germany who performed donor insemination experiments on Jews, gypsies and concentration camp prisoners, which were reflective of Nazi eugenic ideals.¹⁶ Such experiments highlight the potential misuse of artificial insemination by donor, a fear that is still prevalent today.¹⁷

¹⁰ Sperm obtained from a male to whom the woman is not married or in a relationship with.

¹¹ Gregoire AT and Mayer RC, "The Impregnators" (1965) 16 *Fertil Steril* 130.

¹² A letter by Addison Davis Hard appeared in the American journal *Medical World*: Eichler M, "Of Desperation Born: The Struggle for Children at Any Cost" in Turner J (ed), *Living the Changes* (University of Manitoba Press, Manitoba, 1990) p 230.

¹³ The first successful use of donor semen in the United States of America is attributed to Dr Robert L Dickson who was a pioneer in birth control, sex education and marriage counselling.

¹⁴ The earliest statements reflecting this view by the Vatican were made at the *Sacred Congregation of the Holy Office* in 1897, and were reiterated in *Pius XII* (1949), *Donum Vitae* (1987) and *Evangelium Vitae* (1995).

¹⁵ Bateman Novaes, n 5, p 111.

¹⁶ Cohen BC, *The Ethics of Using Medical Data From Nazi Experiments* (Copyright 2012, American-Israeli Cooperative Enterprise), <http://www.jewishvirtuallibrary.org/jsource/Judaism/naziexp.html> viewed 22 February 2012. See the statements cited in Cohen of Dr Jay Katz (deceased), formerly of Yale University School of Law, who described the Nazi experiments with one phrase: "They're of no scientific value"; of Brigadier General Telford Taylor, chief counsel for the prosecution at Nuremberg, who described Nazi experimentations as "a ghastly failure as well as a hideous crime ... [that] revealed nothing which civilized medicine can use"; and of Lord Immanuel Jakobovits, Chief Rabbi of the British Commonwealth of Nations and a pioneer of Jewish medical ethics, who said that "using the Nazi data offers not a shred of meaning to 6,000,000 deaths. In fact, use of the data would serve to dishonor them even more so."

¹⁷ King D, "Preimplantation Genetic Diagnosis and the 'New' Eugenics" (1999) 25 *J Med Ethics* 176. For discussion of the use of the word "eugenics" in relation to preimplantation genetic diagnosis see Wilkinson S, "'Eugenics Talk' and the Language of Bioethics" (2008) 34(6) *J Med Ethics* 467.

However, experimentation and practice did not stop. In fact, post-World War II scientific advances,¹⁸ first with animals, and then with humans, marked the entry of artificial insemination by donor into more public realms. In 1949, Christopher Polge, a doctoral student, developed improved methods of freezing and thawing sperm.¹⁹ In 1950, Cornell University scientists discovered that antibiotics could be added to the sperm solution in artificial insemination processes to protect against possible contamination.²⁰ In 1953 the first successful pregnancy from artificial insemination by donor with frozen and thawed sperm was reported.²¹ These were significant discoveries as the capacity to freeze sperm meant that it was no longer necessary for all persons involved to be present (or close to hand). Nonetheless, although practical obstacles were addressed, the moral and legal debate about such practices continued. Such discussion focused primarily upon issues of adultery, illegitimacy, paternity and the rights of legal inheritance of the child from the donor and/or husband/non-biological father.²² Attitudes towards donor insemination remained very negative. For example, Daniels and Taylor noted:

[L]ittle had changed by 1960 when a UK interdepartmental committee, chaired by Lord Feversham determined that donor insemination was “undesirable” and should not be practiced [sic] ... Donation itself was also viewed with deep suspicion, with the personal motivation of donors being called into question. The committee decided that donation “is an activity which might be expected to attract more than the usual proportion of psychopaths”.²³

The public response to the Feversham committee inquiry was similarly negative, ranging from disapproval to abhorrence, with little or no support for donor insemination given to the practice other than by the practitioners themselves.²⁴

However, by the 1970s, sperm freezing techniques had improved, sperm banks had developed, instrumental insemination had become commercialised in many countries, and there were significant calls for its use. Technological advances further increased the occurrence of donor conception worldwide with the first in vitro fertilisation (IVF) baby born in the United Kingdom in 1978. Since then, numerous assisted reproductive technologies have been developed. It was during this period and following that laws in some jurisdictions were passed to provide legal certainty regarding the status of children and their parents born as a result of such technologies. Generally, the donor of sperm was declared not to be a parent (thereby having no rights or responsibilities), and the husband of the woman who underwent the procedure, subject to his consent, was declared the father.²⁵ With the passing of such legislation fears surrounding illegitimacy or questions of legal parentage and inheritance were resolved. However, secrecy remained the guiding principle for many of those involved. Daniels and Taylor described the situation in the 1970s and 1980s as one in which doctors continued to tell families not to mention the child’s origins to anyone, including the child; the few

¹⁸ Such advances were not related in any way to the experiments conducted by the Nazis in World War II.

¹⁹ Polge C, Smith AU and Parkes AS, “Revival of Spermatozoa After Vitrification and Dehydration at Low Temperatures” (1949) 164(4172) *Nature* 666.

²⁰ Foote RH and Bratton RW, “The Fertility of Bovine Semen in Extenders Containing Sulfanilamide, Penicillin, Streptomycin, and Polymyxin” (1950) 33 *J Dairy Sci* 544.

²¹ Bunge RG, Keettel WC and Sherman JK, “Clinical Use of Frozen Semen: Report of Four Cases” (1954) 5(6) *Fertil Steril* 520.

²² For example see Spiegel JL, “Seed of Doubt” (1955-1956) 17 *U Pitt L Rev* 659; Unknown, “Child Conceived Through Artificial Insemination by a Third-party Donor Is Illegitimate – Gursky v Gursky, A [legislation]” (November 1964) 63(1) *Mich L Rev* 160; Valeri JR, “Donor Insemination – No Clear Legal Future in Prospect” (Spring 1968) 3(2) *Portia Law Journal* 235.

²³ Daniels K and Taylor K, “Secrecy and Openness in Donor Insemination” (1993) 12(2) *Politics and Life Sciences* 155 at 156.

²⁴ Blizzard J, *Blizzard and the Holy Ghost* (Peter Owen, London, 1977), cited in Daniels and Taylor, n 23, p 156.

²⁵ In Australia see *Artificial Conception Act 1985* (WA); *Family Relationships Act 1975* (SA); *Parentage Act 2004* (ACT); *Status of Children Act 1996* (NSW); *Status of Children Act* (NT); *Status of Children Act 1974* (Tas); and *Status of Children Act 1974* (Vic). In the United Kingdom see *Human Fertilisation and Embryology Act 1990* (UK), s 28. Laws concerning legal parentage around the world differ both among and within states (eg in federal/State systems). For example, in the United States the majority of States have enacted legislation that governs the status of legal parentage of donors and recipients but such statutes vary regarding the degree to which they resolve issues of legal parentage (eg some require marriage). In the States that do not have statutes governing the legal status of gamete donors or recipient parent(s), the issue is generally governed by the common law but again is not uniform in its application or approach. It is beyond the scope and focus of this article to detail these laws further.

studies that had looked at families who were using donor insemination reported that parents had no intention of telling their child(ren); that donors were matched as closely to the legal father as possible; and, as no notation was made on the birth certificate, secrecy was enshrined.²⁶ Adams and Lorbach²⁷ further note that it was “not unusual in the past 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” and that the general belief was that anyone involved in the conception (donor, recipient or donor conceived) “could not and should not seek information about each other”.²⁸

Today, assisted reproductive technology is a growth industry. The European Society of Human Reproduction estimates that there are 3.5 million children worldwide born as a result of such technology. It may therefore be confidently estimated that donor conception touches the lives of several million people including donors, donor-conceived people, those accessing assisted reproductive technology (recipients), siblings of donor-conceived people (biological and non-biological) and extended families. In a number of countries we have moved to celebrate different family forms, and to recognise the children and parents within them. However, for many people, donor conception continues to be shrouded in secrecy, denial and shame.

