Neroli Sawyer*

In Australia there is no federal legislation limiting the use of donor sperm. However, it is important to place limits on the multiple use of sperm donors to reduce the risk of inadvertent half-sibling mating between the offspring of anonymous donors and to control for the consequences of contact between identity-release donors and their donor-inseminated offspring. A nationally mandated donor registry should be established to enable, first, the calculation of updated variable values for use in the development and implementation of a predictive model to estimate the probability of halfsiblings mating and provide policy-makers with empirical evidence to inform the setting of anonymous donor limits; and secondly, the linking of identityrelease donors to their donor-inseminated offspring and an investigation into the psychosocial consequences of that linking so as to be able to implement suitable donor limits as well as management strategies and support systems for these new "extended families" within the donor insemination network.

INTRODUCTION

Australia is unique in its administration of assisted reproductive technologies (ART).¹ Unlike some countries such as Germany and Italy, which have federal regulation regarding ART, or other countries, such as the United States, which rely on existing general legislation in conjunction with professional self-regulation,² only four Australian jurisdictions out of its six States and two Territories have statutes regulating ART procedures.³

Many countries place a limit on how many families any one sperm donor can assist. This has been to reduce the risk of inadvertent half-sibling mating that could occur as a result of the multiple use of *anonymous* sperm donors.⁴ These limits, however, vary greatly,⁵ as they do within the various jurisdictions within Australia⁶.

Currently, with the increasing acceptance and use of *identity-release* donors in donor insemination due to the revocation of donor anonymity in a number of European countries and some States in Australia, it is becoming important also to consider limiting the multiple use of *identity-release*

^{*} BSc (Hons); PhD candidate and sessional lecturer, School of Behavioural and Social Sciences and Humanities, University of Ballarat. The author acknowledges the valuable feedback from her supervisor, Associate Professor John McDonald, PhD, Director of the Centre for Health Research and Practice, University of Ballarat.

Correspondence to: Neroli Sawyer, School of Behavioural and Social Sciences and Humanities, University of Ballarat, Mount Helen, Vic 3352, Australia; email: n.sawyer@ballarat.edu.au.

¹ Jones H, Cohen J, Cooke I and Kempers R, "IFFS Surveillance 2007" (2007) 87 Fertility and Sterility S1.

² Johnson M and Petersen K, "Public Interest or Public Meddling? Towards an Objective Framework for the Regulation of Assisted Reproduction Technologies" (2008) 23 *Human Reproduction* 716.

³ Petersen K, Baker HW, Pitts M and Thorpe R, "Assisted Reproductive Technologies: Professional and Legal Restrictions in Australian Clinics" (2005) 12 JLM 373; Smith M, "Reviewing Regulation of Assisted Reproductive Technology in New South Wales: The Assisted Reproduction Technology Act 2007 (NSW)" (2008) 16 JLM 120.

⁴ Curie-Cohen M, "The Frequency of Consanguineous Matings Due to Multiple Use of Donors in Artificial Insemination" (1980) 32 American Journal of Human Genetics 589. See App 1.

⁵ Sawyer N and McDonald J, "A Review of Mathematical Models Used to Determine Sperm Donor Limits for Infertility Treatment" (2008) 90 *Fertility and Sterility* 265.

⁶ Smith M, n 3; Petersen, Baker, Pitts and Thorpe, n 3.

donors. This is because it is important to determine how well donors and their donor-inseminated children will cope with the contact now possible within the donor insemination network.⁷ There is a growing awareness that aside from the need to control for the risk of inadvertent half-sibling mating, due to the multiple use of *anonymous* donors, limits also need to be placed on the use of *identity-release* donors while an investigation into the psychosocial impact of these new extended family relationships is undertaken and strategies for managing and supporting the process of connection and ongoing contact are developed.⁸

This article examines, first, the way ART, in particular donor insemination, is regulated in the Australian context, and the difficulties encountered when the States and Territories within Australia make independent decisions about guidelines and/or regulations regarding donor limits. Secondly, it describes not only how the use of a model to predict the possibility of half-sibling mating due to the multiple use of donors is impossible in Australia but how there is growing need to investigate and control for the psychosocial impact of multiple families interacting within the donor insemination network. Thirdly, it discusses the absence of adequately maintained records concerning donor insemination in Australia and the subsequent difficulties in

- implementing a predictive model that can assist policy-makers with the setting of *anonymous* donor limits based on empirical evidence;
- facilitating the tracing of, and matching of, *identity-release* donors and their donorinseminated offspring as well as determining donor limits to control for the psychosocial impact of disclosure and the revocation of anonymity; and
- conducting further research into donor insemination epidemiology and outcomes, the assessment of public interest issues and the development of general donor insemination regulatory policy and practice at the federal level.

