Contents

Glossary

ART Assisted Reproductive Technology is the application of laboratory or clinical technology to gametes and/or embryos for the purposes of reproduction.

artificial insemination The placement of sperm inside the female reproductive tract to improve the chances of fertilization and pregnancy occurring. Artificial insemination is also called intrauterine insemination.

Donor insemination Artificial insemination using donor sperm.

DC donor conception (or donor conceived) conception using donated sperm, eggs or embryos.

Embryo The foetus in the womb, from about two weeks after conception to about the end of the seventh or eighth week.

FSA The Fertility Society of Australia

Gamete A reproductive cell, sperm and ova, which fuses at fertilisation to form the zygote.

GIFT Gamete IntraFallopian Transfer.

In vitro Literally, “in a glass”, it refers to observations and procedures made *outside* the body.

Infertility Inability to achieve pregnancy after one year of regular sexual intercourse without contraception.

IVF In Vitro Fertilisation. Fertilisation of the egg outside the body

NHMRC The National Health and Medical Research Council

Recipient parents infertile people who have used donated gametes in order to form their families.

RTAC Reproductive Technology Accreditation Committee, the accrediting committee of the Fertility Society of Australia.

Information about the Donor Conception Support Group of Australia Inc. (DCSG)

The DCSG was formed in January 1993 by a group of parents in Sydney. This small group of parents realised that as a result of family creation by donated eggs, sperm or embryo there are many issues facing them even after conceiving and giving birth:

- Telling children about their conception - openness is essential to good family unity.
- Answering children's questions about their conception and most importantly, about the donor?
- What information do clinics store on the donors? What donor information will clinics give us?
- What if my child needs vital medical information from the donor, will the clinic give us that information or contact the donor to get it?
- How will our child cope with knowing that he/she could have half siblings?

These are just some of the questions and challenges that face donor families.

Over the years the DCSG has grown and now comprises members in every state of Australia and members in a number of overseas countries. Our membership comprises recipient parents, donor offspring, donors, medical professionals, counsellors, social workers, etc.

The DCSG provides information and support for people who are considering using donor conception as a parenting option through to families who already have children born by donor conception. One of the most important roles we have is helping parents who are telling their children the truth about their conception. This can range from parents with very young children through to parents of adult children who have carried the burden of secrecy for decades.

We also provide information and support to gamete donors of whom many have contacted our group over the years. Donors also need support in getting information about the results of their donations and in talking to their own children about their role as a donor. The children that a donor has as a result of their own relationships are also part of the donor conception story as they too are half sibling of donor conceived people.

We have many adults in the group who were born by donor conception and we support them by talking to them, putting them in contact with other donor conceived people and helping them in their search for information about their donors. Many donor conceived people have come to us when they have discovered that the clinic or doctor who facilitated their conception has ceased to practice and we have aided them in their search for information.

Many of the fertility clinics in Australia refer parents, donors and donor conceived people to us for support and information.

The important support and information that the DCSG gives is on a voluntary basis, we receive no funding from the fertility industry nor from government funding or grants. The support we give is not available anywhere else.

Consumer Advocacy.

Within approximately a year of the creation of the DCSG we sent out a survey to ask members what they wanted the group to achieve. Overwhelmingly they responded that they wanted the group to become more active in advocacy for all those involved in donor conception. The main focus of our advocacy has been to encourage governments around Australia to legislate to protect donor conception records and to allow donor offspring the right to know who they are related to biologically. Since this time the Victorian government has put in place the Infertility treatment Act, world leading legislation which gives donor offspring conceived after January 1998 the right to know who their donors are. While this legislation was already in motion when the DCSG was in its infancy it was helped along its way by members of the group. The DCSG was also instrumental in the decision of the WA government to enact legislation. The move towards the Assisted Reproductive Technology Act in NSW was initiated by the DCSG.

The DCSG has written a great many submissions to government enquiries in Australia. Some major ones are:

- National Health & Medical Council Guidelines on Assisted Reproductive Technology (1996)
- New South Wales Human Tissue Act – Assisted Reproductive Technologies (1997)
- NHMRC Report on National Data Collection on Assisted Reproductive Technology (1997)
- Joint Standing Committee on Treaties Inquiry into the Status of the United Nations
- Convention on the Rights of the Child in Australia (1997)
- Western Australia Select Committee on the Human Reproductive technology Act (1999)
- NHMRC Ethical Guidelines on Assisted Reproductive Technology (2001)

- South Australian Working Party Conception by Donation - Access to Information (2001)
- NHMRC Exposure Draft Human Cloning & Research Involving Embryos (2002)
- NHMRC Draft Ethical Guidelines on the use of Assisted Reproductive Technology in clinical practices and research (2003)
- NSW Consultation Draft Bill Assisted Reproductive Technology (2003)
- The Australian Capital Territory Oversight of Assisted Reproductive Technology Practice discussion paper (2005)
- Victorian Law Reform Commission Assisted Reproductive Technology position paper (2005)
- ACT ART Discussion paper (2005)
- Queensland Surrogacy Inquiry (2008)
- Federal Human Rights Consultation (2009)

The group has provided consumer representatives for a number of important government committees including.

- NSW Reference Group looking at reproductive technology
- WA Reproductive Technology Council
- Victorian Infertility Treatment Authority

The DCSG does not limit its advocacy on behalf of those involved in donor conception to just Australia. We have made submissions to government enquiries in a number of countries including New Zealand, UK, Canada and Hong Kong.

Achievements of the DCSG.

Apart from our achievements in the area of consumer advocacy as listed above the DCSG has much to be proud of. In November 1996 we held the world's first consumer run forum looking at donor conception issues. At the Donor Issues Forum we brought together everyone involved in donor conception: recipient parents, donor-conceived adults, egg/sperm/embryo donors, medical professionals, counsellors, and psychologists. The meeting of these parties in one room was also a world first. From this forum which was funded by the NSW Law Foundation we published the book "Let the Offspring Speak" (DCSG ISBN 0 646 32494 2) which has sold 1000 copies worldwide.

Over the years members of the DCSG have been invited to speak at many conferences and seminars. One highlight was in 2002 when one of our members Geraldine Hewitt (an adult born from donor insemination) was invited to present the findings of her research into the feelings and attitudes of donor conceived people at an international conference in Canada. Geraldine's research "Missing Links" is the biggest research project of its type completed anywhere in the world and was done while she was in her final year at high school.

In 2004 the DCSG hosted the largest meeting of donor offspring in the world at the time. Nineteen adults & older teenagers met in Sydney to discuss and share the issues that face them. They all felt a degree of kinship through shared experiences that have continued long after the meeting.

In 2003 Caroline Lorbach, the National Consumer Advocate for the DCSG, published her book "Experiences of Donor Conception – parents, offspring and donors through the years" (Jessica Kingsley Publishers ISBN 1 84310 122 X). In this book she looked at the long term issues surrounding donor conception including such topics as: telling children about their conception, how donors feel, getting information about a child's donor. The book also includes two chapters about adults born from donor conception.

What does the DCSG provide for its members?

The DCSG provides a unique service; there is no other group in Australia that supports donor conceived families and donor offspring long term. We provide that support in a number of ways.

- Support for people considering using donor conception, people undergoing treatment, recipient parents, donors and most importantly donor conceived people.
- Bi-monthly newsletter containing personal stories, news items details of meeting and social events.
- Extensive library which includes, books on general infertility, donor conception, telling children about donor conception, parenting after infertility, life without children etc. We also have videos and published articles from researchers.
- Information meetings; including infertility, male only, telling children about donor conception etc.
- Social events.
- Education and information for clinics and any professionals interested in donor conception.
- Education and information for governments in Australia and overseas.

History of Donor Conception

Sperm donation has been around for a lot longer than most people realise, at least since the end of the 19th century when the first recorded use of donated sperm occurred. In 1884, Dr William Pancoast, a professor in Philadelphia, USA had been treating a woman who was unable to become pregnant. He eventually discovered that she was most likely fertile but that her husband appeared to be producing no sperm. He decided an ‘operation’ would be carried out on the woman to try and achieve a pregnancy. The woman was anaesthetised with chloroform and inseminated with the sperm of another man. There is no record of who the donor was, perhaps a medical student, perhaps Pancoast himself. The woman was never told what had been done to her, but nine months later she gave birth to a son.

Since the end of the 19th century, donor insemination has continued to be used by private doctors in many countries. From the beginning of the 20th century up until the 1940’s there were very few reports of artificial insemination by donor (AID), as it was known then, in medical literature so we have no idea how many women may have given birth following the use of donated sperm. In the United Kingdom and Australia AID began to be more widely used from the 1940’s onwards. One report in an American medical journal of the 1940’s suggested that there had already been nearly 9500 pregnancies in the USA following AID.

The estimates that are given on the number of children born from donor conception in any country are probably lower than the true figures because of the secrecy that has surrounded this form of assisted reproduction. Figures relating to frequency of use of donor conception are not often reported in most countries.

For a long time we have been able to circumvent male infertility by using the sperm of another man but nothing could be done if a woman produced no eggs or eggs of such poor quality that conception was not possible.

Since the first IVF birth in the late 1970's, it became possible for one woman to donate her eggs to another. The most common way for this to occur in the early days was for a woman already undergoing IVF to donate any eggs she did not use in a cycle. However, it was not until 1983 that the first baby was born as a result of a donated egg.

Sperm was successfully frozen as early as the 1950's and eventually the methods used for sperm were adapted for the freezing of embryos. This enabled couples to freeze spare embryos created during one cycle and use them in another. It also made possible the donating of embryos to couples who both had fertility problems or to a couple who could not obtain donor eggs. Although it is possible to freeze eggs, the viability rate after thawing is extremely low.

In the 1990's, the latest technique to aid infertile men has been intracytoplasmic injection (ICSI) where a single sperm is injected into an egg to achieve fertilization. ICSI is used in instances where a man has an extremely low sperm count or has motility problems (sperm which do not move well). This procedure is still expensive and some have had doubts about it because of the possibility of passing on genetic forms of infertility.[1]

We estimate that across Australia there are hundreds of thousands of Australians affected by donor conception. The number of people affected by donor conception is not confined to those conceived by donated gametes but also

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[1] *Experiences of Donor Conception – parents, offspring and donors through the years* Caroline Lorbach 2003 Jessica Kingsley Publishers

includes parents, donors (their partners & children), those that form relationships with donor conceived people plus their children.

It is not possible to be more specific on the numbers involved as records of donor assisted births have not been kept prior to 2003 (it has not been a requirement that clinics report births using donor insemination to the National Peri-natal Statistics Unit). The first official clinic performing donor insemination in Australia started in Victoria in 1970 but private practitioners were performing donor insemination for at least 3 decades before this.

Many figures have been suggested as to how many children have been born by donor insemination in this country. It was quoted in 1982 that there were about 10,000 children under the age of 15 who had been born by donor insemination.[2] In the 1990's when the DCSG first began we asked this question of a number of doctors and were told approximately 2,000 births per year in Australia. Our group would estimate the number of donor conceived people in Australia today to be approximately 60,000.

Since that time there have been some changes to donor conception. With the advent of techniques that can use single sperm to fertilise an egg there has been less donor insemination being used by heterosexual couples but now many more single women and lesbian couples are now accessing donor programs and we must also add to the numbers of people conceived by donor insemination those people now born from donated eggs and embryos.

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[2] pge 54, *Life in a Test-tube,* Dr Daniel Ch. Overduin & Fr. John I. Fleming, 1982, Open Books.

Introduction

Participants in donor conception are often nervously aware that they are engaged in an enterprise for which the psychological, social and legal rules have not yet been fully written.

As pointed out in the Asche report of 1985[3] it is the function of a country to be concerned with the welfare of children. Others have suggested that society has an added duty to Donor Conceived people because it is a publicly sanctioned and Medicare funded procedure.

Tax Payers' Dollars
Spent on Assisted Reproductive Technology

$15 6.1 million

In 2005

A cost-effectiveness analysis of *in-vitro* fertilization by maternal age and number of treatment attempts Alison Griffiths et al. An Australian government-funded study published in Human Reproduction, January 26, 2010

$156.1 million is a large amount of taxpayers' dollars being spent on creating people. The spending of this money puts an obligation on the Federal Government to ensure that lives are not being adversely affected by the very services they are funding.

Society has sanctioned the practice of donor conception but on the whole society has very little understanding of the long term implications of parenting donor conceived children and of the life-long implications on the children themselves.