WHAT ABOUT ME? DONOR-CONCEIVED OFFSPRING

The history of assisted reproductive technology illustrates that the secrecy surrounding the practice focused primarily upon sex, marriage, morality, adultery, masturbation, the presence of a doctor using an instrument to inseminate the woman, inheritance, legal parentage and stigma concerning male infertility. Such secrecy was, and to a significant degree continues to be, steeped in moral, religious and legal views that primarily (if not solely) focus upon the *adults* involved in the process. Notably, such secrecy does not appear to have been ill intended or meant to cause harm to the resultant donor-conceived person. However, the interest and/or need that donor-conceived people may have in knowing about their conception and/or genetic heritage were largely ignored.

On occasion, however, there was a call for openness.²⁹ In some jurisdictions, laws were passed to prohibit anonymous donation. In the present day, several countries (including Sweden,³⁰ Austria,³¹ Switzerland,³² The Netherlands,³³ Norway,³⁴ the United Kingdom,³⁵ Finland³⁶ and New Zealand³⁷)

²⁶ Daniels and Taylor, n 23 at 156.

²⁷ A donor-conceived person and recipient parent respectively, as well as experienced advocates for the release of information to donor-conceived families, and leaders of donor conception support groups.

²⁸ Adams D and Lorbach C, “Accessing Donor Conception Information in Australia: A Call for Retrospective Access” (2012) 19 JLM 707 (below).

²⁹ For example, see Annas GJ, “Fathers Anonymous: Beyond the Best Interests of the Sperm Donor” (1980-1981) 14 Fam LQ 1; Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilisation, *Report on Donor Gametes in IVF* (Melbourne, 1983) (Waller Report); United Kingdom, Department of Health and Social Security, *Report of the Committee of Inquiry into Human Fertilisation and Embryology* (HMSO, London, 1984) (Warnock Report); O’Donovan K, “A Right to Know One’s Parentage?” (1988) 2 *International Journal of Law and the Family* 27; Haimes E, “Secrecy: What Can Artificial Reproduction Learn from Adoption?” (1988) 2 *International Journal of Law and the Family* 46; Royal Commission on New Reproductive and Genetic Technologies, *Proceed with Care* (Minister of Government Services, Ottawa, 1993); Maclean S and Maclean M, “Keeping Secrets in Assisted Reproduction – The Tension between Donor Anonymity and the Need of the Child for Information” (1996) 8(3) *Child and Family Law Quarterly* 243; Blyth E, “Donor Assisted Conception and Donor Offspring Rights to Genetic Origins Information” (1998) 6(3) *International Journal of Children’s Rights* 237.

³⁰ *Lag om insemination (Law on Insemination) 1984* (Swed) (replaced by *Genetic Integrity Act 2006* (Swed)).

³¹ *Fortpflanzungsmedizinengesetz, 275 Bundesgesetz, 1992* (Austria).

³² *Federal Act on Medically Assisted Procreation of 18 December 1998 – FF 1996 III, 197* (LPMA) (Switz).

³³ *Wet donorgegevens kunstmatige bevruchting, 2002* (Neth).

³⁴ *Act on Biotechnology 2003* (Norway).

³⁵ *Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004* (UK).

³⁶ *Act on Assisted Fertility Treatments (1237/2006)* (Fin).

³⁷ *Human Assisted Reproductive Technology (HART) Act 2004* (NZ).

and some Australian jurisdictions (New South Wales,³⁸ Victoria,³⁹ Western Australia⁴⁰ and South Australia⁴¹) provide access to identifying and non-identifying information about donors to donor-conceived people. Such access has placed importance on donor-conceived people being able to learn about their genetic heritage, familial medical history, and kinship. However, even in these jurisdictions, provision for the recording and release of information about donors to donor-conceived people does not guarantee information flow. Without a means to enforce disclosure, recipient parents may maintain secrecy if they so desire. To promote greater openness Victoria implemented an addendum provision to the birth certificate of donor-conceived people born after 1 January 2010, which states that further information is available about them on the Victorian Registry of Births, Deaths and Marriages.⁴² In this way a person will be alerted to the fact of their donor conception, necessary of course to make the choice about whether they wish to access information about the person(s) to whom they are biologically related.

On the other hand, many jurisdictions (in fact, the vast majority worldwide) continue to permit “anonymous donation” and secrecy concerning the method of conception. Even in countries that have laws providing for non-anonymous donation, such laws do so only prospectively (from the date of their enactment), and as noted, most do not *require* that parents tell their children about the method of conception. There are thus a significant number of individuals worldwide who continue to be deprived of knowledge about the method of their conception and/or who may be denied access to information about their donor and their genetic identity and heritage.

There are a number of increasingly well-known reasons why donor-conceived people are searching for information and arguments that support the release of information to them.

A sense of self

One of the most significant reasons for searching for information about donors involves questions about self-identity: the “who am I?” questions that many ask. For some, this simply involves a desire to know more about themselves and their biological heritage. For others, there may be a stronger sense of “lost identity” and a corresponding desire to know more about their donor.⁴³ The confusion and distress of an unknown heritage is referred to as “genealogical bewilderment”.⁴⁴ Such bewilderment may exist despite a child’s development being shaped by social as much as biological factors, because knowledge of one’s immediate genetic heritage is considered integral to the self-identity of most people.

In studies conducted to evaluate the consequences of non-disclosure for an individual’s sense of identity, some respondents described feeling as though they were “freaks” or “products of experiments” or that they were in some way “incomplete”. McNair wrote:

³⁸ *Assisted Reproductive Technology Act 2007* (NSW).

³⁹ *Infertility (Medical Procedures) Act 1984* (Vic); *Infertility Treatment Act 1995* (Vic); *Infertility Treatment Regulations 1997* (Vic); *Assisted Reproductive Treatment Act 2008* (Vic).

⁴⁰ *Human Reproductive Technology Act 1991* (WA).

⁴¹ *Assisted Reproductive Treatment Act 1988* (SA), s 16; *Assisted Reproductive Treatment Regulations 2010* (SA), reg 4(c).

⁴² *Assisted Reproductive Treatment Act 2008* (Vic), ss 153, 17B(2).

⁴³ Turner A and Coyle A, “What Does it Mean to be Donor Offspring? The Identity Experience of Adults Conceived by Donor Insemination and the Implications for Counselling and Therapy” (2000) 15(9) *Hum Reprod* 2041; Jadva V, Freeman T, Kramer W and Golombok S, “Experiences of Offspring Searching for and Contacting Their Donor Siblings and Donor” (2010) 20 *Reprod BioMed Online* 523 at 524.

⁴⁴ Turner and Coyle, n 43; Wellisch E, “Children Without Genealogy: A Problem with Adoption” (1952) 13(1) *Mental Health* 41; Sants H, “Genealogical Bewilderment in Children with Substitute Parents” (1964) 37(2) *British Journal of Medical Psychology* 133.