The author suggests that these important processes are hampered, if not entirely thwarted, by the inadequacy of record-keeping regarding donor insemination practice in Australia, at both State and federal levels, and recommends that a federally mandated donor registry be established.

REGULATION OF ART

Australia is in a unique position with regard to the supervision of both reproductive and research activities in respect of ART. As described in the International Federation of Fertility Societies (IFFS) Surveillance 2007,⁹ countries that implement some form of surveillance over their ART practices generally fall into one of two broad categories:

- those that tend to employ federally mandated legislation, as Germany and Italy;¹⁰ or
- those that primarily rely on self-regulated professional guidelines, such as the United States where the ART industry operates within a basically unregulated free market.¹¹

Australia is different, however, because, although it does not have federal legislation that oversees the practice of ART, Victoria, South Australia, Western Australia and New South Wales have legislation that regulates, to varying degrees, reproductive and research ART procedures.¹² Statutes in these four States address the social and legal aspects of ART and operate in conjunction with the ART profession's self-regulatory structures, as outlined by the Fertility Society of Australia (FSA). These guidelines are administered by the Reproductive Technology Accreditation Committee (RTAC) Code

⁷ Scheib JE and Ruby A, "Beyond Consanguinity Risk: Developing Donor Birth Limits that Consider Psychosocial Risk Factors" (2009) 9 *Fertility and Sterility* e12.

⁸ Scheib and Ruby, n 7.

⁹ Jones, Cohen, Cooke and Kempers, n 1.

¹⁰ Robertson J, "Reproductive Technology in Germany and the United States: An Essay in Comparative Law and Bioethics" (2004) 43 *Columbia Journal of Transnational Law* 189.

¹¹ Johnson and Petersen, n 2.

¹² Karpin I and Bennett B, "Genetic Technologies and the Regulation of Reproductive Decision-making in Australia" (2006) 14 JLM 127; Petersen, Baker, Pitts and Thorpe, n 3.

of Practice and the National Health and Medical Research Council (NHMRC) ethical guidelines, which define clinical and scientific standards.¹³ In these jurisdictions legislation has precedence over both the RTAC Code of Practice and NHMRC guidelines.¹⁴

Until recently, the Australian federal government was not active in the regulation of ART and there was no Commonwealth legislation governing ART. Even in the United Kingdom, which the Victorian form of regulation most closely resembles, laws and guidelines relating to ART are nationally based.¹⁵ Innovations in health technologies, however, brought about investigations which have resulted in federal legislation regarding gene technology, human embryo research and cloning technology.¹⁶ Generally though, supervision of ART in Australia still consists of an extensive regulatory framework comprised of statutes, professional self-regulatory standards and processes and ethics committees. This is viewed by many as seriously flawed because the national set of rules that brings together the State laws and regulations is based on guidelines, not statutes, and thus is not accountable to the checks and balances or formal reviews to which legislation is subject.¹⁷

Federally based guidelines and legislation in Australia are primarily concerned with general ART clinical standards and practice, and research involving embryos. There are no federal guidelines or legislation requiring record-keeping in regard to donor insemination and its outcomes.¹⁸

Sperm donor limits

Donor insemination, originally used by physicians to combat male infertility or when the husband was a carrier of a serious inherited disease or abnormality or when children died from Rh incompatibility,¹⁹ is now also being used by ART professionals to inseminate single and lesbian women.²⁰ Despite high international levels of donor-assisted pregnancies, donor insemination has continued to be a process "shrouded in secrecy"²¹ and the exact numbers of offspring born as a result are unknown.²² Many countries still, either through legislation or less commonly through voluntary guidelines, limit the number of offspring each *anonymous* sperm donor can father.²³ This, apart from anything else, is to reduce the risk of half-sibling mating, which is viewed by many²⁴ as an ongoing issue and one that "cannot and should not be ignored".²⁵ Guidelines or legislation concerning sperm donor limits vary considerably between countries and are not, at this time, informed by a universally recognised model for calculating limits.²⁶

¹³ Szoke H, "The Nanny State or Responsible Government?" (2002) 9 JLM 470.