A former Federal Human Rights Commissioner, Chris Sidoti has spoken out about the rights of people born by donor conception. He has referred to the use of anonymous sperm donors as creating a "social time bomb"

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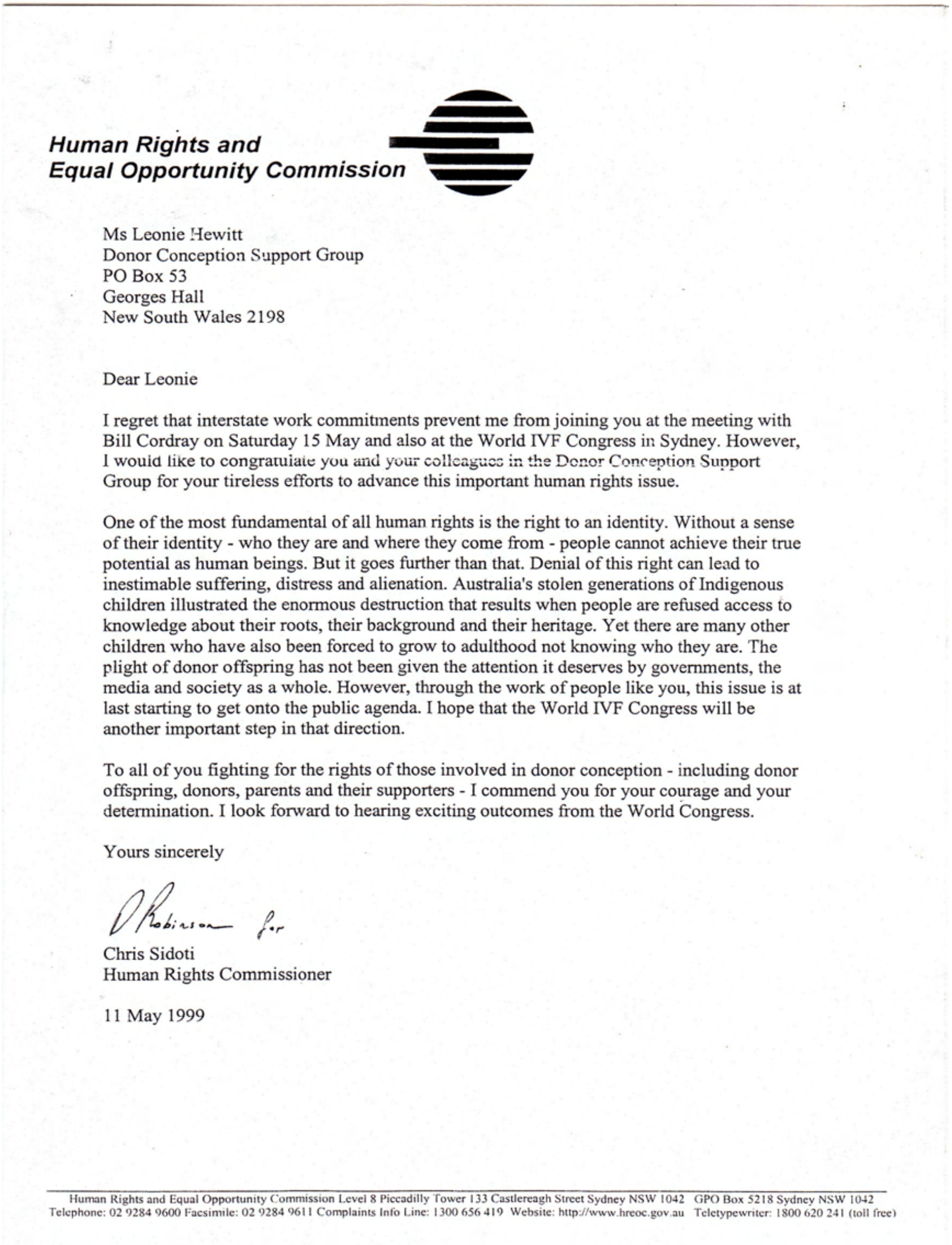
[3] *"Creating Children: Report of the Family Law Council of Australia"* Australian Government Publishing Service

and that it is a breach of the rights of people born by donor conception. "This practice is denying the right of these children to know their biological fathers."[4]



Human Rights and
Equal Opportunity Commission

Ms Leonie Hewitt
Donor Conception Support Group
PO Box 53
Georges Hall
New South Wales 2198

Dear Leonie

I regret that interstate work commitments prevent me from joining you at the meeting with Bill Cordray on Saturday 15 May and also at the World IVF Congress in Sydney. However, I would like to congratulate you and your colleagues in the Donor Conception Support Group for your tireless efforts to advance this important human rights issue.

One of the most fundamental of all human rights is the right to an identity. Without a sense of their identity - who they are and where they come from - people cannot achieve their true potential as human beings. But it goes further than that. Denial of this right can lead to inestimable suffering, distress and alienation. Australia's stolen generations of Indigenous children illustrated the enormous destruction that results when people are refused access to knowledge about their roots, their background and their heritage. Yet there are many other children who have also been forced to grow to adulthood not knowing who they are. The plight of donor offspring has not been given the attention it deserves by governments, the media and society as a whole. However, through the work of people like you, this issue is at last starting to get onto the public agenda. I hope that the World IVF Congress will be another important step in that direction.

To all of you fighting for the rights of those involved in donor conception - including donor offspring, donors, parents and their supporters - I commend you for your courage and your determination. I look forward to hearing exciting outcomes from the World Congress.

Yours sincerely

D Robinson for

Chris Sidoti
Human Rights Commissioner

11 May 1999

Human Rights and Equal Opportunity Commission Level 8 Piccadilly Tower 133 Castlereagh Street Sydney NSW 1042 GPO Box 5218 Sydney NSW 1042
Telephone: 02 9284 9600 Facsimile: 02 9284 9611 Complaints Info Line: 1300 656 419 Website: http://www.hreoc.gov.au Teletypewriter: 1800 620 241 (toll free)

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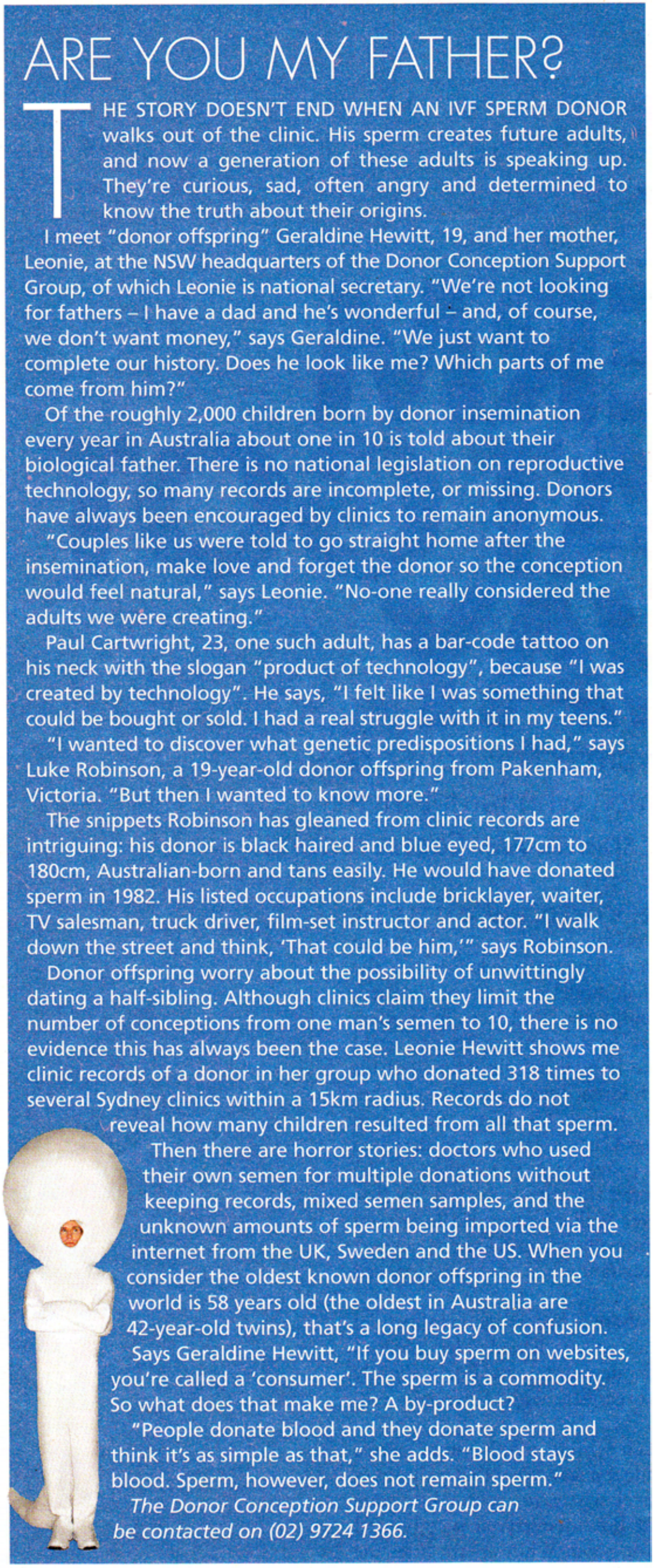
[4] Courier Mail 17th February, 1997.



ARE YOU MY FATHER?

THE STORY DOESN'T END WHEN AN IVF SPERM DONOR walks out of the clinic. His sperm creates future adults, and now a generation of these adults is speaking up. They're curious, sad, often angry and determined to know the truth about their origins.

I meet "donor offspring" Geraldine Hewitt, 19, and her mother, Leonie, at the NSW headquarters of the Donor Conception Support Group, of which Leonie is national secretary. "We're not looking for fathers – I have a dad and he's wonderful – and, of course, we don't want money," says Geraldine. "We just want to complete our history. Does he look like me? Which parts of me come from him?"

Of the roughly 2,000 children born by donor insemination every year in Australia about one in 10 is told about their biological father. There is no national legislation on reproductive technology, so many records are incomplete, or missing. Donors have always been encouraged by clinics to remain anonymous.

"Couples like us were told to go straight home after the insemination, make love and forget the donor so the conception would feel natural," says Leonie. "No-one really considered the adults we were creating."

Paul Cartwright, 23, one such adult, has a bar-code tattoo on his neck with the slogan "product of technology", because "I was created by technology". He says, "I felt like I was something that could be bought or sold. I had a real struggle with it in my teens."

"I wanted to discover what genetic predispositions I had," says Luke Robinson, a 19-year-old donor offspring from Pakenham, Victoria. "But then I wanted to know more."

The snippets Robinson has gleaned from clinic records are intriguing: his donor is black haired and blue eyed, 177cm to 180cm, Australian-born and tans easily. He would have donated sperm in 1982. His listed occupations include bricklayer, waiter, TV salesman, truck driver, film-set instructor and actor. "I walk down the street and think, 'That could be him,'" says Robinson.

Donor offspring worry about the possibility of unwittingly dating a half-sibling. Although clinics claim they limit the number of conceptions from one man's semen to 10, there is no evidence this has always been the case. Leonie Hewitt shows me clinic records of a donor in her group who donated 318 times to several Sydney clinics within a 15km radius. Records do not reveal how many children resulted from all that sperm.

Then there are horror stories: doctors who used their own semen for multiple donations without keeping records, mixed semen samples, and the unknown amounts of sperm being imported via the internet from the UK, Sweden and the US. When you consider the oldest known donor offspring in the world is 58 years old (the oldest in Australia are 42-year-old twins), that's a long legacy of confusion.

Says Geraldine Hewitt, "If you buy sperm on websites, you're called a 'consumer'. The sperm is a commodity. So what does that make me? A by-product?

"People donate blood and they donate sperm and think it's as simple as that," she adds. "Blood stays blood. Sperm, however, does not remain sperm."

The Donor Conception Support Group can be contacted on (02) 9724 1366.[5]

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[5] Sunday Life Magazine 18/8/2003

Legislation

There must be a clear commitment on the part of society and the government to the interests of all parties involved in ART. This commitment should most particularly be shown to those people already in existence as a result of donor conception and those who will be born in the future.

In July 2001, the Council of Australian Governments (COAG) committed itself to achieving nationally consistent provisions in legislation to ban human cloning, and also asked jurisdictions to work towards nationally consistent approaches to regulate ART and related emerging technologies.[6]

In April 2009 the Standing Committee of Attorneys General agreed to convene a working group of officials to prepare a draft discussion paper that explores options to harmonise the collection and recording of, and access to, donor information. We have had numerous communications with the Attorney General's department since then and each time have been told the same thing; that they have agreed to prepare a draft discussion paper but nothing has happened.

> *"When society becomes party to the conception of children by medically assisted means, it assumes a responsibility, as in adoption, for ensuring that this is done according to the interests of the children. It seems reasonable to assert that society has a duty to regulate both those who offer medically assisted conception and those who wish to avail themselves of the service."*[7]

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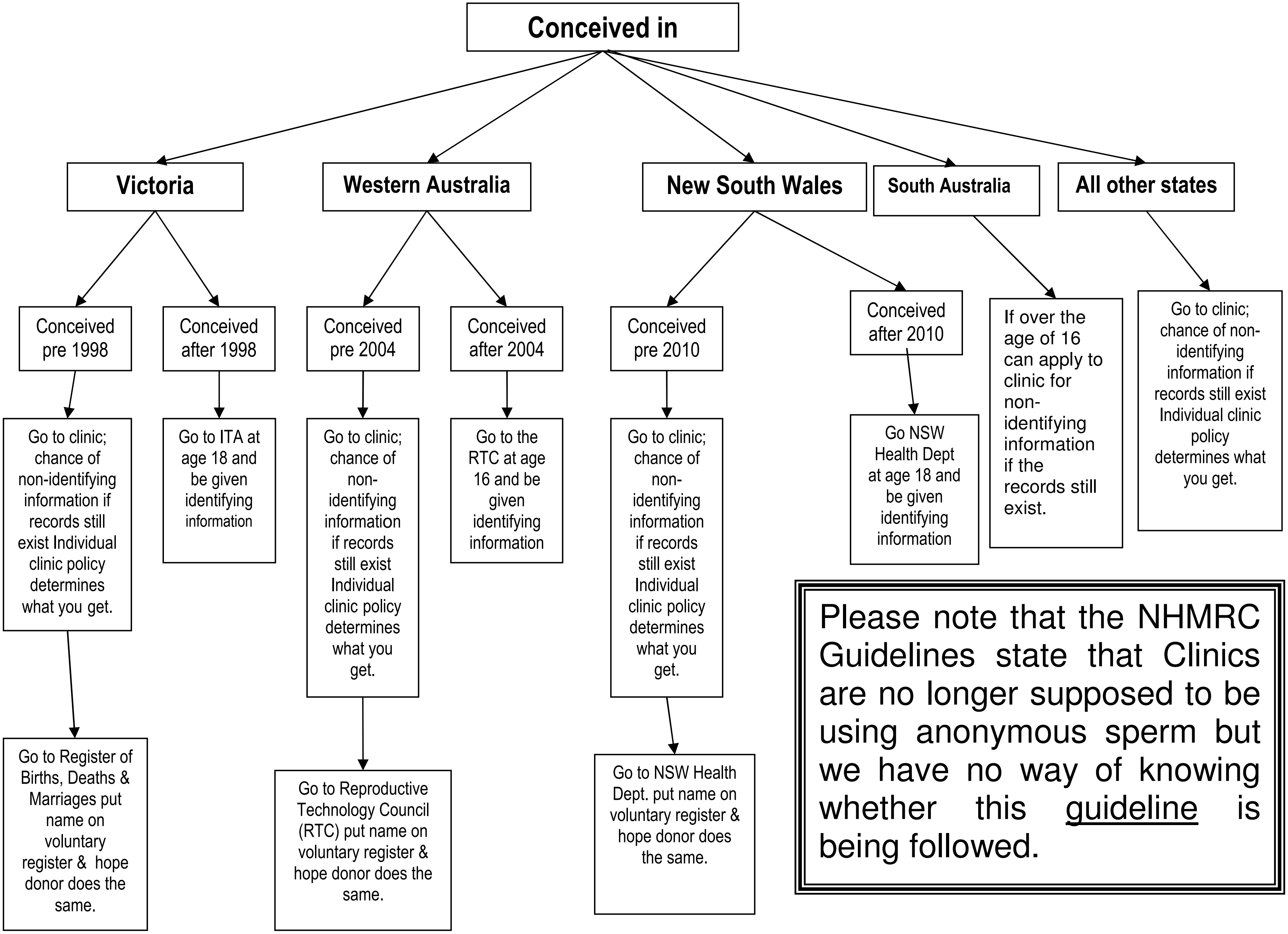
[6] http://www.aph.gov.au/senate/committee/clac_ctte/completed_inquiries/2002-04/emb_cloning/report/c01.pdf

[7] Pge 184 *"Semen Donors: Their Motivations and Attitudes to their Offspring"* Journal of Reproductive and Infant Psychology, 1989.