These sentiments suggest that identity is related to genetic inheritance in some way, and a fuller sense of identity for a donor-conceived person may only be achieved through access to details about their donor.⁴⁵

Bewilderment may be particularly acute for people who discover later in life that they were donor-conceived. There is evidence to suggest that some donor-conceived people in these circumstances may undergo a “fracturing” in their identity due to knowledge of their status, and feel significantly deceived about who they are.⁴⁶ The curiosity about their donor and the propensity for donor-conceived people to search for information is not related to the desire to escape negative family issues; rather, most donor-conceived people report positive relationships with their parents.⁴⁷ Such feelings coexist with the strong desire to know about one’s donor and frustration at being denied information.⁴⁸

Chisholm has stated:

In short, there is a formidable argument to the effect that knowledge of one’s genetic origins is, at least for many people, a matter of fundamental importance to their sense of identity and self-worth; and that ignorance, as well as undermining this sense, could lead to risks of a medical kind, and a risk of inadvertently partnering a half-sibling.⁴⁹

Concerns about medical history and the risk of forming consanguineous relationships are discussed below.

Medical history

Some donor-conceived people wish to find out more information about their familial medical history. The importance of knowing whether or not there is a familial history of heart disease, diabetes, cancer, mental health issues, and/or other heritable diseases is undeniable and strongly encouraged in this day and age.⁵⁰ Donor-conceived people who are denied access to familial medical histories are therefore placed at increased risk as a result of not having access to information. This becomes very significant as people age. There are many conditions such as type-2 diabetes mellitus or heart disease which often develop later in life, and a donor who donated in the 1970s or 1980s, when donor conception was shrouded in secrecy, may not have been aware that they are a carrier of these diseases. Similarly, a donor-conceived person may become aware of a heritable condition, but has no way presently to notify their donor(s) or half-siblings conceived using the same donor gametes.⁵¹ This may have ramifications not just for the person unaware of such information but for generations to come. On the other hand, the release of medical information raises issues about health privacy and confidentiality which are generally protected. However, there are some circumstances in which the release/reporting of such information to third parties is allowed and prescribed by legislation, and a right to privacy is not absolute.⁵²

⁴⁵ McNair R, *Outcomes for Children Born of ART in a Diverse Range of Families* (Victorian Law Reform Commission, Victoria, 2004) p 43.

⁴⁶ Dennison M, “Revealing Your Sources: The Case for Non-anonymous Gamete Donation” (2008) 21(1) *Journal of Law and Health* 1 at 13; Ravitsky V, “Knowing Where You Come From: The Rights of Donor-conceived Individuals and the Meaning of Genetic Relatedness” (2010) 11(2) *Minnesota Journal of Law, Science & Technology* 655 at 670, referring to Warnock M, “The Good of the Child” (1987) 1 *Bioethics* 141 at 151.

⁴⁷ 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” (2010) 93(7) *Fertil Steril* 2236.

⁴⁸ Turner and Coyle, n 43; Jadva et al, n 43 at 524; Dennison, n 46.

⁴⁹ Chisholm R, “Information Rights and Donor Conception: Lessons from Adoption?” (2012) 19 *JLM* 722 at 734 (below).

⁵⁰ Centers for Disease Control and Prevention (CDC), “Awareness of Family Health History as a Risk Factor for Disease” (2004) 53(44) *Morb Mortal Wkly Rep* 1044.

⁵¹ See eg *Donor Disclosure*, <http://www.youtube.com/watch?v=1mLdw3v1pkI> viewed 30 March 2012.

⁵² For more detailed discussion of such exceptions see Allan, n 1 at 369-371.

Risk or fear of forming consanguineous relationships

Another significant driver in the search for information for some donor-conceived people is the fear of unknowingly forming relationships with siblings or possibly their unknown donor.⁵³ While the probability of such an occurrence is unknown, such a risk may be significant within smaller populations, or where there are no controls on the number of families for which the same donor's gametes may be used.⁵⁴ While one way to avoid half-siblings forming relationships is to restrict a donor to one donation or to one recipient family, it is clear that this is not, and has not been, the approach to donor conception in most jurisdictions.⁵⁵ The reality is that a significant number of donors are likely to have donated multiple times. Some may also have donated at multiple clinics, and in a number of jurisdictions.

Entering consanguineous relationships may have negative legal ramifications.⁵⁶ There is also the chance that such relationships would bear children, leading to the risk of genetic or chromosomal abnormalities.⁵⁷ The fear of this occurring can cause great distress for some donor-conceived people.⁵⁸ Psycho-social and ethical dilemmas also exist. Most importantly, the threat of consanguinity poses yet another challenge to the emotional and social wellbeing of some donor-conceived people. Crawshaw⁵⁹ describes how some donor-conceived people question "whether their attraction to someone may be 'genetic sexual attraction', and that an otherwise innocent statement such as 'you look just like so-and-so' carries a very different significance to those personally affected by donor conception".⁶⁰

The chances of such situations occurring and/or the fear of forming consanguineous relationships would be removed if donor-conceived people and donors were able to obtain information about each other.

Openness and honesty

There are other reasons beyond those detailed above that drive some donor-conceived people to search for information. Some report simply wanting to know a name for their donor; others wish to say thank you; while others want to know whether they have any half-siblings. Whatever the reasons, be they to address harm that has been suffered, to prevent future harm, or for the many other psychological, social, ethical and personal reasons that lead people to search, it is clear that underpinning their search is a strong desire for openness and honesty. Simply put, they call for an end to secrecy and anonymity, and an opportunity to choose for themselves.

Chisholm highlights general support for openness and honesty (or in the negative sense "a concern about any system that depends on deception or concealment") in the legal system in "not only

⁵³ Senate Report, n 1, Submission 156 (M Crawshaw) p 7.

⁵⁴ New South Wales Law Reform Commission, *Artificial Conception: Human Artificial Insemination, Discussion Paper 11* (1984).

⁵⁵ Some jurisdictions limit the number of families to which a donor may donate. For example, in Victoria, the maximum number of families is 10: *Assisted Reproductive Treatment Act 2008* (Vic), s 29. In New South Wales, the number is five: *Assisted Reproductive Technology Act 2007* (NSW), s 27(1). In Western Australia, the number is five: *Human Reproductive Technology Act 1991* (WA) (see "Human Reproductive Technology Directions (WA)", *Western Australian Government Gazette* (30 November 2004) p 5434 at [8.1]).

⁵⁶ For example, the Australian *Marriages Act 1961* (Cth), s 23(1)(b), makes marriages involving "prohibited relationships" void. Section 23(2)(a)-(b) states that "marriages between an individual and their parent and an individual and their sibling, including half siblings" are "prohibited relationships". State criminal law also makes incest between individuals and their parents and half-siblings a punishable offence: eg see *Crimes Act 1958* (Vic), s 44(2), (4).

⁵⁷ Bennett RL, Motulsky AG, Bittles A et al, "Genetic Counseling and Screening of Consanguineous Couples and Their Offspring: Recommendations of the National Society of Genetic Counselors" (2002) 11(2) *Journal of Genetic Counseling* 97. The authors, in recognising the risk associated with forming consanguineous relationships, recommend genetic counselling and screening for consanguineous couples and their offspring. Donor-conceived individuals who are unaware of their relatedness to others would not have the opportunity to undergo such counselling or screening.

⁵⁸ Commonwealth, Senate Committee, *Hansard* (3 November 2010), oral evidence of donor-conceived individuals.

⁵⁹ Honorary Fellow in Social Work, University of York; National Adviser to United Kingdom DonorLink; Co-Chair of PROGAR (Project Group on Assisted Reproduction).