¹⁴ Smith M, "Revisiting Old Ground in Light of New Dilemmas: The Need for Queensland to Reconsider the Regulation of Assisted Reproductive Technologies" (2007) 7 Queensland University of Technology Law and Justice Journal 425.

¹⁵ Petersen K and Johnson M, "SmARTest Regulation? Comparing the Regulatory Structures for ART in the UK and Australia" (2007) 15 *Reproductive BioMedicine Online* 236.

¹⁶ Karpin and Bennett, n 12.

¹⁷ Szoke, n 13.

¹⁸ Smith M, n 3.

¹⁹ Danks DM, "Genetic Considerations" in Wood C (ed), Artificial Insemination by Donor (Melbourne, Brown Prior Anderson, 1983) pp 94-102.

²⁰ Dempsey D, "Active Fathers, Natural Families and Children's Origins: Dominant Themes in Australian Political Debate over Eligibility for Assisted Reproductive Technology" (2006) 4 *Australian Journal of Emerging Technologies and Society* 28.

²¹ Elster N, All or Nothing? The International Debate over Disclosure to Donor Offspring (Institute on Biotechnology & the Human Future, 18 October 2007), http://www.thehumanfuture.org/commentaries/assisted_reproductive_technology/art_commentary_elster01.html viewed 17

http://www.thehumanfuture.org/commentaries/assisted_reproductive_technology/art_commentary_elster01.html viewed 17 July 2008.

²² Jones, Cohen, Cooke and Kempers, n 1.

²³ Jones, Cohen, Cooke and Kempers, n 1.

²⁴ Loughnane S and Kirkman M, Parents Disclosing Donor Conception to Their Children: What Does the Literature Tell Us? (Infertility Treatment Authority, 2006), <u>http://www.ita.org.au/</u> viewed 18 July 2007.

²⁵ Elster, n 21.

²⁶ Sawyer and McDonald, n 5.

In Australia there are legislated donor limits in just three States:

- in New South Wales the *Assisted Reproductive Technology Act 2007* (NSW) stipulates five families per donor;
- the recently passed Assisted Reproductive Treatment Act 2008 (Vic) in Victoria specifies 10 families per donor; and
- in Western Australia the *Human Reproductive Act 1991 and Amendment Act 1996* (WA) limits each donor to five families.²⁷

These figures, however, are not founded on any evidence-based quantitative research.

Due to the revocation of donor anonymity in a number of European countries and some States in Australia,²⁸ there is a need to consider and investigate the psychosocial impact of the multiple use of *identity-release* donors on donor-inseminated children and their donors within the donor insemination family network. There is concern about the possible reduction in the number of identifiable donors if donors are faced with the possibility of being asked to consider contact with multiple offspring. There is also anecdotal evidence that suggests that some families resist contact because they are overwhelmed by the possible numbers of family connections.²⁹ However, it is important to note that there is still an increasing tendency for parents to embrace disclosure and be more open with their donor-inseminated children about their donor origins.³⁰

Thus, with the increasing acceptance and use of donor insemination there needs to be adequate control not only for the risk of inadvertent half-sibling mating but an investigation into the psychosocial impact of the multiple family relationships within the donor insemination community.³¹ Further, there is a need for strategies to manage and support the linking and ongoing contact between extended donor-inseminated family members. Currently, the Australian Institute of Health and Welfare National Perinatal Statistics Unit collects donor insemination data from fertility centres in Australia and New Zealand but this does not include the number of live births or cycles undertaken in hospitals or in private clinics that are not fertility centres.³² Further to this, the RTAC does not stipulate the number of children that may be generated by a given donor or that a sperm donor report if and where they have previously donated.³³

There is an urgent need for more rigorous and thorough record-keeping in regard to donor insemination practice at the federal level because the vast regulatory framework that currently supports the States and Territories in independently deciding on guidelines and/or regulations cannot keep track of donors across the country and thus cannot provide information to donor-inseminated offspring about their *identity-release* donor or be used to make estimates of the likelihood of half-sibling mating due to the multiple use of *anonymous* sperm donors.

Comprehensive donor insemination records, at the federal level, would also provide data and other information that could be used in assessing public interest issues³⁴ relating to donor insemination and the development and reviewing of general donor insemination regulatory policy and practice.³⁵

²⁷ Smith, n 14; Smith, n 3.

²⁸ van den Akker O, "A Review of Family Donor Constructs: Current Research and Future Directions" (2006) 12 *Human Reproduction Update* 91.