The Federal Government has, in the past, justified their inaction in the area of donor conception by saying that it is a health matter and only the states have the jurisdiction to legislate in this area. We would put forward three points against this. Firstly health departments are not the best place for legislation to do with donor conception. The issues that families and individuals involved in donor conception face are social & emotional for the most part; they deal with lack of genetic and social heritage very much like adoption. Secondly most states have declined to do anything about donor conception, And thirdly the Federal Government has already set a precedence in legislating in the health area with its Prohibition of Cloning for Reproduction and Research Involving Human Embryos Acts. The Prohibition of Cloning Act in particular prohibits the creation of a human embryo which contains genetic material provided by more than 2 persons. ; this procedure has been used to create children overseas.

There is a growing understanding that donor conceived people have a need for information in order for them to complete their own sense of identity. In some states legislation has been enacted that gives people conceived after the enactment dates of certain state legislation the right to know the identity of their donors. This has left the tens of thousands of already born donor conceived people wondering why they are not considered worthy of the same right. The following table is a simple representation of the muddle of different state systems that occur around Australia.



Please note that the NHMRC Guidelines state that Clinics are no longer supposed to be using anonymous sperm but we have no way of knowing whether this guideline is being followed.

As we have said legislation in the area of reproductive technology has traditionally been conducted in the health area. This has obviously been seen as the easiest area in which to place legislation that is covering medical activity. The problem with this is that donor conception as a whole then becomes medicalised. Apart from the preparation and storage of semen, egg & embryos and the actual conception nothing else is medical. The recruitment of donors, the counselling of recipients and donors and what comes after the conception are definitely not within the parameters of medical treatment.

> "Many of the treatments for Infertility require knowledge of this sort ('medical knowledge'), and it is tempting to argue that this in itself should place infertility within the scope of medicine proper. This temptation should be resisted!"[8]

We would ask that any government preparing legislation to cover the long term issues of using donor conception as a method of family creation thinks seriously about a better place in which legislation can reside.

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[8] Soren Holm - Department of Medical Philosophy & Clinical Theory, University of Copenhagen, Denmark. Pge 75 *"Creating the Ch `ild - The Ethics, Law & Practice of Assisted Procreation"* Edited by Donald Evans.

Legislation in other parts of the world.

United Kingdom

The most comprehensive system established to try and provide for the needs of donor conceived people has been set up in the United Kingdom under their Human Fertilisation and Embryology Act (1990).

In 2004 a pilot program was established by the UK Health Department called Donorlink; this enabled donor conceived people and donors to place information on a register so that matched could be made. DNA matching was also available where needed.

A new service has just been announced which will run from the Human Fertilisation and Embryo Authority (which licenses clinics and research) which enables donor conceived people to make contact with others who have been conceived using the same donor.

The Donor Sibling Link (DSL) allows those conceived after 1st August 1991 or who are over 18 to join and find out whether anyone else shares the same donor. If so, people who have consented will be able to share their contact details with each other. The service is only open to donor conceived people and not available to any other family members, including their own parents. It also allows donor conceived people to opt out at any point.[9]

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[9] http://www.hfea.gov.uk/donor-sibling-link.html

New Zealand

New Zealand also has a register called the HART Register. The Human Assisted Reproductive Technology (HART) Act was passed in November 2004. This act has also set up a linking system whereby donors and donor conceived people can locate each other; but the New Zealand system is more limited in that participants must have the donor identification code before a match can be made. In the UK and in states like Victoria matches have been made based on dates, clinics and non-identifying information. [10]

Sweden

Sweden was the first country in the world to outlaw anonymous sperm donation. In Sweden donor conceived people can have access to donor information from the age of 14 years.

Netherlands

In the Netherlands donor conceived people, at the age of sixteen, can access identifying data such as name and physical address of the donor. Disclosure will in principle only be refused by the foundation that runs the register if the donor's interests prevail.[11]

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[10] http://www.dia.govt.nz/diawebsite.nsf/wpg_URL/Services-Births-Deaths-and-Marriages-Human-Assisted-Reproductive-Technology-%28HART%29-Register?OpenDocument

[11] Art. 3(4) Dutch Artificial Insemination (donor insemination) Act.

Austria

the introduction of the Reproductive Medicine Act (1992) in Austria affording a donor-conceived person reaching the age of 14 the right to learn the donor's identity was predicated on the Austrian government's interpretation of Article 7 of the United Nations Convention on the Rights of the Child (the right of a child '... as far as possible... to know... his [*sic*] parents') and Article 8 of the European Convention on Human Rights and Fundamental Freedoms (the right to 'respect for ... private life')[12]

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[12] Donor anonymity and secrecy versus openness concerning the genetic origins of the offspring: international perspectives 2006 Eric Blyth, PhD CQSW

Comparison with Adoption

There are many similarities between adoption and donor conception but also some differences. The main difference is that the two areas have been under the control of very different groups. Adoption has always been under the main control of government or religious welfare services. Donor conception has been under the control of medical professional individuals and organisations. This has caused any legal examinations of donor conception to be conducted by health departments. While there may be medical long term implications of donor conception because of missing medical histories for the most part the long term implications are emotional and social and because of where legislation lies these important issues are often not fully explored.

It is ironic that the culture of secrecy was being promoted in donor conception practices during the same period that the wall of secrecy was being broken down in adoption.

Donor conception has in the past three decades gradually taken over from adoption in being the most common way for people unable to have their own biological children to achieve a family. So it would seem appropriate that given the long term consequences that are evident in donor conception that we give the same support to donor conception that we have given to adoption practices.

When governments attempt to legislate in certain areas there are often concerns by some people that the state is being paternalistic in its attitude. What we must remember is that the society has already accepted that the state should have a role in adoption. The role of the system in relation to adoption is to protect the needs and interests of the children and the adults they will become.

The adoption model of legislative and social reform provides a unique insight into some of those issues that will impact upon children born as a result of donor conception. We would now like to look at the experience of adoption reform within NSW as an example of the type of discussion that was repeated around the country.

The retrospective access to information was a central issue of debate prior to the enactment of the *NSW Adoption Information Act, 1990* (AIA).

It is a basic human right to know of one's origins. Every person should have a right of access to information and to contact to those who make up their biological and social heritage, enabling them to complete a picture of themselves and their identity. The NSW Legislative Council Standing Committee on Social Issues, in its Report[1] , *Accessing Adoption Information*, Stated:

> *"… the Committee considers that the major principle in the adoption information issue is the right of all human beings to have access to origins information. This is a basic entitlement of the whole community and one from which parties to adoptions should not be excluded.* [2]

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[1] The NSW Legislative Council Committee on Social Issues represented all shades of political opinion form the most conservative to the most progressive, and the remarkable aspect of its recommendations was the consensus reached despite very grave initial reservations held by a number of its members.

[2] *Accessing Adoption Information*. Report of the NSW Legislative Council Standing Committee on Social Issues. 1989, pg 34

It was discussions such as those that preceded the enactment of NSW legislation that all allowed all adoptees in NSW the right to access birth parent information no matter when they were born.

The denial of such right of access to one group, i.e. donor offspring, within the broader community can have severe adverse effects on their perception of themselves and their position in the world. We are concerned that denial of such rights purely on the basis of their date of birth will produce a minority group afforded less rights than those of their younger counterparts. This is supported again in the adoption experience, and by the Committee on Social Issues Report, where they state:

> *"The evidence which addressed this question [retrospectivity] came out strongly in favour of applying the new legislation retrospectively. The Committee is persuaded by this argument, since to do otherwise would amount to excluding all existing adoptions from the benefits of the new legislation, leaving different levels of access in place from previous periods. Such a situation violates the principle of information provision as a fundamental human right."*[3]

Prior to the enactment of the AIA adult adoptees who were not able to access information have spoken of the feelings of forever remaining a child of adoption. At age 18 or 21 years they were granted adult status, and therefore adult rights and responsibilities in all aspects of the law except adoption. Many resented being bound for a lifetime by past

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[3] *Accessing Adoption Information.* Report of the NSW Legislative Council Standing Committee on Social Issues. 1989, pg 35

decisions made for and about them, and experienced this as a lack of control and self-determination over their own lives and futures.

We understand the controversial nature of retrospective information rights, and empathise with the fears of clinics and of some parents. However we believe that the needs and interests of our children, and all people created through the use of donor conception must be of paramount concern. We believe strongly that the provision of retrospective, and therefore equal rights to information for all donor offspring can only be in their best interests.

Many of the fears expressed in regards to retrospectivity in the donor conception experience were also expressed during the NSW debate on the right to information in adoption. Opposition to proposed changes was primarily two-fold.

Firstly that privacy (and secrecy) was enshrined in The Adoption of Children Act, 1965, and therefore retrospectivity would be a breach of a 'contract' entered into years before. That the perceived loss of privacy would undermine the parental role of adopting parents, risk their relationship with their child(ren), and question their right to have chosen not to tell their child(ren) of their adoptive status. Experience has shown that in the large majority of cases of those adoptees who have sought reunion most have found their relationship with their adoptive parents unchanged or even strengthened. The majority of adoptees who seek out birth parents do not seek another mother and father or substitute parents, rather they seek answers to questions of identity, and as such the position of their adoptive parents as 'mum' and 'dad' remains unchallenged. In discussing the fear of invasion of privacy, Margaret McDonald[13] said,

> *"Judging from agency experience in New South Wales of people to whom an approach is made for contact, any initial feeling of their privacy being invaded quite quickly gives way to acceptance, to some degree, of the approach, even where it has been feared. This would seem to reflect the experience form Victoria where, in one study of 422 cases of people approached, 85% agreed to contact, 6% agreed to exchange of information without meeting and only 9% declined to meet or exchange information"*[14]

The enactment of the AIA facilitated the revealing of the adoptive status to an adoptee. Adoptees firmly voice their right to know of this information about themselves, and the belief that parents do not have a right to withhold such a fundamental piece of information about themselves. Adoptees who have discovered their adoption later in life have spoken of the sense of betrayal, the difficulty in redefining themselves, and in many cases the fact they always knew there was something different. The fact that some parents will choose not to tell their children the facts of their conception should not be used as a reason for opposing information rights and retrospectivity. In the adoption experience it is often voiced that it was the secrecy that past practices enshrined that has caused the most heart-ache.

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[13] Margaret McDonald worked in adoption in NSW for 30 years as a case worker, a manager and an advisor to the state government.

[14] McDonald, M., *Developments in Adoption Information Legislation in Australia.* Unpublished paper. Circa 1992.

Secondly, was the way in which the information would be used, and Gerard McPhee explained the fear eloquently:

> *"It was argued first that few adoptees would wish to know their origins, and secondly that the few who did would be driven by some compulsion to find and confront their birth parents in such a way that the secret of the birth parents' past would be revealed, and that the secure happy lives of those birth parents would be destroyed by this exposure."*[5]

Attached to this fear were debates around the effectiveness of any Contact Veto system. The effectiveness of the Contact Veto system was questioned by comments such as "anyone desperate enough to apply for the certificate is unlikely to be deterred by a fine or a prison term".

In the review of the NSW *Adoption Information Act* 1990 in 1992 it was stated:

> *The vast majority of adopted persons and birth parents welcome the rights to information, and exercise them responsibly.*
>
> *Compliance with the contact veto system is very high. Although there were rumours or suggestions of breaches, a careful examination of the evidence revealed only one incident that appeared to be a breach of a veto.*
>
> *Post-adoption contact and reunions are seen as beneficial by almost*

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[5] Gerard McPhee, "Testing Adoption Assumptions Through Legislation" in *To Search for Self*. Editors: Phillip and Shirley Swain. Federation Press, 1992.

> *all who initiate them, and positive or acceptable by the majority of those who are contacted*[15].

In a Queensland discussion paper of 2008 on adoption reform stated:

> *It has now been three years since information vetoes were removed in Western Australia and the administering department reports that no breaches of contact objections have since been reported.*[16]

Margaret McDonald discussed why this might be the case in 1992 as:

> *"It seems less the penalty than fear of rejection and respect for the expressed wishes of the other person that acts as the deterrent. The impression of those who have interviewed people signing the undertaking is that despite their distress and disappointment they accept the decision of the person lodging the veto and appear unlikely to attempt illegal contact."*[6]

What appears remarkable in light of the secrecy so strictly enshrined in the NSW *Adoption of Children Act, 1965*, was that despite the opposition to openness NSW achieved progressive and enlightened rights under the AIA. The overwhelming call for access to information came from adoptees [7] who felt that the secrecy was in contravention to their interests being of paramount concern. That their interests were secondary to those

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[15] http://www.lawlink.nsw.gov.au/lrc.nsf/pages/R69EXEC

[16] http://www.childsafety.qld.gov.au/consultations/documents/balancing-privacy-and-access.pdf

[6] McDonald, M., *Developments in Adoption Information Legislation in Australia.* Unpublished paper. Circa 1992.

[7] The NSW Legislative Committee on Social Issues received 165 submissions from adoptees, of which only one anonymous submission opposed the opening of access. 18 adoptees gave evidence, all of whom supported access to identifying information.

of the adults who made significant and life changing decisions about their lives and their futures, and that even in adulthood they would be bound by the secrecy implemented to protect them as children. The Committee on Social Issues, expressed in its summary of its findings:

> *"It is a unique form of discrimination against adult adoptees that they are not able to access identifying information about their own origins."*[8]

Fears around retrospectivity in the donor conception experience have been expressed similarly to those of adoption history. Yet in the adoption model research has shown that the fears initially expressed have either not been realised in the large majority of cases, or not to the depth or extent to which they were initially expressed. Why would donor conception be any different?