⁶⁰ Senate Report, n 1, Submission 156 (M Crawshaw) p 7.

background commentaries but in explicit form in some adoption legislation”. In addition, he notes that “this approach is also reflected in numerous legal decisions in Australia and elsewhere”.⁶¹ In the context of donor conception, he quotes the Canadian Royal Commission on New Reproduction Technologies:⁶²

Commission research showed that maintaining secrecy about the means of conception can be contrary to the best interest of the child ... Adults born through DI reported that the decision to keep DI a secret was very damaging – they felt deceived and said they had always sensed that something was “wrong” in the family. Some told the Commission that they found out about the method of conception at a time of family crisis, such as a divorce or death in the family ... Discovering the truth in this way is doubly traumatic; the shock of discovery during an already stressful period is coupled with the realisation that your parents had lied to you all your life.

WHAT ABOUT ME? THE DONOR AND RECIPIENT PARENTS

Contracts for anonymity, privacy and confidentiality

Some argue that sperm donors and recipient parent(s) signed or had a verbal contract which assured the donor of anonymity.⁶³ Such contracts are sometimes used as an argument against releasing information to donor-conceived people.⁶⁴ However, Rees questions whether, at least in the Australian context, such “contracts” actually existed.⁶⁵ She asserts:

Potentially a reason that the “contract” argument is consistently raised is because merely stating that donors’ medical records must be kept confidential might meet the argument that disclosure of the identity should be one of the recognised exceptions to protection of privacy and/or confidentiality. Laws protecting privacy and confidentiality recognise that these are not absolute concepts and permit a balancing of interests.

In looking at samples of consent forms used in the past (the only form of written agreement that appears to exist), Rees concludes that declarations and statements of consent which contained “anonymity” promises “fall short of the binding contract that one might expect, given the frequent arguments that there are contractual guarantees of anonymity”.⁶⁶ They simply do not meet the formalities or requirements for enforceable contracts at law, and do not in themselves support arguments against release of information.

Further, using a contract for anonymity as a starting point for deciding whether access to information should be granted or denied proves unsatisfactory.⁶⁷ Even where a “contract” may have existed, there are two obvious problems. First, the donor offspring made no promises, and were not party to the contract, and thus any rights they have cannot be excluded by a contract between the other adults involved.⁶⁸ Secondly, the law of contract recognises that some contracts should not be enforced,

⁶¹ See eg *Brianna v Brianna* (2010) 43 Fam LR 309; [2010] FLC 93-437; [2010] FamCAFC 97, discussed in Chisholm R, “Parentage: Some Testing Problems” (2010) 24 AJFL 242 at 391 (Brennan and McHugh JJ); *S v McC* (formerly *S*) [1972] AC 24 (Lord Hodson); *G v H* (1994) 181 CLR 387; *G v H* (1993) 113 FLR 440; 16 Fam LR 525; [1993] FLC 92-380 at 79,942 (Fogarty J); *Taylor v Burgess* (2002) 29 Fam LR 167; [2002] FLC 93-120; *W and G (No 1)* (2004) 35 Fam LR 417; [2005] FLC 93-247; *Re D (Paternity)* [2007] 2 FLR 26 (Hedley J), discussed by Bryant CJ in *Brianna v Brianna* (2010) 43 Fam LR 309 at [23], and by Smart C, “Law and the Regulation of Family Secrets” (2010) 24(3) *International Journal of Law, Policy and the Family* 397, cited in Chisholm, n 49 at 734.

⁶² *Pratten v British Columbia (Attorney General)* 2011 BCSC 656 at [38].

⁶³ For example, see Senate Report, n 1, Submission 49 (Canberra Fertility Centre) p 7; Submission 106 (Fertility Society) p 11.

⁶⁴ Senate Report, n 1, Submission 49 (Canberra Fertility Centre) p 7.

⁶⁵ Rees A “Keeping Mum about Dad: ‘Contracts’ to Protect Gamete Donor Anonymity” (2012) 19 JLM 758 (below).

⁶⁶ Rees, n 65 at 768.

⁶⁷ Allan, n 1 at 371-373; Chisholm, n 49 at 732.

⁶⁸ Allan, n 1 at 372; Chisholm, n 49 at 732.

most obviously those that are illegal or contrary to public policy.⁶⁹ Doubts about the propriety of deceiving donor offspring may therefore make any such contract voidable.⁷⁰

However, “rejecting the contract analogy ... does not mean disregarding what underlies it”,⁷¹ particularly where one is looking at retrospectively opening records as this may create difficulties for some individuals who participated in donor conception with the expectation of anonymity. All authors in this Special Issue agree that issues related to their privacy/confidentiality need to be considered. However, suggestions vary as to how to address these issues. For example, in a recent article on the question of whether retrospective release of information was possible, the current author suggested a model that mirrors the approach taken toward adoption in some jurisdictions in Australia – that is, a model in which donor privacy interests may be protected by “contact vetoes”, while allowing donor-conceived people access to information.⁷² In this Special Issue, Chisholm explores the option of contact vetoes, and contends they are a reasonable compromise. He also suggests it might not be necessary to go so far as to impose criminal sanctions for breach, relying instead on people’s sense of decency and respect. Cahn similarly calls for “contact vetoes”, while also describing the less strict approach of contact preference forms.⁷³ Tobin, in relation to retrospective release of information, suggests contacting each donor and asking for them to voluntarily record their information on a register.⁷⁴ Rees does not state a position on what might practically be done, ultimately calling, however, for the legislature to make clear the position regarding contracts and release of information.⁷⁵ Notably, the issues surrounding contract, privacy and/or confidentiality are not seen by any of the authors, however, to negate the call for information from donor-conceived people.

Other considerations

It is also briefly noted here that some recipient parents and donors have also called for release of information and an end to secrecy.⁷⁶ They wish to be open and honest with the people who are most affected by donor conception practices, and to end the secrecy which they feel they have been forced to maintain.⁷⁷ As such, the contract and/or privacy interests of those donors who do not wish for information to be released need also be weighed against the interests of recipient parents and other donors who call for information exchange.⁷⁸

EXPLORING PARADIGMS IN WHICH LEGAL RIGHTS OR INTERESTS MAY BE BALANCED

The question thus becomes: how do we balance the interests of all parties involved? There are different legal paradigms which may be used to further consider this question. Is it a question of “rights” or “interests”? Interestingly, both approaches support release of donor information, but, depending on how the approach is applied (and by whom), the practical suggestions related to releasing information may differ.

Human rights discourse

Arguments based upon a human rights framework for releasing information have existed for some time. For example, in 1998, Ramsey stated:

⁶⁹ Allan, n 1 at 371-372; Chisholm, n 49 at 732.

⁷⁰ Chisholm, n 49 at 732.

⁷¹ Chisholm, n 49 at 732.

⁷² Allan, n 1 at 363, 375.

⁷³ Cahn N, “Legal Parent Versus Biological Parent: The Impact of Disclosure” (2012) 19 JLM 790 (below).

⁷⁴ Tobin J, “Donor-conceived Individuals and Access to Information About Their Genetic Origins: The Relevance and Role of Rights” (2012) 19 JLM 742 (below).

⁷⁵ Rees, n 65 at 768.

⁷⁶ Further discussion of the call for information by recipient parents and donors is found in Allan, n 1 at 366-368.

⁷⁷ Allan, n 1; Adams and Lorbach, n 28 at 709.

⁷⁸ Allan, n 1.