²⁹ Cahn N, "Accidental Incest: Drawing the Line – or the Curtain? – for Reproductive Technology" (2009) 32 Harvard Journal of Law and Gender 59.

³⁰ Scheib JE, Riordan M and Rubin S, "Choosing Identity-release Sperm Donors: The Parents' Perspective 13-18 Years Later" (2003) 18 *Human Reproduction* 1115 - 1127.

³¹ Scheib and Ruby, n 7.

³² Wang Y, Dean J, Badgery-Parker T and Sullivan E, "Assisted Reproduction Technology in Australia and New Zealand 2006", *Assisted Reproduction Technology Series No 12* (AIHW cat no PER 43, Sydney, 2008).

³³ Petersen, Baker, Pitts and Thorpe, n 3.

³⁴ See App 1.

³⁵ Johnson and Petersen, n 2.

THE MULTIPLE USE OF SPERM DONORS IN DONOR INSEMINATION Risk of inadvertent half-sibling mating

In 1980 Curie-Cohen developed a model for predicting the possible number of half-sibling matings and maximum donor limits to prevent inadvertent inbreeding in the United States.³⁶ This model was intended for use in the setting of a maximum number of children per sperm donor for any designated State or jurisdiction. It assumed donor anonymity and only considered half-sibling mating. In other words, it did not consider other possible unions between a donor-inseminated child and a paternal relative such as a donor's donor-inseminated daughter and his brother.³⁷ This model later formed the basis for the calculations of sperm donor limits in The Netherlands³⁸ and in Taiwan³⁹ where essentially the same variables and many of the same values⁴⁰ were used. The model, however, has not since been updated or applied in any other country or context.

The simplest form that Curie-Cohen's model can take⁴¹ is that of $Y = S^*\overline{m} * P$ where Y is the predicted number of half-sibling matings in a given year. The value for Y is obtained by multiplying together S, the number of effective sperm donors used in that year; \overline{m} , the expected number of potential matings between children of a single donor; and P, the probability that a random pair of half-siblings will mate. In this simple form of the model S and \overline{m} pertain to the donor and are potentially easy to calculate but P, which is relevant to the donor-inseminated child, depends on l, the likelihood of a child reproducing combined with assortive mating for age (d_-) , phenotype characteristics (C), and geographic location (2*Q/A). It is approximated by $P = l^*d * C^*(2*Q/A)$. Rearranged and then written out in full, this equates to $Y = 2^*\overline{m} * l^*d * C^*\Sigma(Si*Qi/Ai)$.

To investigate the probability of half-sibling mating due to the multiple use of sperm donors in Australia, the author attempted to use the Curie-Cohen model to predict the number of half-sibling matings per year using Australian data to estimate variable values. The data used for generating the variable values were gleaned from government publications,⁴² and sources previously referred to by

³⁶ Curie-Cohen, n 4.

³⁷ Bittles AH, A Background Summary of Consanguineous Marriage (Centre for Human Genetics, Edith Cowan University), http://www.consang.net/images/d/dd/01AHBWeb3.pdf viewed 24 July 2006.

³⁸ deBoer A, Oosterwijk JC and Rigters-Aris CAE, "Determination of a Maximum Number of Artificial Inseminations by Donor Children per Sperm Donor" (1995) 63 *Fertility and Sterility* 419.

³⁹ Wang C, Tsai M, Lee M, Huang S, Kao C, Ho H and Hsiao CK, "Maximum Number of Live Births per Donor in Artificial Insemination" (2007) 22 *Human Reproduction* 1363.

⁴⁰ deBoer, Oosterwijk and Rigters-Aris, n 38; Wang et al, n 39.

⁴¹ Sawyer and McDonald, n 5.

⁴² Australian Bureau of Statistics, Age-Specific Fertility Rates and Total Fertility Rates (Cat No 3301.0 – Births, Australia), http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/0C4C341C51104DC4CA2573800015C2DC/\$File/33010_2006.pdf viewed 17 October 2008; Australian Bureau of Statistics, Births Registered, Sex of Child (Cat No 3301.0 – Births, Australia), http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/0C4C341C51104DC4CA2573800015C2DC/\$File/33010_2006.pdf viewed 17 October 2008; Australian Bureau of Statistics, 2006 Census of Population and Housing Age by Sex (Cat No 2068.0 – 2006 Census Tables),

http://www.censusdata.abs.gov.au/ABSNavigation/prenav/ViewData?breadcrumb=POTLD&method=Place%20of%20Usual%20Residence&subaction=-