> *7.54 The proper domain for ensuring that the adoptee is informed of his or her adoptive status in a manner appropriate to his or her age is through education, both in preparation of applicants for adoption and in post-adoption support programs. The issue would also be a factor in assessing applicants' suitability to adopt. Ultimately, responsibility for informing adoptees should rest with DOCS or the private agency and the adoptive parents, not with legislative provisions.*

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[8] *Accessing Adoption Information*. Report of the NSW Legislative Council Standing Committee on Social Issues. 1989, pg xii.

> *7.55 At any rate, adoptive parents would be aware that after their adopted child turns 18, members of the child's birth family may make contact under the Adoption Information Act, even if the child has not been told of his or her adoptive status. This may have the effect of a deferred legislative enforcement.*[17]

From the information sheet for prospective adoptive parents produced by the NSW adoption and Permanent Care branch of the Department of Community Services.

> *For the purposes of the Regulation, the relevant decision-maker is to consider the following matters when assessing the suitability of a person to be approved to adopt:*
>
> *the person's appreciation of the importance of and capacity to facilitate: contact with the child's birth parents and family, and exchange of information about the child with the child's birth parents and family* [18]

While there are a great many comparisons between adoption and donor conception there is one fundamental difference. While children are adopted because of tragedy or unintended mistakes donor conceived

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[17] (1997) - Review of the Adoption of Children Act 1965 (NSW) http://www.lawlink.nsw.gov.au/lrc.nsf/pages/R81CHP7

[18] http://www.community.nsw.gov.au/docswr/_assets/main/documents/adoption/adoption_thinking_about.pdf

people feel that their loss has been brought about by a deliberate arrangement that robs them of the right to have a connection with people to whom they are biologically related.

Some donor conceived people will be interested in accessing their genetic information while others will have no interest. It is a basic human right to know of one's own heritage, a right which most children are born into and most adults take for granted. People may argue that some individuals in today's society do not know a part of their heritage for a variety of reasons, however their right to seek information is not denied to them through any legislative or regulatory framework.

The Contradictions of Donor Conception.

Truthfulness is typically one of the first ethical lessons we try to teach our children. There is also a prevalence of commitments to honesty and integrity in organisational codes of ethics and value statements across the country, and by the fact that most of us continue to regard lying or deceit in our personal relationships as extremely hurtful to those relationships. Indeed our country even legislates against various forms of dishonesty.

Even though our society has always held honesty to be one of our most important ideals and even though in adoption practice it had long been realised that adopted children needed to be told the truth this has only recently transferred to donor conception. As late as the 1990s recipient parents were still being advised to withhold the truth from their children.

The medical profession continually tells us that knowing about our family medical history can be vital for a prompt and clear diagnosis.

> *it is clear that the family history is still a critical part of the assessment of the patient's wellbeing and the diagnosis of possible illnesses in the emergency setting.*[19]

"As family history offers an increasing range of opportunities for improved health outcomes, any failure to routinely assess it is a lost opportunity to improve the health of those at increased risk of familial disease."[20]

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[19] www.privacy.gov.au *submission 2001 from Geoff Sam Chief Executive, Adelaide Community Healthcare Alliance*

> The AMA is firmly of the view that the taking of family and social histories must extend to the collection of health information about third parties to ensure that medical practitioners continue to provide a complete health service.
>
> The AMA supports the collection of health information about third parties without consent where it is necessary to enable health service providers to provide a health service directly to the consumer, and the information is relevant to the family, social or medical history of that patient.[21]

Even though the majority of medical professionals espouse the importance of family medical history some have decided that for donor conceived people family medical histories are not important.

One of our members who was adopted wrote about her concerns for her donor conceived child:

> *I am concerned that my daughter will go through similar difficulties in relation to establishing her identity not to mention difficulties relating to medical history. Over the years I have experienced difficulties with the medical profession when I was unable to supply any family medical history and have had to undergo extra procedures (that perhaps were unnecessary) "just to be safe".*[22]

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[20] Dr Andrew Laglands Royal Perth Hospital http://www.ama.com.au/node/5707

[21] http://www.ama.com.au/node/4151 AMA comments on the Review of Australian Privacy Law, Discussion Paper 72 11 January 2008

[22] See appendix 1 for full letter

> *"In regard to blood ties, one area remains in which we know that knowing the identity of the donor may be of central importance for donor children and their parents: the medical domain. It can be important to have knowledge of the donor's heredity and physical characteristics when certain diseases occur in donor children. This can be of vital interest to the parents in their care of the child. It can also be of interest to the child when as an adult she or he plans to start its own family. In countries like Norway, in which secrecy has entailed the destruction of medical records, no consideration is given to the legitimate interest in openness, despite the formidable development of medical genetics."*[23]

> *"Later in life, there might be a need for pertinent medical information. As medicine develops, namely genetic testing and predictive diagnosis, it will become more and more important to be able to give a true account of past diseases in the family. Unfortunately, people not told of their 'half adoption' will report inaccurate data to their physician. Some will be put at risk by this deception. It is then in the interests of the child, not only to know about his double lineage, but also, at least to receive some data about the donor, or better to have a means, for instance through a third party, to get up-to-date information directly from the donor."*[24]

There have been parents with serious concerns about the screening that donors go through before they donate.

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[23] Knut Ruyter - Centre for Medical Ethics, University of Oslo, Norway. pge 190 *Creating the Child - The Ethics, Law & Practice of Assisted Procreation"* Edited by Donald Evans. Martin Nijhoff Publishers, 1996.

[24] Jean-Marie Thevoz - Foundation Louis Jeantet de Medicine, Geneva, Switzerland. Pge 201 *"Creating the Child - The Ethics, Law and Practice of Assisted procreation"*

My twins contracted a Viral infection and ended up in ….hospital ……….The hospital staff were very helpful and suggested a few blood tests to rules out things like diabetes' and I agreed for the fact that diabetes runs in my family. By the 6th April, this was ruled out, but they found my son had Thalassemia.

I went to my GP to test myself for Thallasemia minor, which was negative, so then I assumed that the Donor must be the Carrier,

Once I had found out what my son had, I immediately rang the …..Fertility Clinic and to also see if I could get a medical history on my Donor. They said it would be a long process but they would see what they could do. After a week, with no contact, so I rang back and was put through to a laboratory technician, which I didn't get his name, and I was told by him "That my son possibly have Thalassemia Major as he would not have survived."

Then I said "If that's the case, what are all these older children and adults in our hospitals receiving blood transfusions for Thalassemia, they just didn't get it over night they were born with it" and he again replied "All I am saying is that your son doesn't have Thalassemia Major and I said That I didn't want to know what my son might or might not have, what I wanted to know was, if the Donor had the Thalassemia Gene which passes to his Offspring, he then simply said "That was all the

> *information he was allowed to give out and if I needed more I was to speak to Dr …….", so I left a message for him to ring me.*
>
> *Dr………. rang me on the 21st April wanting to know what he could do for me, he sounded like he knew nothing about my conversations with his staff, which annoyed me even more. Upon explaining to him that I wanted to know medical details about my Donor he stated that Don't you remember, when you were receiving Donor Sperm, that no records were kept.* **[25]**

This woman's children were born in 1995 and by 1997 the Doctor was saying that he did not have any records. Even by any acceptable medical practices at that time he should still have had records in his keeping.

We have had a number of donors come to our group over the years talking about medical records. Many have said that there was family medical history information that was not known to them at the time they donated. We have always advised them to go back to the clinic and ask that the clinic contact recipient parents or at the very least that the information be placed in their file in case parents asked. One donor whose letter is below wanted to share serious medical information with recipients but found out that his records had been destroyed without his permission. As you can see by this letter he was told that the clinic had tried to contact him and he was puzzled that they couldn't find him as he had never moved.

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[25] See appendix 2 for full letter

> *Now, 15 years on and with a new wife and two kids of my own (son 5 and daughter 2). I have a totally different outlook on conception and all its responsibilities, especially the consideration of the child. While the donor's anonymity, where requested, should be respected, I believe all offspring deserve to at least have access to the donor's identity. They should also have the chance to make contact with the donor, as should the donor with the offspring. Again, though, anonymity should be respected where requested.*
>
> *To reinforce my point I have a congenital hear defect (bicuspidal aortic valve). So any child created using my sperm is highly likely to be afflicted with the same problem. He or she, like me, may not become aware of it until later in life. I was unaware of the valve defect when I donated.*
>
> *This year I tried to get my records, but the clinic advised me they had been destroyed after the clinic apparently tried to contact me. I didn't move house or change telephone numbers at any time while I lived in Sydney.* [26]

His letter covers so many important points. Firstly that a great many donors, even though they accepted anonymity when they donated, have since come to change their minds about it and see things from the point of view of the children. Secondly that too many clinics have told people that they have destroyed records. Our group is in no position to

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[26] See appendix 3 for full letter

know if this is true; did clinics actually destroy records or did they just tell donors, recipients & donor conceived people that they did in order to stop them making inquiries? And thirdly it is not the first time that we have heard of a clinic saying they had been unable to contact someone when in fact that person had never moved.

The people most affected by missing medical histories are of course donor conceived people. Many of them worry about what genetic conditions they may have inherited that hey could be looking out for or doing something to prevent if only they knew about them. How many donor conceived people have had delayed diagnosis or had to undergo extra testing because of missing family medical histories?

> *And what about the worry that some donor conceived people have about the fact there is no one to ask about their medical historie.s*
> *What I am getting at, is there a possible link between IVF/D.I. babies with illnesses & all the chemical-laboratory conditions?*
> *Both my brother & I have developed quite severe allergies, and tends to make me curious.*
> *Granted, it could just be passed on from our donor father, but doesn't that still pose a serious question about how donors are screened?*[27]

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[27] See appendix 4 for full letter

Birth Certificates

Many donor conceived people have very strong views about their birth certificates. Some have called them sanctioned untruths.

> "The position of DI offspring is unique. (At some point AID[28] became DI. Perhaps it sounds more comfortable if you lose the 'artificial', but both are misnomers: sperm is sold, not donated.) The nearest comparable group is adoptees. But the adopted child is almost certain to know that they are adopted and if their adoptive parents do not tell them, their birth certificates will.
>
> The birth certificate of a DI child, however, yields no clue about their origins: it is a statutorily sanctioned fraud. If an adoptee wishes to try to try their birth parents, the law supports them and public agencies will help them. If DI offspring express the same wish, they can expect to meet reactions all the way from helpless sympathy to open hostility."[29]

Some people, in particular donor-conceived people, and people involved in adoption, told us they believe that birth certificates should always display the names of a child's genetic parents, to reflect the biological truth about his or her parentage, and to guard against the secrecy that has historically accompanied donor conception and adoption:

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[28] AID Artificial Insemination Donor – the term by which donor insemination was known.

[29] a DI offspring in his fifties.

I find it absolutely disgraceful that even today, almost 22 years later, donor conceived people's birth certificates are still legally forged. We are the only people on earth whose birth certificates are untrue.

Why is it up to the parents of people like myself to tell us about who we are? A document that is supposed to be our primary source of identity is false. What does this tell me about the entire practice of donor conception? It tells me that when we want something kept a secret, it is usually because we are not comfortable with what that secret entails.[30]

The adoption agency Connections Adoption and Permanent Care proposed that:

perhaps there could be a different type of Birth Certificate issued to people born of donated gametes so that if they have not been told as a child of their origins, and the Infertility Treatment Authority or the like has not contacted them for permission to release identifying information to the donor, they could in fact still find out about their origins via the Registry of Births, Deaths and Marriages as is the case with Adoption.[31]

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[30] Ch 14 Birth Regsitration **Victorian Law Reform Commission -** Assisted Reproductive Technology & Adoption: Final Report

[31] Ibid

In 2008 the new Assisted Reproductive Treatment Act 2008 was passed through the Victorian Parliament

17B Birth registration of child conceived by a treatment procedure

(1) If a birth registration statement specifies the child was conceived by a donor treatment procedure, the Registrar must mark the words "donor conceived" against the entry about the child's birth in the Register.
(2) Subject to subsection (3), when the Registrar issues a certificate certifying particulars contained in an entry about the birth of a person conceived by a donor treatment procedure, the Registrar must attach an addendum to the certificate stating that further information is available about the entry.
(3) The Registrar must not issue the addendum referred to in subsection (2) to any person other than the person conceived by a donor treatment procedure named in the entry.

This amendment to the Victorian ART Act is a step in the right direction. All donor conceived people deserve the dignity of knowing the truth about their conception and identity. The only way to ensure that all donor conceived people know the truth is to have their birth certificates reflect that truth.

Secrecy and Openness in Donor Conception.

"Secrecy hinders the dissemination of information about DI to the public, and hence many people remain unaware of the factors involved."[32]

When the DCSG was formed in 1993 donor conception was still surrounded in secrecy. There was still a great many doctors suggesting to their patients that no one needed to know how their children were being conceived and in this they included the children.

The DCSG set out to change things. We took every opportunity to present to the world how important it is for the welfare of families that parents are open and honest with their children about how they came into the world.