Principles from the domain of human rights can provide an important framework for responding to one of the most pressing challenges confronting reproductive technology ... access by donor offspring to information about their origins ... [P]ut at its most succinct, from a human rights perspective, one might ask the question – how can one argue against the basic human right to know one’s genetic identity?⁷⁹

Such a view has been the basis for the *Convention on the Rights of the Child* (the Convention) being used to justify laws in some European nations that prohibit anonymous donation, and require information release.⁸⁰ Particular emphasis has been placed upon Art 7 of the Convention, which specifies that every child has a right to know and be cared for by their parents as far as possible.⁸¹ With respect to this Article, the *Implementation Handbook for the Convention on the Rights of the Child* states:

[A] reasonable assumption is that, as far as the child’s right to know his or her parents is concerned, the definition of “parents” includes genetic parents (for medical reasons alone this knowledge is of increasing importance to the child) and birth parents, that is the mother who gave birth and the father who claimed paternity through partnership with the mother at the time of birth (or whatever the social definition of father is within the culture: the point being that such social definitions are important to children in terms of their identity).⁸²

As early as 1994, the United Nations Committee on the Rights of the Child also noted the possible contradiction between Art 7 of the Convention and the policy of the state party in relation to artificial insemination by donor, “namely in keeping the identity of sperm donors secret”.⁸³

Similar emphasis has been placed upon Art 8 of the Convention, which states that every child has a right to preserve her or his identity, including nationality, name and family relations as recognised by law without unlawful interference. Denying donor-conceived people access to information about their genetic heritage may contravene this right by denying them access to important information that can help in the development of identity and preserve family relations. With respect to this Article, the *Implementation Handbook* notes:

The concept of “children’s identity” has tended to focus on the child’s immediate family, but it is increasingly recognized that children have a remarkable capacity to embrace multiple relationships. From the secure foundation of an established family environment, children can enjoy complex and subtle relationships with other adults and with a range of cultures, to a much larger degree than may be recognized. Thus children’s best interests and senses of identity may be sustained without having to deny them knowledge of their origins, for example after reception into state care, through “secret” adoptions or anonymous egg/sperm donations and so forth.⁸⁴

The European Court of Human Rights has also recognised in relation to Art 8 of the *European Convention on Human Rights* that people “have a vital interest, protected by the Convention, in receiving the information necessary to know and to understand their childhood and early development”.⁸⁵ The message, at first glance, appears clear: pursuant to the above Articles, secrecy and anonymity are not in the best interests of the child.

However, Tobin illustrates that the answer is not as clearly resolved by applying a human rights lens when trying to balance competing interests. He recognises a need to move beyond the rhetoric of human rights arguments to engaging in a substantive rights-based approach regarding the issues

⁷⁹ Ramsey S, “Keeping Secrets and Telling Stories”, opening address at Donor Issues Forum organised by the South Australian Council on Reproductive Technology, Adelaide, 30 May 1998.

⁸⁰ For example, Sweden and Norway.

⁸¹ *United Nations Convention on the Rights of the Child*, opened for signature 20 November 1989, [1991] ATS 4 (entered into force 2 September 1990).

⁸² Hodgkin R and Newell P, *UNICEF Implementation Handbook for the Convention on the Rights of the Child* (3rd ed, UNICEF, 2007) p 105.

⁸³ Norway CRC/C/15/Add.23 at [10].

⁸⁴ Hodgkin and Newell, n 82, p 142.

⁸⁵ *Gaskin v United Kingdom* (ECHR, Application No 10454/83, 1989). That Art 8 of the *European Convention on Human Rights* may be engaged in the context of donor conception was recognised in *Rose v Secretary of State for Health and Human Fertilisation and Embryology Authority* [2002] EWHC 1593 (Admin) at [48].

concerning donor-conceived people.⁸⁶ Such an approach involves balancing competing rights and assessing the reasonableness of the proposed or actual interference with the human right in question. To this end, there must be a consideration of the donor's right to privacy too.

In considering the reasonableness of providing information to donor-conceived people by applying this approach, Tobin concludes that there is a pressing social need that "donor anonymity must be prohibited *prospectively* and donor-conceived individuals must be entitled to information about their genetic parents".⁸⁷ In particular, Tobin states that "a failure to ensure this access would represent an inference with the rights of donor-conceived individuals for which there is no reasonable justification".⁸⁸

Regarding laws that may permit *retrospective* access to information, Tobin concludes that the amendment of a law to allow for retrospective access to donor-identifying information runs counter to the requirement under international human rights law that any interference with the right to privacy must not only be prescribed by law, but that the law in question must be *accessible and sufficiently foreseeable*.⁸⁹

He argues that retrospective legislation allowing information release to donor-conceived people would never have been accessible and sufficiently foreseeable at the time donors were "guaranteed" anonymity.⁹⁰ Importantly, however, he notes that a human rights approach would not support retrospective release of information to an adoptee where anonymity was guaranteed either.⁹¹ Of course, this is contrary to what has occurred in numerous jurisdictions⁹² that legislated to open records for adoption retrospectively.

Nonetheless, while prospective release of information to donor-conceived people is strongly supported by Tobin's application of a human rights framework, there appears room for debate about how to balance competing interests regarding retrospective release using a human rights framework. Tobin concludes that the aim should still be to provide information in this context, stating that the government has an obligation to contact donors and ask them to agree to release information, or provide counselling to the donor-conceived person to support them in the event of a denial. In the alternative, we may seek other resolutions (like the contact veto system),⁹³ or look to other frameworks that may help to resolve these issues. In fact, Tobin notes that he does not

seek to dismiss or discredit discourses other than human rights that could be used to resolve the issue of access to information for donor-conceived individuals. Instead [his] aim is to clarify, in a substantive way, what it means to apply a human rights-based approach to this issue.⁹⁴

Similarly, Chisholm recognises that the problems are "surely too subtle and complex to be resolved by any single formula, but the approaches discussed might help us develop a compassionate

⁸⁶ Tobin, n 74 at 745-746.

⁸⁷ Tobin, n 74 at 743.

⁸⁸ Tobin, n 74 at 742.

⁸⁹ Tobin, n 74 at 754 (emphasis added).

⁹⁰ It may, on the contrary, be argued that the possibility of law enabling access to information by donor-conceived people has always been "sufficiently foreseeable". That is, donors might never have *reasonably* expected to remain anonymous. For example, the 1983 Waller Committee said that "the donor shall be advised that there can be no guarantee of permanent, complete anonymity": Waller Report, n 29, pp 19-20. The Western Australian Reproductive Technology Council has also for some years notified donors that "some time in the future it is possible that legislation may be further amended to make it a retrospective right for all donor offspring to access identifying information about the donor": see Western Australia, Reproductive Technology Council website, http://www.rtc.org.au/faqs/index.html#anonymous_known viewed 4 April 2012.

⁹¹ Tobin, n 74 at 756.

⁹² Including all States and Territories in Australia.

⁹³ Which in the author's view might better balance competing interests (as opposed to giving the donor the absolute decision-making power).

⁹⁴ Tobin, n 74, fn 8.

outcome”.⁹⁵ It is to Chisholm’s analysis of the adoption analogy, which considers various other discourses and arguments for and against release of information that we now turn.

Adoption analogy: An interests-based approach

Psychologists have drawn many parallels between the experiences of donor-conceived people and adoptees, particularly in relation to the problems described above that some people experience in relation to genealogical bewilderment as a result of being denied access to information,⁹⁶ and the secrecy that in the past shrouded both practices. Similarly, the Supreme Court of British Columbia recently held that the circumstances of adoptees and those of donor offspring, with regard to the need to know and have connection with one’s roots, are closely comparable.⁹⁷ In a legal context, where the retrospective opening of adoption records has occurred, a “legal interests” approach has involved weighing the possible injustices to one party that might be required to rectify a manifest injustice to others. In drawing conclusions on this point, retrospective legislation is permissible if it serves to rectify that manifest injustice.⁹⁸

Chisholm examines the information rights created in recent Australian adoption legislation to date.⁹⁹ In detailing the secrecy that surrounded early adoption practices and the move towards openness, the analogy between adoption and donor conception is drawn. While recognising that adoption and donor conception are not in every way the same, he concludes that experiences from adoption may inform decision-making about access to information by those involved in donor conception. He notes that similar to donor conception practices, adoptive families used to be advised to keep secret from the community and from the child what had occurred, but that studies have since shown that openness and honesty about adoption are healthier for all concerned.