 $[\]underline{1\& issue=2006\& product type=Census\%20 Tables\& document product no=0\& text version=false\& document type=Details\& collection that the text version of text version o$ n=Census&javascript=true&topic=Age%20%26%20Population%20Distribution&action=404&productlabel=Age%20by%20S ex&order=1&period=2006&tabname=Details&areacode=0&navmapdisplayed=true& viewed 17 October 2008; Australian Bureau of Statistics, How Many Children Do Australian Women Have? (Cat No 4102.0 - Australian Social Trends, 2008), http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4102.0Chapter3202008 viewed 17 October 2008; Australian Bureau of 3302.0.55.001), Statistics, Life Tables, Australia, 2003-2005 (Cat No http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3302.0.55.0012003%20to%202005?OpenDocument viewed 17 October 2008; Australian Bureau of Statistics, Marriages - 2006 (Cat No 3306.0.55.001 - Marriages 2006), http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3306.0.55.0012006?OpenDocument viewed on 17 October 2008.

Curie-Cohen⁴³ that relate to assortive mating for phenotype and for age in Western society.⁴⁴ Despite the author's best efforts, it was impossible to use the Curie-Cohen model for Australia as there are inadequate records kept regarding relevant donor insemination-related data from which to compute variables. Although the Australian Institute of Health and Welfare National Perinatal Statistics Unit, in conjunction with the FSA, does produce an annual report on the use of ART and does collect data regarding ART cycles and births, it has limited information about donor insemination.⁴⁵ Most significantly, no data were available regarding *S*, the number of sperm donors used per year, either at the State or federal level, which consequently made the calculation of \overline{n} , the average number of donor-inseminated offspring for each donor impossible to estimate and thus $\overline{m} = (var(n) + (\overline{n})^2 - \overline{n})/4 + (\overline{n} * f)/2$, the number of potential matings between the children of a single donor, also impossible to estimate. It was possible to estimate *f*, the average number of births per State,⁴⁷ *l*, the probability of reproducing⁴⁸ and, at the federal level only, the value for *Q*, marriages between people who are both born in Australia,⁴⁹ although this value is unreliable due to changes in marriage and reproductive trends. The values for both *d*, assortive mating for age, and *C*, assortive mating for phenotype, were based on Curie-Cohen's estimates.⁵⁰

In 1980 Curie-Cohen estimated that an average of only one half-sibling mating every 19 years would be due to multiple use of donors in the United States but it must be noted, at this juncture, that he stated it was "probably underestimated".⁵¹ This was due to a number of reasons, including the fact that he did not factor into his formula that donor-inseminated recipients, and thus their children, were likely to be of similar socio-economic background and possibly be similar in other non-genetic characteristics, such as religion. Significantly, he stated that assortive mating for geography was greater than he allowed for and that after migration, random mating was assumed.⁵² With regard to assortive mating for race, he stated in 1979 that, "In fact several half-sibling matings have nearly occurred and our data further suggests that inbreeding may be more frequent than expected".⁵³

The revocation of anonymity in Australia

In the Australian State of Victoria, the effect of the *Infertility (Medical Procedures) Act 1984* (Vic) (enacted in 1988) was realised on 1 July 2006 when the first donor-inseminated offspring turned 18 years old and both donors and offspring were able to request contact with each other. Since then there has been a pro-active campaign in Victoria to encourage parents to disclose donors' origins to their donor-inseminated children and to provide support in managing the psychosocial impact of donor

⁴³ Eckland BK, "Theories of Mate Selection" (1982) 29 Soc Biol 7; Finegold W, *Artificial Insemination* (Charles C Thomas, Springfield, Ill, 1964); Rodman H, "Mate Selection: Incest Taboos, Homogamy, and Mixed Marriages", in Rodman H (ed), *Marriage, Family, and Society* (Random House, New York, 1965) pp 48-65; Schull WJ and Neel JV, "The Effects of Parental Consanguinity and Inbreeding in Hirado, Japan. V. Summary and Interpretation" (1972) 24 *American Journal of Human Genetics* 425.

⁴⁴ National Center for Health Statistics, *Vital Statistics of the United States, 1988. Volume III, Marriage and Divorce* (United States Department of Health and Human Services), <u>http://www.cdc.gov/nchs/data/vsus/mgdv88_3.pdf</u> viewed 17 October 2008.