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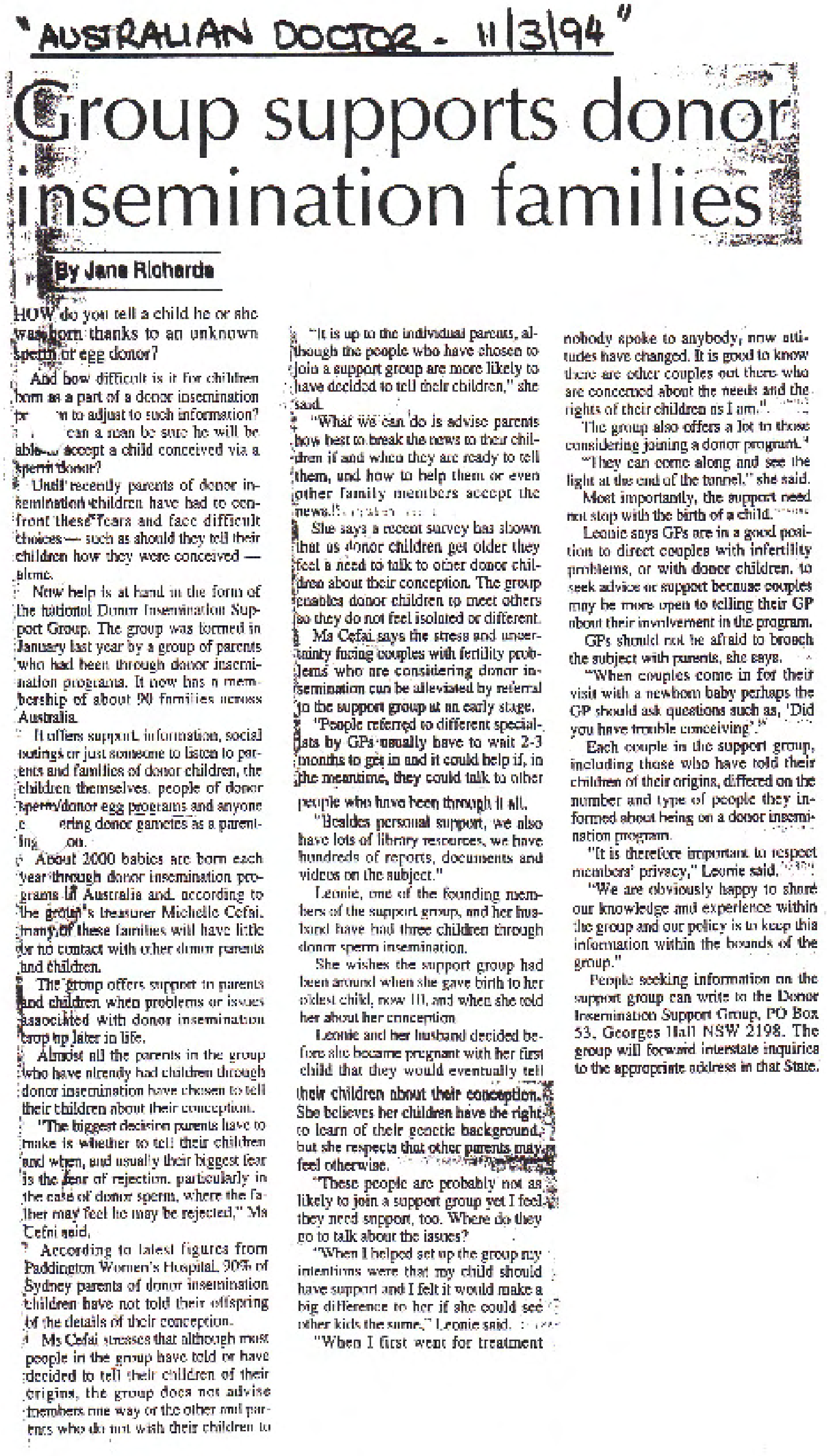
[32] Daniels & Taylor *"Openness in Donor Insemination"* Politics & the Life Sciences, Beech Tree Publishing 1993.



"AUSTRALIAN DOCTOR - 11/3/94"

Group supports donor insemination families

By Jane Richards

HOW do you tell a child he or she was born thanks to an unknown sperm or egg donor?

And how difficult is it for children born as a part of a donor insemination pr[illegible] to adjust to such information? [illegible] can a man be sure he will be able to accept a child conceived via a sperm donor?

Until recently parents of donor insemination children have had to confront these fears and face difficult choices — such as should they tell their children how they were conceived — alone.

New help is at hand in the form of the national Donor Insemination Support Group. The group was formed in January last year by a group of parents who had been through donor insemination programs. It now has a membership of about 90 families across Australia.

It offers support, information, social outings or just someone to listen to parents and families of donor children, the children themselves, people of donor sperm/donor egg programs and anyone c[illegible]ering donor gametes as a parenting [illegible]on.

About 2000 babies are born each year through donor insemination programs in Australia and, according to the group's treasurer Michelle Cefai, many of these families will have little or no contact with other donor parents and children.

The group offers support to parents and children when problems or issues associated with donor insemination crop up later in life.

Almost all the parents in the group who have already had children through donor insemination have chosen to tell their children about their conception.

"The biggest decision parents have to make is whether to tell their children and when, and usually their biggest fear is the fear of rejection, particularly in the case of donor sperm, where the father may feel he may be rejected," Ms Cefai said.

According to latest figures from Paddington Women's Hospital, 90% of Sydney parents of donor insemination children have not told their offspring of the details of their conception.

Ms Cefai stresses that although most people in the group have told or have decided to tell their children of their origins, the group does not advise members one way or the other and parents who do not wish their children to

"It is up to the individual parents, although the people who have chosen to join a support group are more likely to have decided to tell their children," she said.

"What we can do is advise parents how best to break the news to their children if and when they are ready to tell them, and how to help them or even other family members accept the news."

She says a recent survey has shown that as donor children get older they feel a need to talk to other donor children about their conception. The group enables donor children to meet others so they do not feel isolated or different.

Ms Cefai says the stress and uncertainty facing couples with fertility problems who are considering donor insemination can be alleviated by referral to the support group at an early stage.

"People referred to different specialists by GPs usually have to wait 2-3 months to get in and it could help if, in the meantime, they could talk to other people who have been through it all.

"Besides personal support, we also have lots of library resources, we have hundreds of reports, documents and videos on the subject."

Leonie, one of the founding members of the support group, and her husband have had three children through donor sperm insemination.

She wishes the support group had been around when she gave birth to her oldest child, now 10, and when she told her about her conception.

Leonie and her husband decided before she became pregnant with her first child that they would eventually tell their children about their conception. She believes her children have the right to learn of their genetic background, but she respects that other parents may feel otherwise.

"These people are probably not as likely to join a support group yet I feel they need support, too. Where do they go to talk about the issues?

"When I helped set up the group my intentions were that my child should have support and I felt it would make a big difference to her if she could see other kids the same," Leonie said.

"When I first went for treatment nobody spoke to anybody, now attitudes have changed. It is good to know there are other couples out there who are concerned about the needs and the rights of their children as I am."

The group also offers a lot to those considering joining a donor program.

"They can come along and see the light at the end of the tunnel," she said.

Most importantly, the support need not stop with the birth of a child.

Leonie says GPs are in a good position to direct couples with infertility problems, or with donor children, to seek advice or support because couples may be more open to telling their GP about their involvement in the program.

GPs should not be afraid to broach the subject with parents, she says.

"When couples come in for their visit with a newborn baby perhaps the GP should ask questions such as, 'Did you have trouble conceiving'."

Each couple in the support group, including those who have told their children of their origins, differed on the number and type of people they informed about being on a donor insemination program.

"It is therefore important to respect members' privacy," Leonie said.

"We are obviously happy to share our knowledge and experience within the group and our policy is to keep this information within the bounds of the group."

People seeking information on the support group can write to the Donor Insemination Support Group, PO Box 53, Georges Hall NSW 2198. The group will forward interstate inquiries to the appropriate address in that State.

The Australian 23.4.98

Donor children deserve to know truth

THE following points need to be made in response to the article Dear Dad (Whoever You Are . . .), which appeared in *The Australian Magazine* (18-19/4):

- Medical professionals should not be treated as experts on the long-term effects of sperm-donor inception. Of the five doctors you quoted not one has done research on families with donor-conceived children. My partner and I, as parents of three children born by donor insemination, have more experience than those doctors will ever have.
- Why is it that doctors get to ponder the ethics of whether or not to contact a past donor? What training do they have in what is an essentially "social" area? What rights do doctors have to deny a donor the chance to say "yes" or "no" to contact with a donor offspring?
- The fact that most parents of donor children have not told their children of their conception is probably not that they don't want to, but that in the past doctors encouraged secrecy. Unlike adoption, where there are good long-term support services to help parents in telling their children, nothing exists like that for donor families.

We are telling our three children the facts of their conception because we love them, want them to be raised in an atmosphere of openness and honesty and we respect their rights as people to know the truth about themselves.

PATRICE AND CAROLINE LERBACH
Lalor Park, NSW

WHAT is the real extent of infertility? How are those who are experiencing infertility coping with the pain they must feel if they are yearning for children?

These questions emerge from Roy Eccleston's excellent article Dear Dad (Whoever You Are . . .).

As a former worker in the adoption and foster-care field, I ache for those couples who grieve for the children they cannot have.

But when we reflect on the negative outcomes of post-adoption practices, are we as a society acting responsibly with regards to reproductive technologies — or are we once again creating generations of people who do not know who they are or from where they came?

COLLEN A. FITZPATRICK
Director,
Lutheran Community Care, SA

I AM struck by the irony of the practice that men are paid for sperm donations. In Australia, to my knowledge, we do not offer or accept payment for any other human tissue or organs. We give blood, bone marrow and often tissue donations. So how is it that men are entitled to payment for sperm donations? Even if the claim is that it is not for the actual tissue, but for the inconvenience or bother, one is hard put to think of a tissue more easily obtained. Donating blood, for example, requires much more invasiveness.

If, instead, it's about human reproductive tissue, why don't women receive payment for donor eggs where the effort and inconvenience of invasiveness is infinitely more.

What has happened to the seminal notions of altruism and goodwill?

M. C. GALE
Launceston, Tas

We have continued this ever since. While we have gone some way in de-mystifying donor conception in the eyes of the public and have helped thousands of donor conceived families it will always be a subject that is not openly spoken about while the country as a whole refuses to deal with the long term effects of denial of identity.

> *"Even though the need to face reality took time to win approval in adoption practice, today it enjoys a broad consensus. The opposite is usually true in regard to donors in medically assisted conception. In this area substantial efforts have been made to conceal realities, through secrecy, donor anonymity and even the destruction of medical records."*[33]

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[33] Knut W. Ruyter - Centre for Medical Ethics, University of Oslo, Norway. Pge 185, *Creating The Child - The Ethics, Law and Practice of Assisted Procreation"* Edited by Donald Evans, Martin Nijhoff Publishers, 1996.

The protection and privacy for the adults involved in DI is complete. It is imperative that questions are asked about whose interests are actually being served by this practice of secrecy."[34]

Secrecy also means that members of the helping professions such as social workers and counsellors and indeed the medical practitioners themselves have been largely ignorant of the problems of donor conception to a large extent and so are not in such a good position to offer guidance and help.

"I want to suggest to you that one of the main arguments for advocating greater openness in this area is not so much to do with the rights of children, although I wouldn't want to deny these, but rather that when you have secrecy operating you stand a very high chance of damaging family relationships. In other words, secrets in families are invariably damaging. Secrets impede intimacy and place limits on communication, keeping a secret adds a pressure or burden to the persons who are keeping that secret."[35]

The fact that tens of thousands of prospective parents were advised by medical professionals to never tell their children the truth about their conception has meant that parents have carried a huge burden of secrecy.

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[34] Daniels & Taylor *"Openness in Donor Insemination"* Politics & the Life Sciences, Beech Tree Publishing 1993.

[35] Ken Daniels *"Gamete Donation and Its Impact on Relationships"* Presentation to the Western Australian Reproductive Technology Council 1996.

Richard tells how he felt after agonizing over whether to tell his child about her conception using donor sperm and then finally telling her.

> *What a weight I feel lifted off me now there are no more secrets.*
>
> *We can build on trust now that all the cards are on the table.*[36]

Openness allows parents to more easily seek out support among family, friends and others, such as support groups of people going through similar experiences. Openness can be directly beneficial to the couple themselves, but, people need guidance in openness and we will discuss this further in our section on support and counselling.

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[36] Pge 134. *Experiences of Donor Conception – parents, offspring and donors through the years* Caroline Lorbach 2003 Jessica Kingsley Publishers

Record Keeping and Access to Information

How good has the record keeping in donor conception been?

The truth is we really do not have an accurate picture of the way that clinics have kept records in the past. The reason for this lack of accurate information is because of the way in which fertility clinics are regulated. This will be gone into in some depth in a later section.

What we do know from evidence of our group and its members is that the quality of record keeping varies a great deal from clinic to clinic. This mother wrote to us in 1997 about her request for information for her son.

> *My family consists of one adopted child aged 9 yrs and a donor child aged 5 yrs conceived at Dr ………'s clinic.*
> *Our adopted child came to us at the age of 5 weeks with a booklet entitled 'MY STORY' containing non identifying information such as birth parents hobbies, interests, medical history and a personal letter from his birth mother. If my adopted son wishes to (when he is 18 yrs old) find his birth parents, the records exist for him, to do so. I believe this is his right.*
> *As any parent would, I want my children to have equal opportunities in life. This is why I felt the need to contact Dr …..'s clinic in search of more non-identifying information about my son's donor. I was told that all this information had been 'destroyed'. My 2nd child will never have the opportunity to trace his biological roots. This should never have happened.*

I understand (by law) that Dr ….. should still have my childs donor records. If these records, by any chance, do exist can you make sure they are kept available for my child at least till he is 18yrs of age (year 2010).
Dr ……. Should be more responsible in considering the lives he is helping to create.[37]

The reason that this mother believed that the clinic should legally still have the records is that she requested information well within the minimum of seven years from the date of the last entry that NSW medical records had to be kept.

This parent made a statutory declaration (see appendices) as part of an investigation by the NSW Health Care Complaints Commission against a doctor who you will see in later documents was fined for not keeping accurate records but still allowed to keep practicing.

The next parent tried to find out information about her two son's donor/s (she did not know if the same donor had been used for both conceptions) and was told that the clinic had destroyed the records.

1. *Was …. And ….'s donor the same person. (yes)*
2. *Is there any more information that she could provide me on the donor other than what was given to me from … - (said Records have been destroyed. I am waiting for … to provide me with the donors code)*
3. *Did the letter that I wrote approximately 5 years ago to the donor via … get forwarded onto him, (still pending an answer)*

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[37] See appendix 5 for full letter plus statutory declaration written by this parent at the time.

4. *Could …. And …. Write out some questions to the donor and would the Infertility Clinic please forward these questions on. (apparently not due to destruction of records)*
5. *How many half brothers and sisters do the boys have that are known to have been conceived from sperm donated at ….. by the boy's biological father. – (at least 5 most of who would be siblings. Waiting for …. To advise us of sexes and how many of these children are from the same family)*[38]

There is a serious problem in what happens to the records of clinics that close and private doctors who once performed donor insemination and have now retired or are deceased. We have been told by the FSA that this problem has been solved by other clinics agreeing to take over records if a clinic closed. But that is only a recent change to their code of practice and does not apply to older records. Our group knows of a number of doctors who have held onto their records once they retired or in some cases the records are being held by descendants of the doctors.