Chisholm concludes that donor-conceived people deserve the same, for the reasons of openness and honesty and knowledge of oneself discussed above, and also based upon the Kantian principle that individuals should not be used as a means to an end. In relation to this principle, Chisholm shows a difference between adoption and donor conception that he states further demands release of information to donor-conceived people. That is, unlike adoption – which is intended to benefit a child already in existence – donor conception involves the creation of a new person. Chisholm states:

Although, of course, the parents will love their much-desired child intensely, we might hesitate to describe the process as designed for the benefit of the individual created by it (in contrast to adoption). Arguably, donor conception in circumstances of secrecy involves the creation of human beings in circumstances where they will be misled about the truth of their genetic origins. It seems strongly arguable that such a practice violates the Kantian principle.¹⁰⁰

He states that at the broadest level, the approach in adoption was to implement a system that respects people’s rights to information, especially that which is of central importance to who they are and how they live their lives. He agrees that contact vetoes may be used to protect peoples’ privacy by ensuring they are left alone, while not preventing people from discovering the truth. His statement in relation to donor-conceived people at the end of his article resounds:

[T]he case for information rights for donor offspring is at least as strong as the case for adoptees, and arguably even stronger. In short, the adoption comparison provides strong support for the view that donor offspring, when adult, should have an unconditional right to information about their genetic origins.¹⁰¹

Here it is useful to return to Tobin’s analysis for a moment. He, like Chisholm, recognises that, in adoption, the child is already in existence, while with donor conception the child is not. However,

⁹⁵ Chisholm, n 49 at 635.

⁹⁶ Turner and Coyle, n 43.

⁹⁷ *Pratten v British Columbia (Attorney General)* 2011 BCSC 656 at [3]. This case is discussed further below.

⁹⁸ For detailed discussion of when legislatures may pass retrospective legislation see Allan, n 1 at 356-357.

⁹⁹ Chisholm, n 49.

¹⁰⁰ Chisholm, n 49 at 735.

¹⁰¹ Chisholm, n 49 at 739-740.

Tobin's view is that, as "the motivation for [artificial insemination by donor] is to serve the prospective parents interests", retrospective release of information to donor-conceived individuals can not rest on the same foundations as the release of information to adoptees. This again is important, as it demonstrates that differences in starting point – child- or adult-focused, framework chosen, and how that framework is applied – may lead to subtle differences in conclusions about whether and/or how to release identifying information.

Nonetheless, in all articles in this Special Issue, there is a common thread: that information release is generally called for, and all parties involved in donor conception need to be supported through education, counselling and support services in relation to such release. Such services are discussed following consideration of the actual experiences of those searching for information, and the government inquiries that have ensued.

THE SEARCH FOR INFORMATION

The search for information is not restricted to donor-conceived people searching for their donor. The current state of law in most jurisdictions also affects parents who are prevented from being able to provide their children with information that many actually desire to impart; and donors, some of whom do not wish to remain anonymous. What is apparent is that, given the absence of law or support systems to assist them in most Australian jurisdictions, the search for information can lead to frustration and despair.¹⁰² The experiences of people regarding their search are most enlightening when trying to determine whether legislation is needed to rectify their situation.

On being told of their donor conception, it appears that those who search follow a fairly uniform path. Most donor-conceived people will begin their search for information looking for contextual information (ie what donor conception actually is), and then proceed to asking the doctor or clinic where the insemination took place for answers.¹⁰³ Adams and Lorbach highlight the frustrations that information-seekers may meet when approaching the clinics involved in their conception.¹⁰⁴ In describing both a survey they conducted and the experiences of donor-conceived people, recipient parents and donors, they illustrate just how difficult the search for information is.¹⁰⁵ They report that clinics may not respond, or if they do, applicants may be given different information at different times. They also highlight that there is no standardised consensus between clinics as to the amount of personal and non-identifying information that is collected.¹⁰⁶ Similarly, they report that while some clinics say they are willing to facilitate contact or help with the search for information, the information made available varies, as does the knowledge that clinic staff may have of the regulations and legislation governing the industry in which they work. Adams and Lorbach emphasise that, for some, this has led to fruitless and frustrating experiences with clinicians who are often the "gatekeepers" of information.¹⁰⁷

While some simply give up their search at this point, others may turn to "sleuthing", such as those who were born in the 1970s and early 1980s searching medical school yearbooks for potential look-a-likes because of the belief that many donors in those times were medical students.¹⁰⁸ Others move (or are thrust) down the path of clinic or jurisdiction-based voluntary registers and DNA testing.¹⁰⁹ However, Adams and Lorbach illustrate that these voluntary registers and certain types of DNA testing prove unsatisfactory. As a result, they argue that the emergence and popularity of genetic

¹⁰² Adams and Lorbach, n 28.

¹⁰³ Cushing AL, "I Just Want More Information About Who I Am": The Search Experience of Sperm-donor Offspring, Searching for Information About Their Donors and Genetic Heritage" (2010) 15(2) Information Research, <http://www.informationr.net/ir/15-2/paper428.html> viewed 31 March 2012.

¹⁰⁴ Adams and Lorbach, n 28.

¹⁰⁵ Adams and Lorbach, n 28 at 710.

¹⁰⁶ Adams and Lorbach, n 28 at 710.

¹⁰⁷ Adams and Lorbach, n 28 at 710.

¹⁰⁸ Cushing, n 103.

¹⁰⁹ Adams and Lorbach, n 28 at 713-715.

genealogy and publicly available online voluntary registers simply make clear that the models and efforts currently employed by clinics and even government departments are failing offspring, their families and donors, such that they are willing to undertake considerable time, effort and expense in an attempt to discover information that is otherwise unavailable to them.¹¹⁰ They argue that their years of experience and exchanges with recipient parents, donors and offspring show a consensus that the best way to resolve issues relating to information access is for the law to provide uniform access for all.

Here it is important to recognise that the starting point of such searches is for *information*, not for a second parent, or even a relationship.¹¹¹ Cahn states that “arguments regarding disclosure of information to donor-conceived individuals are entirely distinct from recognising parental rights and responsibilities for the biological parents or gamete providers”.¹¹² She notes that disclosure of information is not equivalent to saying, “donors are parents”.¹¹³ Rather, information release would simply provide donors, donor-conceived people and recipient parents with a basis to exchange information. Put in this context, it is important to ensure and recognise that if laws were passed to provide for such information release, such laws do not give rise to any other legal rights and responsibilities for the donor. In addition, as with the suggestion for contact vetoes and/or contact preference forms, such laws might include a requirement for disclosure of information but make clear that this does not institute a requirement for contact unless all parties are agreeable.¹¹⁴

In the meantime, Adams and Lorbach describe support networks that have been created in response to little institutional support for the information quest.¹¹⁵ Such support groups also have engaged in years of lobbying government and policy-makers to change the laws that relate to information release, focusing both upon prospective and retrospective release of identifying and non-identifying information. But again Adams and Lorbach describe the constant disappointments and frustrations in relation to this. Even where their lobbying has resulted in significant inquiries – such as the Australian Senate Committee Inquiry into Donor Conception in 2010, and a report which followed that recommended that a national register be set up as a matter of priority (discussed below) – information release has yet to be achieved, eg through legislative reform.