⁴⁵ Wang, Dean, Badgery-Parker and Sullivan, n 32.

⁴⁶ Australian Bureau of Statistics, n 41 (Age-Specific Fertility Rates and Total Fertility Rates).

⁴⁷ Australian Bureau of Statistics, n 41 (Births Registered, Sex of Child).

⁴⁸ Australian Bureau of Statistics, n 41 (*How Many Children Do Australian Women Have?*); Australian Bureau of Statistics, n 41 (*Life Tables, Australia, 2003-2005*).

⁴⁹ Australian Bureau of Statistics, n 41 (Marriages - 2006).

⁵⁰ Curie-Cohen, n 4. See App 2 for a more detailed description of Curie-Cohen's estimations for d and C.

⁵¹ Curie-Cohen, n 4.

⁵² Curie-Cohen, n 4.

⁵³ Curie-Cohen M, Luttrel L and Shapiro S, "Current Practice of Artificial Insemination by Donor in the United States" (1979) 300 NEJM 585.

contact.⁵⁴ Additionally, the *Infertility Treatment Act 1995* (Vic) legislates that only *identity-release* donors could be used for donor-inseminated conception after 1 January 1998. In Western Australia amendments to the *Human Reproductive Technology Act 1991* (WA) permit mature donor offspring access to identifying information about their donors and remove donor anonymity for gametes used after December 2004.⁵⁵ The *Assisted Reproductive Technology Act 2007* (NSW) has similarly secured the right of donor-conceived children to discover their genetic origins and has legislated for a central ART donor register in New South Wales.⁵⁶ It is therefore becoming important to consider limiting the multiple use of *identity-release* donors in Australia because it is as yet unknown how well donors and their donor-inseminated children will manage contact with multiple half-siblings and donor-inseminated children.⁵⁷

DISCUSSION

Currently in Australia the only federal legislation regarding ART is that responding to concerns about the use of embryos in research and human cloning.⁵⁸ There are, however, accreditation guidelines and ethics committees that operate under the direction of the FSA. The national Code of Conduct is administered through the RTAC Code of Practice, and ethical guidelines for the use of ART, in clinical practice and research, are issued by the NHMRC and the Australian Health Ethics Committee (AHEC). There is, however, no national legislation to oversee many other aspects of ART, including the keeping of records regarding donor insemination. For accreditation and funding purposes the RTAC requires clinics to record ART success rates but, with regard to donor insemination, it does not require, for instance, that potential donors report if and where they have previously donated or stipulate the number of children that may be generated by a donor.⁵⁹ This poses a problem if there is a need to keep track of *identity-release* donors, to enable the provision of information to donor-inseminated offspring or make estimates of the likelihood of half-sibling mating due to the multiple use of *anonymous* sperm donors.

A review of published papers⁶⁰ has previously described the various forms of Curie-Cohen's model for predicting the likely number of half-sibling matings resulting from the multiple use of sperm donors in donor insemination.⁶¹ However, an attempt to use this model in the Australian context, by using Australian variable values, has proved to be unsuccessful. This is due, primarily, to inadequate reporting and recording of donors and donor-inseminated births in Australia but also to changes in marriage and reproductive trends and major flaws not only in the implementation of the 1980 model but in the model itself.⁶²

Hence, apart from the need to have a federal mandate regarding donor insemination record-keeping, there is a need to develop a more applicable model to reflect changing reproductive trends and social conditions in Australia.⁶³

There is also evidence to suggest that the concern about half-sibling mating resulting from the multiple use of donors has been joined by a perhaps more urgent concern: the management and

⁵⁴ Infertility Treatment Authority Newsletter, Voluntary Donor Registers (Victorian State Government, August 2008), <u>http://www.ita.org.au/www/257/1001127/displayarticle/newsletters--1001385.html</u> viewed October 2008.

⁵⁵ Godman KM, Sanders K, Rosenberg M and Burton P, "Potential Sperm Donors', Recipients' and Their Partners' Opinions Towards the Release of Identifying Information in Western Australia" (2006) 21 *Human Reproduction* 3022.

⁵⁶ Smith, M, n 3.

⁵⁷ Scheib and Ruby, n 7.

⁵⁸ Karpin and Bennett, n 12.

⁵⁹ Petersen, Baker, Pitts and Thorpe, n 3.

⁶⁰ Sawyer and McDonald, n 5.

⁶¹ Curie-Cohen, n 4.