I've tried contacting the clinic, but it's been sold and the doctor has retired, so it's been really hard to get any information.
I'm constantly looking at other young people with similar features to me, wondering if we're related. When and if I meet my donor, I'd love to find out if he's been thinking about me. I hope so." [39]

One such retired doctor wrote to a member of our group informing her of the destruction of the records that would have let her know who her donor was.

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[38] See appendix 6 for full letter

[39] Cleo 21. Marie Claire Magazine "Secrets & Lies, Donor daughters searching for the truth" 2005

> *As I said to you in my previous letter the program was set up in such a way that even we could not be certain of the father of a particular child as DNA testing (then not available) would be the only way. This came about as more than one donor was used in any conception cycle. Because of the age difference between you and …., the same donor would not have been in the program.*
> *With the closure of the program at the introduction of compulsory frozen sperm the donor records were pulped. So you can see there is no way of knowing or finding that part of your conception.* [40]

The DCSG spoke with the Fertility Society about the matter of record keeping by this doctor, while they were able to obtain answers to our questions from the doctor in question we were left wondering how accurate the information was that the Doctor had given to the inquiries that were made by some donor conceived people.

There are moves in New Zealand for the Registrar of Births, Deaths and Marriages (where the Human Assisted Reproductive Technology Register resides) to take up old records. While they admit there are clashes with their privacy laws they do not feel that these are insurmountable.[41]

A continuing theme in many of the phone calls, emails and letters we get from recipient parents is that there is no set of rules for how to get information about their child's donor; the letter below outlines some of the efforts one parent was going to in order to try and get information.

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[40] See appendix 7 for full letter
[41] See Appendix 8 for letter

> *Phoned both clinics & not very encouraging.*
> *Clinic1- Secretary away. I need to find the donor code which is on my file stored "somewhere"- Spoke to (scientist) who seemed very doubtful they'd be able to locate the file, but suggested I speak to the secretary when she returns from leave.*
> *Clinic 2 - Spoke to (nurse) who was very helpful, but says that identifying information was not kept at that time (to protect the anonymity of donor etc). But she said she'd dig up my file – see if any physical characteristics were kept. Has been a week, but I haven't heard back yet. Will follow up next week.*
> *PS. Sorry this has been sitting in my bag for a week …….Good news – got donor code for (son) from (Clinic 1). Will write a letter this week. (told them I was thinking of having another baby & wondered if they had any sperm left from (son's) donor – just slightly stretching truth – but it's amazing how quickly (24 hrs) they can produce the info if $$ are at stake.*[42]

Currently no one knows how many donor conceived people have been created in Australia. This is because until 2002 infertility clinics were not required by their own rules of accreditation to send details on births by donor insemination to the National Perinatal Statistics Unit.[43] There have been collections of data on Assisted Reproductive Technology since the first IVF baby was born in Australia in 1979 but these figures never included donor insemination they only included figures on conceptions, miscarriages and births where they involve IVF, GIFT and other 'high-tech'

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[42] See appendix 9 for full letter

[43] Information available from http://www.preru.unsw.edu.au/PRERUWeb.nsf/page/Assisted+Reproduction+Technology+Reports

methods of conception. The reason given for this is to track the incidence of long term effects of these ARTs.

The lack of information on the number of donor conceived people in Australia has always concerned the DCSG but it does not seem to concern some doctors as demonstrated here in an ABC television interview:

> *JANINE COHEN: Anonymous donor sperm has helped many Australian families have children. But exactly who and how many have been conceived in clinics like this, nobody knows. Are there any records recording who donor children are in Australia and how many there are?*
>
> *PROFESSOR DOUGLAS SAUNDERS, RTAC CHAIRPERSON: No.*
>
> *JANINE COHEN: Are you not concerned about that?*
>
> *PROFESSOR DOUGLAS SAUNDERS: No, not particularly, no.* [44]

Without accurate figures it is very hard to research the long term effects of donor conception in families.

We would suggest that donor conception has some very long term effects, some may be similar to more ‘high-tech’ methods in that they involve the use of drugs to hyper stimulate egg production which may

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[44] Australian Broadcasting Corporation Four Corners Transcript Janine Cohen's report, "Secrets of the Fathers". 24/10/2005. http://www.abc.net.au/4corners/content/2005/s1489657.htm

have long term effects on women, but, others are psycho-social. Just because the long term effects are not medical but social in nature does not make them any less important and potentially damaging. Not having the true figures on donor conception can hamper research being done on an area that desperately needs to be studied.

Some recipient parents have been given a small amount of information on their child's donor, here is a quote from a couple in our group from 1997; they still have no more information to provide their now 18 year old son:

> *"As parents of a five year old donor son we now face the challenge of attempting to provide sufficient information to our son to satisfy his need regarding his background when we only have scant facts of the donor. Even the scant facts held by our clinic are difficult to obtain and even worse, inconsistent. We have been given different eye colour and nationality with two separate enquiries for the donor.*
>
> *Further our enquiries have shown that the donor's mother had colon cancer. Our family GP advises that the extent of risk for our son developing this cancer depends on the age of the mother at the time of developing the cancer and the result of medical checks on the donor. We have no way of ever knowing these facts as the clinic does not carry out any medical follow-up questionnaires.*
>
> *It is essential that the clinics be made to store donor information in a central register. Further we strongly urge you to allow donor offspring the right to have identifying information similar to the Adoption legislation."*[45]

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[45] Verbal communication with DCSG 1999

Apart from the added burden this couple has had in being unable to answer the questions of their growing son they also have understandable doubts about the accuracy of the information they were being given. Similar concerns have been raised by many of our members.

There has been no recognized policy of how, when or what information may be gotten from clinics by parents or donor conceived policy. In the 1990's when our group first formed we had members who were the first parents to ever have requested donor information from clinics. It was not easy for them as they were going into uncharted waters. The clinics had no policies for what do to about requests like this and most had no idea how they should deal with the requests. The reactions parents were met with when requesting information from clinics varied from antagonistic to puzzlement through to a complete lack of understanding as to why a parent would want this information. Those pioneering parents had to be quietly determined and most of them did manage to get some information if it still existed.

We would like to state here that even today most parents are quite fearful of asking for information and even more fearful of asking for communication with a donor. Clinics have still not realized what a position of power they are in and how this can make parents and donor conceived people feel.

We have mentioned before a case of a doctor being taken to the Health Care Complaints Commission for not adequately keeping records. The excerpts from letters that follow were part of the correspondence that a parent had in regards to the case. She had been trying to get information about the egg donor who helped to conceive her twins.

> *It took the clinic nearly 6 months to get back to me and that was after I sent them a letter about 2 months ago. Leonie, I know something is not right with that clinic, They must have lab reports from the day when the twins were conceived and we know that one of the recipients of egg retrieval on that day must have been the donor. Are they hiding something?? What if the donor doesn't even know she was one?? If I did not have the support of you and your group I don't know how I would cope.*[46]

As she felt she was receiving no help from the clinic she turned to the NSW Health Care Complaints Commission. The full letters of what happened at the investigation are included in our appendices. The Doctor in question and his wife (also a doctor at the same clinic) were both found guilty of failing to make and preserve appropriate documents of an egg donor and participating in a policy of denying the existence of records to patients when they knew that some records did still exist. The Commission was unable to determine conclusively whether or not records of this patient's egg donor did in fact exist. After the case was heard by them she wrote to the then NSW Health Minister Craig Knowles.

> *I am writing to you about a very important matter concerning my two children born in 1991.*
>
> *In 1997 I returned to the I.V.F. clinic where they were conceived to find*

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[46] See appendix 10 for full letter

> *out some medical and non-identifying information for them. After several attempts to try to get the clinic to help and receiving none, I was unhappy about this so I turned to the Health Care Complaints Commission. After eighteen months I was called as a witness in March this year along with four other families, to give evidence, at the NSW Medical Board, with the Professional Standards Committee and the doctor. I am not happy with the outcome of this and neither is my husband, please see attached verdict.*
>
> *I feel that the penalty is inappropriate. This I feel is just a slap on the wrist. I wonder why he wasn't required to pay for advertisements in major papers for past donors at the time of my treatment to come forward and do a DNA test, as he is responsible for the destruction of the donors and my records. He is in breach of good medical practice, proven by the attached document, by not maintaining (sic) medical records.*
>
> *How is it that he is still operating a fertility clinic? Is anyone checking that he is keeping records today? Who is going to answer my children's questions about their personal, genetic and medical information? Other clinics have egg and sperm donor records, how can it be that Dr ……… could make his own laws? Where do I go from here? My children are at a disadvantage. Who will make Doctor …….. accountable for the destruction of these important and crucial records? What if my children form a relationship with a half sibling? or worse still, what if the donor was not even aware that she was a donor?*[47]

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[47] Ibid

The Health Minister was of no help and this mother could still not get any information with which to answer her children's questions. What hope do people have against a culture of secrecy and a state government that refuses to get involved?

The DCSG asked the Fertility Society's Reproductive Technology Accreditation Committee that oversees accreditation of all fertility clinics how they would handle such complaints and they responded that RTAC "is unable to deal with individual patient complaints". They suggested that these sorts of complaints should be taken to the clinicians involved and if that did not resolve the matter then he suggested that ACCESS[48] may be of assistance. [49]

This policy is still the same today. On the ACCESS website there is a description of the patient complaint mechanism which state:

> *ACCESS appoints consumer representatives to RTAC. If you feel that any guidelines have been breached, please feel free to contact them, sending copies of your letters endeavouring to resolve your concerns. All contact with RTAC is confidential. Your name will not be divulged without your consent.*
>
> *Please note that it is not a function of RTAC to deal with patient complaints and RTAC has no formal mechanisms for processing individual complaints about treatment. Information provided to RTAC will be used only in the context of compliance with guidelines.* [50]

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[48] ACCESS is a nationwide infertility support group there is further mention of this group later in our submission

[49] See appendix 11 for full letter

[50] http://www.access.org.au/about_access/clinic_accreditation/health_care_complaints

So as you can see if a patient, donor or donor conceived person has a complaint against a clinic it is very hard for them first of all to find out how the complaint can be resolved and then get a satisfactory resolution.

There is a misconception out there that most donor conceived people are still very young but you would have seen at the beginning of our submission that donor conception is a very old practice. Our group knows of donor conceived people in Australia in their fifties and we are sure that there are some even older than this.

Our group has had contact with many donor conceived people trying to find out information about their donors.

This young woman was one of the first adult donor conceived people in our group who was trying to get information. Even after years of trying and being the subject of a number of newspaper articles she still has no information about him. She was seeking basic information to help her to form her identity and wanted to know such things as:

> *My father's medical history and that of his family*
> *My father's racial origins and his physical characteristics*
> *An account of his life experience.*
> *Is he still alive? Are my grandparents still alive?*
> *Information concerning half-siblings born through my father's donated genetic material. Number of half-siblings, their age, gender and whereabouts.*
> *Information concerning children born to my father through marriage/s and/or relationships. Number of half-siblings, their age, gender and*

> *whereabouts.* [51]

She also wrote to members of the Victorian Parliament

> *I believe that access to information concerning birth origins should be the birthright of all people in our community. DI off-spring's rights to information should be equal in law to that of adult adopted persons who since 1984 have been able to access identifying information concerning their birth parents and other relatives.* [52]

It is because of letters like hers and the work of many other people including members of the DCSG that Victoria became the first jurisdiction in Australia (and the third in the world after Sweden 1985 and Austria 1992) to enact legislation (Infertility Treatment Act 1995) that gives donor conceived people the right to identifying donor information. Unfortunately it didn't help this young woman as the law was not made retrospective.

The following are excerpts from letters written about the search that a young man made (with the help of his mother) to find information about his donor and hopefully have the opportunity to meet him. It took them two years before they reached a conclusion.

> *I am almost twenty years old and for most of my life I have had feelings that the father that I grew up with was not my biological father. Since the age of ten I repeatedly asked my Mother to tell me the truth about my birth, I was constantly aware that something was not quite right. At Christmas last year my Mother gave me the information that I had been asking for – she told me that I was conceived through donor*

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[51] See appendix 12 for full letter
[52] Ibid

> *insemination because of my social father's infertility. It is my understanding that my Mother's wish was to tell me from a very young age but was restricted by the information given to her at the time of attending the fertility clinic at (hospital). This was that all information would be destroyed and their advice was not to tell the child because "it is not like adoption, there will never be anyway of your child finding out, therefore he will always be left wondering".*[53]

This mother and son then waited for the clinic to contact them but heard nothing. While they were waiting they saw a TV segment about a clinic in their city recruiting donors.

> *It made me wonder if the information they are giving to donors allows them to make informed choices. (Son) saw the segment and jokingly said he might donate. This is an interesting prospect isn't it? What if one of his siblings was infertile and attended the fertility clinic for treatment, he could become the father of his sister's child!! Far fetched but remotely possible. I wonder if the clinics have any policy guidelines about progeny of donors becoming donors themselves.*[54]

Finally they were informed that the clinic had passed the son's letter onto the donor. And not long after they had some good news.

> *I would just like to briefly let other members know that (son) has had the wonderful goof fortune to be able to meet with and get to know his donor…………….. we have been blessed with a donor who is a very responsible and considerate person who decided that (son) had a right to information about his genetic and biological background.*[55]

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[53] See appendix 13 for full letter

[54] Ibid

The next two letters are from a mother and her son trying to get basic information; they again highlight the fact that these requests for information are often done as a family.

> *I have always been honest with (son) about the circumstances of his birth and it is only in the last 2 years that he has mentioned that he would like to know more about his donor father. At present, he mainly wished to find out more about his history.*
> *As (son) is now over 21 years of age he will include his own letter with my application to obtain my full medical records and all non-identifying information.*[56]

> *Could you please help me obtain my records regarding my donor father. I would like to know as much information as I can regarding his history. It would help me to obtain medical history, such as any family history of condition that may develop later in life. I would also like to know if his history has been updated in the past few years, which would then include these facts. I would like to know of other half brothers or sisters conceived in the same way and what years they were born? Did he have any other natural children at the time and afterwards?*[57]

The emotional toll on donor conceived people cannot be underestimated; they struggle with the thoughts that there are people out there who are closely related to them that they will never know; that there are people who know this information but refuse to give it to them. The young man who write the letter above felt that he was just considered a

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[55] Ibid
[56] See appendix 14 for full letter
[57] Ibid

product by the fertility industry and had a barcode tattooed on the back of his neck.