RESEARCH AND INQUIRIES

In response to the call for information, there has been a growing body of research and inquiries that focus upon arguments for and against releasing information to donor-conceived persons. In this Special Issue, Blyth et al provide an exposé of the “relatively recent trend in academic research to understand the perceptions and experiences of donor-conceived people who have learned of the nature of their conception”.¹¹⁶ They also note that the “American Society for Reproductive Medicine and the Australian National Health and Medical Research Council openly advocate parental disclosure while a 2008 amendment to the United Kingdom’s *Human Fertilisation and Embryology Act 1990* (UK) provides legislative endorsement for *early* parental disclosure (s 13(6C))”, and further that “some parents have explicitly taken a lead in advocating both disclosure of donor conception and the use of donors who are willing to disclose their identity to offspring”.¹¹⁷ In their review, Blyth et al conclude:

¹¹⁰ Adams and Lorbach, n 28.

¹¹¹ Noting that for some people, establishing some kind of contact might be important and may be negotiated between the parties. For discussion of how such linking may occur see Johnson L, Bourne K and Hammarberg K, “Donor Conception Legislation in Victoria, Australia: The ‘Time to Tell’ Campaign, Donor-linking and Implications for Clinical Practice” (2012) 19 JLM 803 (below) and further discussion below.

¹¹² Cahn, n 73 at 791.

¹¹³ Cahn, n 73 at 791.

¹¹⁴ Allan, n 1.

¹¹⁵ Adams and Lorbach, n 28.

¹¹⁶ Blyth E, Crawshaw M, Frith L and Jones C, “Donor-conceived People’s Views and Experiences of Their Genetic Origins: A Critical Analysis of the Research Evidence” (2012) JLM 769 (below) which focuses on empirical studies published in English-language, peer-reviewed journals.

¹¹⁷ Blyth et al, n 116 at 771.

[E]xisting research findings support the conclusion that the future choices of donor-conceived people are necessarily limited when gametes or embryos from an anonymous donor are used and when parent(s) choose not to tell them about the nature of their conception. If a donor-conceived person *never* learns of the circumstances of her or his conception it has sometimes been presumed that no great harm may be done. The accounts of many donor-conceived people in the reviewed studies regarding their thoughts and feelings about themselves, their family and their place within their family both prior to and following disclosure suggest that this presumption may not be robust. In addition, it is clear from these studies that some (though not all) donor-conceived people experience great and long-lasting distress in discovering the circumstances of their conception later, rather than earlier, in life. This review shows quite clearly that neither the fact of donation nor the identity of an ostensibly anonymous donor will necessarily remain concealed, even if parents are planning never to tell; nor can the reactions of donor-conceived people to acquiring this information be predicted.

Such conclusions are similarly found in the 2010 Australian Senate Legal and Constitutional Affairs References Committee (the Senate Committee) report on Donor Conception Practices in Australia. The Senate Committee recommended that jurisdictions which do not already have legislation in place should, “as a matter of priority”, introduce legislation to regulate donor conception,¹¹⁸ and that the “Australian Government pursue all available policy and political options ... to ensure that nationally consistent legislation relating to donor conception is developed”.¹¹⁹ In addition, 17 recommendations related to the preservation, recording and release of records concerning identifying and non-identifying information¹²⁰ about donors to donor-conceived people.¹²¹ These included a call for the establishment, “as a matter of priority”, of a national register of donors¹²² and that this central register should operate according to principles which provide for donor-conceived people to be able to access identifying information about their donor.¹²³

In a recent inquiry into donor conception practices, the Victorian Law Reform Committee (VLRC) recommended that the Victorian Government introduce legislation to allow *all* donor-conceived people to obtain identifying information about their donors regardless of when they were born. As the basis to their recommendations, the VLRC found, among other things, that:

- some donor-conceived people suffer substantial distress when they are unable to obtain information about their donor, and/or if told of their donor-conceived status later in life;
- current arrangements in Victoria for access to information by people conceived from gametes donated prior to 1988 are confusing, inconsistent, and applied in a haphazard manner. Outcomes differ depending on the treating clinic, and/or the treating physician, from which a person’s parents received treatment;
- the introduction of measures to provide all donor-conceived people with access to identifying information will require legislative change;
- the circumstances of donor-conception and adoption with regard to a person’s right to identifying information are largely comparable;
- all donor-conceived people should be aware of the manner of their conception. A person’s parents should be principally responsible for informing that person of her or his donor-conceived status; and

¹¹⁸ Senate Report, n 1, p 103, Recommendation 1.

¹¹⁹ Senate Report, n 1, p 103, Recommendation 2.

¹²⁰ Identifying information would include the donor/donor-conceived person’s name, date of birth and address; non-identifying information might include education (level and qualifications); eye colour; hair colour; height; weight; marital status; number of children (if any); sex; year of birth; place of birth; nationality/culture with which the donor identifies; religion (if any); reason for becoming a donor; number of offspring born through other donations; identity of other offspring born through other donations; interests/hobbies/sporting activities; anything else the donor considers central to their personality. (It is difficult to delineate some of the information as identifying or non-identifying as some information in combination might lead to the identification of a person, but alone would be considered non-identifying.)

¹²¹ Senate Report, n 1, pp 103-109, Recommendations 3, 5-14, 19-21, 25, 31-32.

¹²² Senate Report, n 1, p 104, Recommendation 5.

¹²³ Senate Report, n 1, pp 104-105, Recommendation 9. Arguably, such a register would also enable donors to receive information about their offspring, and donor-conceived siblings to receive information about each other.

- if current arrangements permitting donor anonymity are changed to allow the release of identifying information, measures to protect donors and donor-conceived people from unreasonable interference in their private lives should be considered.¹²⁴

In relation to the final point, the VLRC have accepted the recommendation that a contact veto or a contact preference form will protect donors from unwanted contact, while allowing for information to be released. The VLRC did explore the option of contacting donors and asking for their consent; however, in the end it rejected this option as it may simply leave donor-conceived people in the same position – absent of information. Rather, the VLRC report suggests that once we acknowledge that information is needed, then the best method of ensuring that this occurs is to enact legislation that permits the opening of records. In balancing the competing interests of those donors who may not wish for information to be released and the donors, recipients and donor-conceived people who call for information, the VLRC states:

While the release of identifying information to donor-conceived people may *potentially* cause discomfort and distress to donors (although this will not always be the case), it is certain that donor-conceived people are *actually* suffering from their lack of knowledge about donors. Although debates about the consequences of releasing identifying information often focus on the suffering that donors may experience, the fact is that many donor-conceived people are already suffering, in some cases quite profoundly, from not having access to this information.¹²⁵

The report signifies a shift to considering and hearing the voices of donor-conceived people, and emphasising that the “best interest of the child” principle should not be empty rhetoric.

Notably, a government report that so clearly supports the retrospective release of information to donor-conceived people is a world first. It may lead to changes that have long been called for but, perhaps, were not expected. This is illustrated by the Chair of the Committee’s opening remarks. Mr Clem Newton Brown says:

When the Committee commenced this Inquiry, it was inclined toward the view that the wishes of some donors to remain anonymous should take precedence – as they made their donation on that basis – and that identifying information should only be released with a donor’s consent. Upon closer consideration, however, and after receiving evidence from a diverse range of stakeholders – donor-conceived people, donors, parents, medical and counselling professionals, department representatives, and academics – the Committee unanimously reached the conclusion that the state has a responsibility to provide all donor-conceived people with an opportunity to access information, including identifying information, about their donors.¹²⁶

That the Committee’s conclusions were unanimous is striking.