⁶² These are described further in App 3.

⁶³ Sawyer and McDonald, n 5.⁻

support of multiple families within the donor insemination network.⁶⁴ A nationally-based donor registry would provide information to enable not only the linking of donor-inseminated family members but assist in investigating and establishing interim donor limits to control for the yet unknown psychosocial impact of donor insemination resulting from the revocation of anonymity.

There are constitutional impediments, however, to the national regulation of ART. This is because, in general, matters that relate to health come under the Australian State jurisdiction unless they are referred to the Commonwealth.⁶⁵ Nevertheless, at the 2003 meeting of the Council of Australian Governments (COAG), there was an indication that both the federal and State governments desire to work towards uniform legislation across Australia and to standardise the regulation of ART.⁶⁶

Access to information that identifies gamete donors is at present a State issue and there is a need for urgent national attention through Commonwealth supervision and/or some type of State cooperation.⁶⁷ If the implementation of sperm donor limits could be viewed as a public health issue and placed in the context of children's rights and wellbeing,⁶⁸ as well as under the mandate of the World Health Organisation (WHO), policies on best practice that address public interest could be invoked⁶⁹ and viewed as a Commonwealth, not just a State, responsibility.

CONCLUSIONS AND RECOMMENDATIONS

There are multiple advantages to the creation of a centrally-based national record of donors and their offspring to provide the information and data necessary for

- the calculation and implementation of a predictive model that can assist policy-makers with the setting of *anonymous* donor limits based on empirical evidence;
- facilitating the tracing of, and matching, of *identity-release* donors and their donorinseminated offspring;
- investigating and then controlling for the psychosocial impact of disclosure and the revocation of anonymity and the implementation of suitable management and support systems for these new "extended families";
- the sharing of appropriate health and genetic information with donor families and enabling ART programs to share donor information; and
- further research into donor insemination epidemiology and outcomes and the assessment of public interest issues relating to donor insemination.

⁶⁴ Infertility Treatment Authority, *The Telling Campaign* (Victorian State Government, 2006), <u>http://www.ita.org.au</u> viewed 17 October 2008; Scheib and Ruby, n 7 at e12; Sawyer N, "Reply of the Authors: Beyond Consanguinity Risk: Developing Donor Birth Limits that Consider Psychosocial Risk Factors" (2009) 91 *Fertility and Sterility* e13.

⁶⁵ Petersen K, "The Regulation of Assisted Reproductive Technology: A Comparative Study of Permissive and Prescriptive Laws and Policies" (2002) 9 JLM 483.

⁶⁶ Bell K, "An Overview of Assisted Reproduction in Australia and Directions for Social Research" (2006) 4 Australian Journal of Emerging Technologies and Society 15.

⁶⁷ Szoke, n 13.

⁶⁸ Australian Federal Government, National Research Priorities (Department of Education, Employment and Workplace Relations, 2003),

http://www.dest.gov.au/sectors/research_sector/policies_issues_reviews/key_issues/national_research_priorities/default.htm viewed 20 October 2008.

⁶⁹ Nicholson A, "Children's Rights in the Context of Infertility Treatment", in ITAOD Symposium (ed), What About Me? The Best Interests of the Child (Museum of Victoria, Melbourne, 2006).

APPENDIX 1 Use of the term "anonymous" sperm donors and "public interest"

For the purposes of this article, "anonymous" sperm donors are regarded as anonymous either by virtue of historical convention or by default, in jurisdictions where the use of anonymous donors has been revoked but parents have not disclosed donor origins to their donor-inseminated offspring. The term "public interest", as used in this article, refers to "considerations affecting the good order and functioning of the community and government affairs, for the well-being of citizens".⁷⁰

APPENDIX 2 Estimation of *d* and C

In the 1970s when Curie-Cohen conducted his study, most donors only donated sperm for a period of one to four years. Thus, using vital statistics from 1973,⁷¹ Curie-Cohen calculated that, if the time_of birth for each donor-inseminated child was uniformly distributed over a three-year period, then d, assortive mating for age, would be the sum of the product of the distribution of age differences between donor-inseminated paternal half-sibling, p(r), and the distribution of age differences between mates, d(r). He provided a table of these distributions and calculated $d = \sum p(r)^* d(r)$. Because most donors at the time were young medical students, Curie-Cohen made the point that this value may have been overestimated as a donor's natural children may be born long after his donor-inseminated children.⁷²