Other donor conceived people feel frustration and sadness.

> *I have made no progress with my own personal search for knowledge of my biological origins. I guess I am skeptical that there will ever be light at the end of the tunnel. I am afraid that if I pursue this search too vigorously, and learn nothing, that it would only make me feel a little worse about having missing pieces in the puzzle.*[58]

There are some donor conceived people who have also tried to make people understand the need for change such as this young man who wrote to the then Attorney General Philip Ruddock.

> *I am searching in vain for information about my donor. I cannot access the records relating to my conception as they are the property of the doctors; the donor was anonymous (i.e. his information is not able to be released because I assume he signed a statement which guaranteed his anonymity); and Tasmania has no voluntary register in which donors and donor conceived people can put their names down if they wish to be found.*
>
> *I think this situation is discriminatory. While it infringes no current Australian law, it is time for those such as yourself who are interested in the issue of discrimination to investigate and report on this issue and rectify it. This is because I am placed in a greatly disadvantaged position in comparison to other Australians who do know their biological lineage. I have no idea if I have latent hereditary diseases*

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[58] See appendix 15 for full letter

> *from my donor's side or whether I am forming a relationship with my half-sibling. This is not to mention the lingering sense that a part of my identity is incomplete.*[59]

This letter raises a very important point. Clinics create two different types of records that of the donor and that of the recipient mother (occasionally father as well). There is no record created for the donor conceived person. This means that donor conceived people are always reliant on the will of a clinic to access information because they cannot access records of there own using Freedom of Information because they have no records.

Some donor conceived people have had to go to extreme lengths in order to try and find information about their donor.

The excerpt below is from a letter that was sent to a large number of the Faculty of Medicine graduates for the years between 1977 and 1980. All she had been told by the clinic was that her donor was a medical student at the University of NSW.

> *I would like to make contact with any medical students who donated sperm in October 1977 either at the direct request of Dr…….. who was a lecturer in Gynaecology & Obstetrics at the time or through another source.*
> *I am a 23-year-old offspring of one donation and I would like to complete my medical history as well as satisfy the natural curiosity that I have about my donor.*
> *Please be assured that I am not looking for a father or in having an on*

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[59] See appendix 16 for full letter

going relationship with my donor – I already have two loving parents.[60]

She had been informed by the clinic that no records had been kept at the time of her conception. She received some lovely replies from many of the men wishing her luck in her search but she never found her donor.

Other donor conceived people have resorted to going to the media in the hope that their donor might recognize themselves in the small amount of information that the they have about their donor.

The following pages are from New Idea magazine. Myfanwy came to our group in the hope that we could help her in her search. Her only hope was to go to the media so the group put her in touch with a journalist that would handle the story sensitively. When the original article was published in a national newspaper along with a photo, Myfanwy's donor knew immediately that she was his biological daughter and contacted us so that he could be put in touch with her. Meeting her donor has answered many questions for Myfanwy. The following article tells more about Myfanwy's story.

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[60] See appendix 17 for full letter

Meet

A modern day miracle saw a sperm donor meet and befriend his children

One big happy family: Michael with his children.

What is it like to meet a man whom you've had two children with, but never met? Mary Walker says without irony: 'It seemed extremely natural.'

Mary Walker's two children Myfanwy, 21, and Michael, 18, were both born via artificial insemination. But in an incredible family reunion, they recently met their biological father, Michael Linden, at the Melbourne home he shares with partner Lia Vandersant and her son Liam.

This once-unthinkable reunion occurred after Mary finally confessed to her children the secret she'd kept for two decades.

Mary and her husband were advised by medical practitioners not to reveal the truth about their children's conception.

'I have had to struggle with keeping this secret and it has torn me apart,' Mary says. 'You want to tell your children, but you have to consider the consequences and impact on everyone involved.'

Now that the secret is out, Mary says she feels 10 years younger.

Myfanwy says when she found out in March last year, the news came as no great surprise.

'I accepted it and just wanted to find my biological father,' she says.

Michael didn't find out until last July. But his initial reaction was confusion and apprehension.

'I backed off at first. I wanted to find out what my biological father was like before I met him. It was hard to come to grips with,' he says.

Myfanwy set to work to find her biological father with the assistance of the Donor Conception Support Group – an Australia-wide organisation.

It was no easy task. The hospital where Michael Snr donated his sperm was not allowed to reveal his identity.

Fortunately, Myfanwy's desperate search for her biological father was helped along by some old-fashioned publicity.

A few days before attending a forum in Sydney organised by the Donor Conception Support Group, Myfanwy was interviewed by a national newspaper.

The article carried the brief profile of her donor that Myfanwy had been given by the hospital.

> 'I looked at the picture and knew instantly it was my daughter'

Meanwhile, on the same day, Michael Linden was sitting reading the paper at home in Melbourne, when he was overcome by shock and excitement.

He stared at the young girl on the front page of the newspaper and instinctively knew who she was.

'I was sitting there looking at the article and I read the first paragraph and went: "Hell, that's me!"' Michael says.

'Then I looked at the picture and knew instantly it was my daughter. I didn't know what to do – I just had to think for a while.

'But Lia, my partner, got straight into it. She rang the support group and said it was me.

'We used to crack jokes about all these kids turning up and it had finally happened,' he beams.

Back in Sydney, Myfanwy was sitting at the airport waiting to go home to Melbourne after the forum when a member of the support group gave her Michael's details, including his phone number.

'I sat on the plane for an hour just staring at the piece of paper. I couldn't believe it,' Myfanwy says.

'It's so rare for people as old as me to find their biological fathers – this was a dream come true.

'I finally had the opportunity to find out about my heritage.

'For years you're told your family is half this and half that, but then when you're told that your father isn't your father, you lose half your identity.'

After a long telephone conversation with Myfanwy, Michael knew it was time to meet his children.

'I just asked her: "When are you coming to meet me?" and that was it,' he says.

Adds Myfanwy: 'I was so nervous it was making me sick, but just seeing Michael – it was like seeing an old friend who you hadn't seen for a long time. I finally knew the other half of me.'

But Myfanwy's brother Michael wasn't so sure. He wanted to let the reality of it sink in before jumping aboard.

It was on his 18th birthday – one week after Myfanwy's meeting with her father – that he finally decided to break the ice.

It was also the first time that Mary would meet the man who enabled her and her husband to have two beautiful children.

'At the start I was a bit wary, but I was always going to meet him,' Michael Jnr says.

'If anything, meeting him was more amazing than I had imagined. Now I can finally ask him things about my physical appearance. It's great.'

His father adds: 'It's like a movie or a fairytale – terribly real, but extremely unusual.'

Now everyone agrees that Mary did the right thing when she unburdened her secret, and it's the best thing that could have happened.

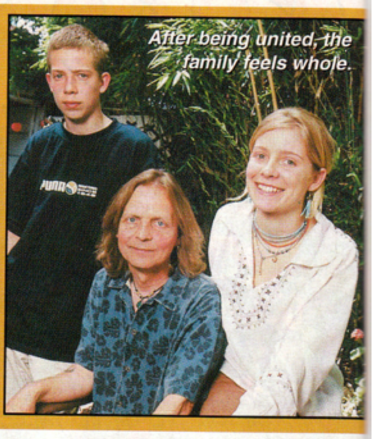
'It's completely wrong not being told how you are conceived,' Myfanwy says. 'I know that I have three half sisters out there whose ▶

Meet the parent

The father: Michael Linden at age six.

The son: Michael Walker at age three.

The daughter: Myfanwy Walker at age five.



After being united, the family feels whole.

◀parents are probably keeping it a secret from them.

'They may eventually find out, but it could be too late. I say this to the mothers and fathers of other people who have been conceived in this way but have never been told.

'Look at what happens once you find out! It's not a bad thing.

'And donors need to go back to the hospital they donated to. Don't deny children the right to know their true identity.'

Myfanwy says sperm donors are extremely undervalued.

'People think that once a man has donated sperm he can just walk away, like giving a kidney or blood. But the sperm becomes a human with wants and needs and this is not taken into consideration,' she says.

'People who are not donor-conceived don't understand the need to find out about yourself. Before this, you only half know who you are.'

No one can deny that this family reunion is a modern day miracle.

It's a miracle that Myfanwy and Michael got told, that Michael read the newspaper and that Myfanwy and Michael were born at all.

Michael, Lia and Liam met up with Mary, Myfanwy and Michael for Christmas and are now in constant contact. 'It's like an extended family,' Myfanwy explains.

Mary urges other parents to tell their children who they really are. She says she would never have been able to forgive herself if she hadn't confessed all to her children.

'I feel so much better it's all out in the open and I don't have to watch what I say,' she says.

'A weight has been lifted off my shoulders. Life couldn't be better!'

By Erin McWhirter
Pictures: Drew Ryan

- *Contact the Donor Conception Support Group on (02) 9724 1366.*

A child's right to know V donor anonymity

About 10,000 to 15,000 Australian children have been conceived using sperm donors. Only those conceived in Victoria after 1998 have the legal right to know who their father is when they turn 18.

These children are the first to benefit from the moral shift to putting the child's right to know before the donor's right to anonymity. Those children of sperm donated before 1998 and in other Australian states can only ask the clinic to request contact from their anonymous fathers on their behalf (if they can be traced) or make public pleas for them to make contact.

While Myfanwy and Michael's genetic father wanted to meet them, some donors don't want to know. One anonymous sperm donor even told a newspaper that he'd consider legal action 'if I was ever outed'.

Caroline Lorbach, consumer advocate for the Donor Conception Support Group and herself the mother of three donor children, doubts most donors would be so against meeting their children.

'It's human curiosity to know. Donor rates in Victoria have not plummeted since the introduction of the donor registry in 1998. In New Zealand, where clinics decided to accept only donors prepared to be identified, one clinic's donor rates increased after that decision.

'Donors are now counselled on the consequences of their donation, and in states other than Victoria that anonymity is no longer a given in the future.'

In NSW, the organisation Sydney IVF prefers donors to let themselves be identified to minimise problems arising from anonymity.

But Dr Francoise Shenfield, a UK-based academic, defends anonymity.

'There's nothing to say children have to know their genetic parents and there's no evidence that it's important,' she recently told the 17th World Congress on Fertility and Sterility in Melbourne.

She also argued that the law shouldn't take away the right of parents of IVF children to keep the exact details of their child's conception a secret.

Caroline refutes this. 'If you say to a parent it's their right not to tell, where is children's right to know – their opportunity to make a choice?'

There are currently no plans for a review of legislation that would require past sperm donors to reveal their identity to their children.

Two sisters contacted our group a number of years ago for help in how they could go about getting information about their donor. Their story was part of the ABC Four Corners programme “Secrets of the Fathers” in 2005. Here are some excerpts from the programme.

JANINE COHEN: But history shows that even the most loved and well-adjusted of children can still have a desperate longing to know who their donor is. Twins Helen Edel and Anne Smee went on a 20-year detective hunt for their biological father.

*

JANINE COHEN: The sisters were born in March 1960, but didn't know until 1980 they were donor conceived. When they did learn the family secret it fuelled a desperate desire to know more. Who was their biological father? Did they look like him? Were there any genetic illnesses in his family? They asked their mother for more information.

*

JANINE COHEN: All their mother could tell them was that she visited the Balmain Hospital and the name of the specialist that treated her. His name was Dr John Doherty.

ANNE SMEE: I rang up the doctor myself, personally. And said, "Is there any possible chance I could have a photo of our biological father?" He got upset and a bit irate. And said, "Don't be ridiculous." And screamed at me and said goodbye.

HELEN EDEL: She got terribly upset because he had no... He had no inkling that this was our whole meaning in our life. And how dare he dismiss us as if we're being frivolous?

*

JANINE COHEN: Three years after discovering they were donor conceived, the sisters persuaded their mother to ask Dr Doherty for any records he'd kept. Then Anne Smee followed up with a letter.

HELEN EDEL: Well, my sister wrote a letter to Dr Doherty asking, "Have you got a photograph? Just a photograph or a bit of history of who he might be, of where we came from... We don't really want to meet him. We just want a photograph. Or a bit of background to our DNA. That's all we're asking for."

JANINE COHEN: To the sisters' amazement, Dr Doherty wrote back a detailed description of the anonymous donor.

MAN READS: "He is fourth-generation Australian. Black hair, brown eyes, about 5 feet 10 inches, olive skin and medium build. Physically, he was considered to be a ruggedly good-looking young man with a squarish face and good teeth when he laughed. He was quite athletic."

JANINE COHEN: But the doctor refused to release the donor's name or any medical history other than to say the man was also a doctor.

*

JANINE COHEN: It would be another 20 years before they'd get to the bottom of the mystery. In 2003, they read about a support group for donor-conceived children.

HELEN EDEL: We showed them our letter. And they said, "Gee, that letter looks funny."

LEONIE HEWITT, DONOR CONCEPTION SUPPORT GROUP: He talked about his academic abilities. His profession. His...teeth, interestingly. And I thought to myself, "How could a doctor know "how the donor's teeth were 20 years later?" I listened to the letter. And I very, very carefully said to them in a very gentle way, "Have you ever thought that the doctor could be the donor?"

JANINE COHEN: What did they say?

LEONIE HEWITT: There was silence at the other end of the phone. It was like I'd landed a bomb in their...in her lap. And I said to her that some doctors were donors.

JANINE COHEN: Now the sisters were on a mission to find the truth. The first thing they wanted to know was what Dr John Doherty looked like. And did he look like them? They went to the medical library at Sydney University and looked through the yearbooks for his picture.

ANNE SMEE: We looked at photos to see if we could see pictures of ourself.

JANINE COHEN: And what did you see staring back from the pages?

ANNE SMEE: Someone that looked like us.

JANINE COHEN: But the twins couldn't be certain that John Doherty was their father. By this time, he'd long retired and left Sydney. And his trail seemed to end there.

*

The twins discovered that Dr Doherty had since died….

JANINE COHEN: What they discovered was that Dr Doherty had a son. They potentially had a half-brother. But how would they ever know?

ANNE SMEE: Helen rang up what would have been our biological half-brother. And asked him would he consent to a DNA test?