Finally, it is important to note that the VLRC has also recognised the importance of sensitivity, counselling, education and public awareness campaigns in raising awareness and offering support for all involved in information exchange.¹²⁷ To this end, their recommendations draw on the experience of the Victorian Assisted Reproductive Authority (VARTA)¹²⁸ in these areas, and suggest they might play an important role should legislation be passed. VARTA’s ability to provide counselling, education and facilitation is discussed in the next section.

EDUCATION, COUNSELLING AND SUPPORT SERVICES

Johnson et al detail two initiatives developed by the former Infertility Treatment Authority (ITA), now the Victorian Assisted Reproductive Treatment Authority (VARTA): the “Time to Tell” information and education campaign, designed to provide parents with strategies for how to tell their children that the family was formed using a donor, and a unique service model developed for linking biologically

¹²⁴ Victorian Law Reform Committee, n 1, p xxix.

¹²⁵ Victorian Law Reform Committee, n 1, p 73.

¹²⁶ Victorian Law Reform Committee, n 1, p xvii.

¹²⁷ Victorian Law Reform Committee, n 1, p xvii.

¹²⁸ The current regulatory body in Victoria for assisted reproduction.

related parties.¹²⁹ The Victorian initiatives were based upon research that parents often find it difficult to tell their children about their donor origins. Reasons for secrecy in this context were cited as including “not wanting the child to feel different or disappointed if they are unable to find their donor, to protect the non-biological parent, feelings of shame or embarrassment, feeling that there is no need to tell, and not knowing how or when to tell”. Johnson et al note that “while the burden of keeping secret the use of a donor is keenly felt by many parents ... they also report fears and anxieties about telling children about their donor origins”.¹³⁰ The Victorian initiatives were therefore aimed to raise awareness of the implications of legislation in Victoria that provided for information release; to inform parents of donor-conceived children about the benefits of telling children about their donor; and to assist them in telling their children about their donor origins.

For the “Time to Tell” campaign, the ITA used media advertising and public relations campaigns, maintained a website to disseminate information about donor conception, and produced resources such as brochures and podcasts to advise parents about how to communicate with children of various ages about their donor origins. Community education activities were also conducted, including public seminars for parents, donor-conceived people and donors, along with assisted reproductive technology clinics and consumer groups. Johnson et al emphasise how attendance at such seminars has steadily grown, and has had significant reach.¹³¹

In relation to the ITA Donor Register Services, Johnson et al detail the unique donor-linking services model, which closely followed the Counselling Guidelines developed by the Australian and New Zealand Infertility Counsellors Association. The steps involved for applications to the Central Register (upon which mandatory identifying and/or non-identifying information may have been held) involved counselling at all levels regardless of whether or not information was available, and whether or not it was identifying or non-identifying.¹³² In cases where identifying information was available, the ITA assisted the applicant to establish contact via a “letter drop service” with the person about whom information was available, and acted as an intermediary between the parties in relation to how much information they wished to exchange.¹³³ Again, counselling was available for guidance throughout the process. In relation to the voluntary register, people were supported in placing their information on the register, searching for a match, and counselled in relation to whether or not such a match existed, and if so how to proceed. Again, what is significant about the service model described by Johnson et al is the level of support provided to applicants for information and the counsellor’s role as an intermediary.

The process, complexities and outcomes detailed by Johnson et al in relation to the donor-linking service provide valuable insight into how connecting people who are genetically related through donor conception is not quick or easy, but is one in which support, education and counselling for all involved can lead to very positive outcomes. As the numbers of donor-conceived people increase, and more people are told about their origins, it is to be expected that the demand/need for such services will grow, recalling the experiences outlined by Adams and Lorbach in relation to those who search for information absent of such support systems at present. If the veil of secrecy shrouding donor conception is removed, we should proceed with the knowledge that a very good service model exists in Victoria and can be emulated in other jurisdictions. The VLRC has recommended a return to this model to facilitate the retrospective release of information to donor-conceived people.¹³⁴

¹²⁹ Johnson et al, n 111.

¹³⁰ Johnson et al, n 111 at 809.

¹³¹ Johnson et al, n 111 at 811.

¹³² Johnson et al, n 111 at 813.

¹³³ Johnson et al, n 111 at 813.

¹³⁴ Victorian Law Reform Committee, n 1.

CONCLUSION

Donor conception is a practice that has been veiled by a long history of secrecy that predominantly focused on legal, moral and religious issues concerning the adults involved (donor, recipient parent and clinicians). Over time, it has become apparent that some offspring born as a result have had a heavy burden to bear in relation to such secrecy.

The question of recent times therefore has been whether the law should operate to abolish anonymous donation in all jurisdictions,¹³⁵ and, more contentiously, to open the records of the past to provide donor-conceived persons already in existence with information about their genetic heritage. The difficulty with the latter is in balancing the competing interests of those who seek information with those who wish to keep the secret (be it a donor who wishes to preserve anonymity or the recipient parents not wishing to tell their child).

Retrospective legislation is permissible in such circumstances (and has been used specifically in the assisted reproductive technology context to recognise legal parentage of donor-conceived people for same-sex partners of birth mothers).¹³⁶ There is also clear precedent, by way of considering information release in the adoption context that shows that the law can, and does, balance interests, and at times makes a compromise. "If a donor-conceived person wishes to identify their donor, and the donor wants to keep their identity a secret, the law cannot satisfy both. The interests are competing, and the law must choose between them, or in addressing the interests it must seek a compromise."¹³⁷ Chisholm, Tobin and Rees clearly articulate the need to be sensitive to all parties involved. Generally, with adoption,

the view that prevailed was that the law should enable adopted persons and birth parents to have the right to information, even though this did mean a change from the position as it was when the adoption order was made. The interests of those who felt threatened by the new law were acknowledged by a number of measures, notably the contact veto system.¹³⁸

The recent Victorian Law Reform Committee inquiry has accepted the proposal that this approach should also be taken when balancing the interests of donor-conceived people and those donors who wish not to have their privacy disturbed. In the adoption context such a decision reflected the starting points explained by Chisholm: openness and honesty, knowledge about oneself, and not using individuals as a means to an end. Again, a parallel may be drawn.

The current author's own view is that the secrecy surrounding donor conception needs to be something of the past. We are no longer in the 19th century, we are in the 21st. We celebrate different family formations, and should support them in being open and honest. While not all donor-conceived people will want information, access for all should be possible. They can then, at least, make the choice. Donors who do not wish to have contact with the offspring created using their gametes may lodge a contact veto. This is an effective way to protect their privacy while not denying information to people for whom access is fundamental to their sense of self and wellbeing.

The recommendations of both the Australian Senate Committee and the VLRC show a growing consensus on this issue, and will undoubtedly be welcomed by those donor-conceived people who have been telling their stories for years, and waiting for people to listen. However, it remains to be seen whether the Parliament will enact legislation that reflects this remarkable shift in the tide. Victoria has always led the way in developing and updating its legislation regulating assisted reproductive treatment and access to information by parties to donor conception. Perhaps the expert and authoritative voices of the authors who have contributed to this Special Issue of the *Journal of Law and Medicine* will be useful in resolving any doubts. We are therefore left not with a conclusion, but a question: do the recent recommendations of the Australian inquiries indicate a future of openness

¹³⁵ Noting that guidelines are not law and the call is for legislative intervention to prohibit anonymous donations and to additionally notify donor-conceived persons of the method of their conception.

¹³⁶ Allan, n 1.

¹³⁷ Allan, n 1 at 375.

¹³⁸ New South Wales Law Reform Commission, *Review of the Adoption Information Act 1990, Issues Paper 7* (1992) at [3.16].

and honesty? The answer will be seen in what Australian legislatures do next and whether or not other jurisdictions in the world follow.