Estimation for assortive mating for phenotype, *C*, refers to the increased likelihood of individuals being attracted to and mating with each other because of similarities in their physical, biochemical and psychological makeup.⁷³ Three phenotype characteristics – ear length,⁷⁴ stature⁷⁵ and IQ⁷⁶ – are known to be largely independent of one another and normally distributed. These were used to calculate the value of *C*. The value for *C* was determined using the correlation between married persons and half-siblings in regard to these three independent phenotype characteristics.⁷⁷

APPENDIX 3

Flaws in the implementation of the 1980 model

There is a "generational lag" and a lack of "temporal alignment" inherent in Curie-Cohen's 1980 model regarding the calculation of variable value estimates. This was because some of the data relating to reproduction, that Curie-Cohen used to estimate values in the model in 1980, will not then have applied 18 to 30 years later – to half-sibling matings from about 1998 – when the first children born through artificial insemination by donor (AID) in the 1980s reached reproductive age.

Thus, there is a "generational lag" and a lack of "temporal alignment" in that the values for the variables used in the model are measured on, and for, two different cohorts within the AID community – the *donor* and then the resultant *donor-inseminated child*. The simplest form of

⁷⁰ New South Wales Ombudsman, Fact Sheet 16 – Public Interest (New South Wales State Government, 25 June 2005), <u>http://www.ombo.nsw.gov.au/show.asp?id=371</u> viewed 20 April 2009

⁷¹ Department of Health, Education and Welfare, *Vital Statistics of the United States*, 1977. *Volume III, Marriage and Divorce* (United States Department of Health and Human Services), <u>http://www.cdc.gov/nchs/data/vsus/mgdv77_3.pdf</u> viewed 17 October 2008.

⁷² Curie-Cohen, n 4.

⁷³ University of Edinburgh, *Dictionary of Genetics* (2001), <u>http://helios.bto.ed.ac.uk/bto/glossary</u> viewed 7 April 2007.

⁷⁴ Nagylaki T, "The Correlation Between Relatives with Assortive Mating" (1978) 42 Ann Hum Genet 131; Spuhler JN, "Assortive Mating with Respect to Physical Characteristics" (1968) 15 Eugen Quart 128.

⁷⁵ Clark PJ, "The Heritability of Certain Anthropometric Characteristics as Ascertained from Measurements of Twins" (1956) 8 Am J Hum Genet 49; Spuhler, n 74.

⁷⁶ Nagylaki, n 74 at 131-137; Reed EW and Reed SC, *Mental Retardation: A Family Study* (WB Saunders, Philadelphia, 1965); Roa DC and Morton NE, "IQ as a Paradigm in Genetic Epidemiology" in Morton NE and Chung CS (eds), *Genetic Epidemiology* (Academic Press, New York, 1978) pp 145-181.

⁷⁷ Curie-Cohen, n 4.

multiplicative model is $Y = S^*\overline{m}$ *P. In 1979, S was the number of effective sperm donors used in that year and \overline{m} was the expected number of potential matings between children of a single donor based on the fertility rates of medical practitioners at the time and information from practitioners performing donor insemination. Both these variables pertain to the *donor in 1979*. On the other hand, P, the probability that a random pair of donor-inseminated half-siblings will mate pertains to the *donor-inseminated offspring, some 20 to 30 years later*. This is when the values for d and C – assortive mating for age and of phenotype – and the present-day value for l, the likelihood of them reproducing, comes into effect. Thus, to more accurately estimate the possible number of half-sibling matings, the "generational lag" needs to be accounted for and the variable values calculated and utilised with a view to maintaining "temporal alignment".

Flaws in the model itself

Furthermore, in the present day, due to the number of couples that "co-habit" and bear children,⁷⁸ rather than marry before having children, d, assortive mating for age based on marriage tables, cannot be used to make a reliable estimate for this variable. Part of an updated and more appropriate model would be to develop alternative ways of estimating a value for this variable. An investigation into, and the development and use of, an improved and updated model will produce results that more accurately reflect the possible number of half-sibling matings in a given year, for present-day settings.⁷⁹

 ⁷⁸ National Center for Health Statistics, *Nonmarital Childbearing in the United States, 1940-99* (National Vital Statistics Reports, 18 October 2000, Vol 48, No 16), <u>http://www.cdc.gov/nchs/data/nvsr/nvsr48/nvs48_16.pdf</u> viewed 20 October 2008.
⁷⁹ Sawyer and McDonald, n 5.