*

JANINE COHEN: Incredibly, the son did agree. And the result was conclusive. The DNA test showed that Dr John Doherty was their genetic father.

*

JANINE COHEN: The sisters wonder if Dr Doherty had donated his sperm to other women. Potentially they could have more half-brothers and sisters.

ANNE SMEE: How many people did Dr Doherty artificially inseminate? How many women? I mean, if people donate lots of sperm, well, how...yeah, you could walk around and you'd be making love to your half-brother or half-sister. I mean, it's bizarre.

HELEN EDEL: It worries us a little bit. We always make jokes there could be half a dozen other people walking out there with a similar DNA and what would happen if they met one of our children?

ANNE SMEE: Sometimes you're attracted to people that look like yourself, you know, they've done studies.

HELEN EDEL: I think there should be a national register of people that are going to donate their sperm. There should be medical histories, their record, so that that could avoid that happening.

JANINE COHEN: Many doctors believe a national register is needed for any children conceived in the future with donor sperm.

DR. LIZ MARLES, MEDICAL ADVISOR, DONOR SUPPORT GROUP: I think that those things are really important from an accountability point of view and they provide security for everybody in the system. They provide security for the donor, to know that his donations are going to be used ethically. They provide security for the parents who can raise the child and be open and honest knowing that the questions that come up will have answers. [61]

It is not only parents and donor conceived people who come to us asking for help in the sharing of information. Donors have been the silent partners in the process of creating donor families and as a result many assumptions have been made about what donors believe. Over the years we have had a great many donors come to us as well. Just about all have wanted to know the results of their donations. We have encouraged them to go back to the clinics and ask for this information.

One male donor wrote about his visits to the clinic at which he donated:

> *"Even though the clinic staff were good and the counsellor very helpful, the program operated on an anonymous basis, and so I only vaguely thought of children at the time, other than perhaps how many. This was all new to me, and there was a surreal quality to the whole thing*

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[61] ABC Four Corners Programme "Secrets of the Fathers" 2005

> *because of the lack of visual feedback. I did look at all the success photos in the waiting room of the parents, children and staff and naively thought why couldn't the donor be there too? I had no problem with openness or being contacted by couples or children and had even left a photo of myself and children in my file at the clinic. I can imagine what the clinic said when I left. Obviously not a normal donor."*[62]

More and more donors seem to want to talk about how they feel. They want to know how recipient families are doing. Nearly all are glad to have made contact with our group and are more than happy to give us contact phone numbers and addresses.

One of the most thoughtful letters we have had was from a donor who contacted us on a number of occasions. He had been a medical student in the 1970's when he donated. He told us he had wondered, from time to time over the years, whether any children had been conceived from his donations. Here is the letter he sent to us.

> *In my own case, I was a sperm donor at ……….. hospital, while a medical student, during the period between July 1978 and June 1979. from time to time over the years, I'd wondered whether any children were conceived from my donation. I'd felt like asking, but my recollection of being told at the time that contact would not be allowed (or wanted!) between donors and the families they helped had stopped me from making any further enquiries.*
>
> *Then I saw the "Sun Herald" article in late April (?) this year, and really understood for the first time how it must be for some of the children*

---

[62] "Let The Offspring Speak" Donor Conception Support group of Australia, 1997.

> *conceived from donated sperm (and ova). Like children adopted out at birth, and later told of their origins, they must surely wonder about their "other" families – the source, after all, of 50% of their genes!*[63]

This donor, encouraged by our group, contacted the clinic where he had donated all those years ago but he was told that no pregnancies had resulted from his donations. He told us:

> *I must say, there's also still the nagging doubt that the record-keeping "back then" was less than perfect and it may not be possible to trace some of the fathers!*[64]

The idea that donors donate and then forget is a myth. In the past the majority of donors were young but as they have grown and had their own families their thoughts have changed.

> *"Mike Fernando, who donated sperm in the late Seventies and early Eighties, is angry that he has had no follow-up information on what children, if any, he fathered as a result of the donations he made. A Sydney-based public servant now in his early forties, Mike says he is proud of what he did all those years ago, and would have no problem either telling his daughter about it or welcoming any offspring who were interested in meeting him."*[65]

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[63] See appendix 18 for full letter

[64] Ibid

[65] Debbie Thorpe *"Fatherless Children"* Elle magazine, November 1997.

> *I was a sperm donor during 1997-1998….., my donations were during the period when Donors had to sign away any future contact. This was a condition of participation and I only wanted to help people – but at the back of my mind was the hope that the rules would change to allow the resultant children to trace their donor fathers, if they wished to do so.*[66]

What this donor is saying is that there was never a choice for donors, anonymous or identifiable. They were told it was anonymous and that was the way it was even as recently as the early 2000's in most clinics.

As far back as 1983 it was discovered in an Australian study by Tyler et al [67] that 56% of donors supported a national register of names and addresses of donor and recipients.

It has also been the experience of the Victorian Assisted Reproductive Treatment Authority (VARTA). The table below shows the number of people registered in certain years on VARTA's two registers.

Register Activity in Victoria 2006 - 2009

Pre-1988 Voluntary Register

Donors 66

Recipient Parents 20

Donor Conceived People 42

Post-1988 Voluntary Register

Donors 77

Recipient Parents 79

Donor Conceived people 4 (This figure is very low because they are not able to register until they are 18 yrs.)

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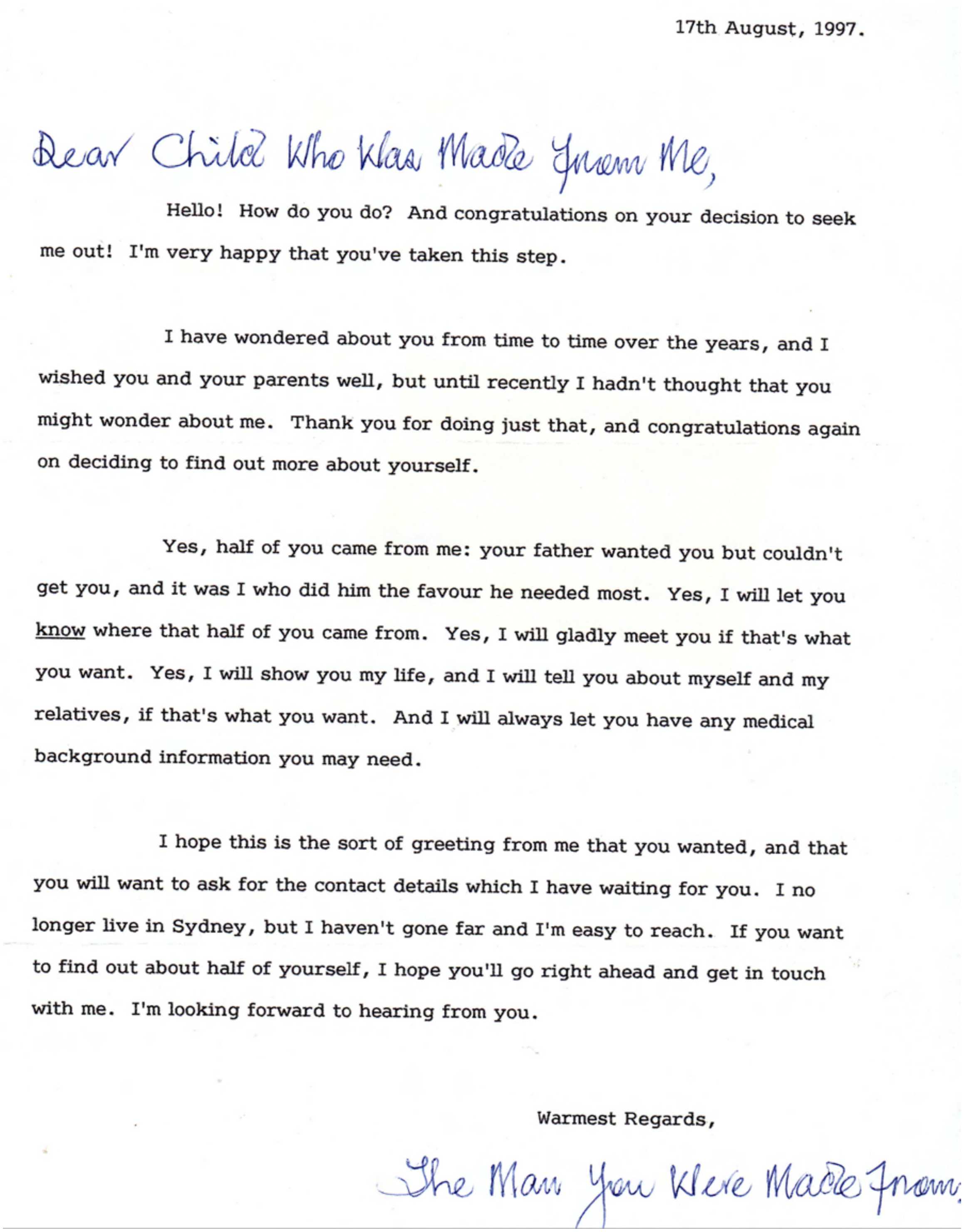
[66] See appendix 19 for full letter

[67] *"Some Attitudes to Artificial Insemination by Donor"* Clinical Reproduction and Fertility, 1983.

VARTA has also contacted 43 donors not on the registers on behalf of donor conceived people. In all but a very few of these the donors agreed to release information to the applicants. Many also exchanged letters through VARTA. Some later exchanged identifying information. Some met.

One donor who our group has spoken to over the years wanted to write a personal letter to any children that he helped to create, he wanted to let them know that he thought about them. He had this letter place on file at the clinic in case any children wanted information, he also allowed us to print his letter in one of our newsletters



17th August, 1997.

Dear Child Who Was Made From Me,

Hello! How do you do? And congratulations on your decision to seek me out! I'm very happy that you've taken this step.

I have wondered about you from time to time over the years, and I wished you and your parents well, but until recently I hadn't thought that you might wonder about me. Thank you for doing just that, and congratulations again on deciding to find out more about yourself.

Yes, half of you came from me: your father wanted you but couldn't get you, and it was I who did him the favour he needed most. Yes, I will let you <u>know</u> where that half of you came from. Yes, I will gladly meet you if that's what you want. Yes, I will show you my life, and I will tell you about myself and my relatives, if that's what you want. And I will always let you have any medical background information you may need.

I hope this is the sort of greeting from me that you wanted, and that you will want to ask for the contact details which I have waiting for you. I no longer live in Sydney, but I haven't gone far and I'm easy to reach. If you want to find out about half of yourself, I hope you'll go right ahead and get in touch with me. I'm looking forward to hearing from you.

Warmest Regards,

The Man You Were Made From.

Support & Counselling

When people are referred to fertility clinics these days part of their acceptance onto a donor conception program is to have at least one session with a clinic counsellor. This is not compulsory but is it usual that most, but not all, doctors will encourage this. In the history of donor conception this is a very recent innovation. If you go back only 15 to 20 years not all clinics even had counsellors and doctors were not encouraging patients to see them. In the early days of donor conception there were no counsellors working in the industry at all.

While our group has found a great many excellent counselors working in clinics we do need to make people aware they are in the employ of the industry. Until recently clinic counsellors had their own independent association ANZICA (Australia & New Zealand Infertility Counsellors Association) but now this comes under the auspices of the FSA.

The DCSG has the experiences of parents who have told their children and searched for information. We have donor conceived people who can share their feelings and experiences and we also have donors who can let us know about their thoughts and experiences. But, we are not trained counsellors, we work on a voluntary basis and all our volunteers also work outside the home so we are very limited in what we can do for people.

Even with this clinics have referred many patients to us over the years for various reasons, needing help in coming to terms with infertility, accepting donor conception as a family creation option, talking to children about their conception and these things we can talk to them about from the parents perspective.

Many need information before they make a decision about using donor conception,

> *Since (husband) and I started exploring the options of having a family we have found that this is not a subject which information is readily available. I have spent many hours searching for the small amount of information that I have on having a family this way, …… When I tried to get information about support groups I was again surprised at how hush hush it all was.*[68]

Once a child is conceived or born fertility clinics no longer see themselves as having a roll in that family's life. This of course is probably wise to a certain extent (with the exception of donor information/exchange) but then where do families go for support and advice?

> *My son was conceived by DI. He is now 5 years old, and although I have always intended to tell him of his birth, I really don't know at what age to do so, not the best way in which to explain.*[69]

To compare donor conception with adoption again in the area of family support; adoption has a long standing tradition of helping adoptive families. All states usually have multiple sources of information. For example within NSW adoptive families may access information and support from the Department of Community Services but also may go to the independent organisation the Post Adoption Resource Centre (PARC)

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[68] See appendix 20 for full letter
[69] See appendix 21 for full letter

which is funded by the Benevolent Society; these are apart from the smaller adoption organisations such as Anglicare and Barnardos. This is repeated in other states. There has been a realisation that adoptive families need ongoing support throughout their lives especially for such things as talking to children about adoption and exploring the issues of contact between adoptees and their biological families. The organisations that are available to adoptive families have decades of experience in adoption counselling and support.

> *My husband and I have just found out that we are unable to conceive children due to my husband being sterile. We are looking at persuing (sic) donor insemination, however, we are confused. We don't know if we keep it a secret or tell people and the child.*[70]

What are donor conceived families supposed to do if they need support after the birth of their child? They can go back to the fertility clinic and possibly get help from the clinic counsellor (if this is made available to them by the clinic) but the counsellors in clinics are trained to deal with the issues surrounding infertility. So where else can families go? They come to our group.

> *The reason I am writing to you is to see if you could provide us with any information about how we can tell our little boy and any future children we may have as to the special way that their lives began.*[71]

The worry about speaking to children about their conception can increase as the child gets older.

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[70] See appendix 22 for full letter
[71] See appendix 23 for full letter

> *I was reading That's Life Magazine issue 22 June 6 2001 when I cam across your stories about The Gift of Life Donor Sperm.*
>
> *Well I to (sic) have a child from a donor sperm, I was married for 12 years and my husband had a low sperm count and could never father children. So in 1991 I had been insemination (sic) with a donor sperm and after I miscarriage (sic) and 6 mths later I was pregnant and had a beautiful baby girl who is now 10 years old.*
>
> *My marriage has broken up and now divorced, I would dearly love to tell my daughter about how she was conceived but I don't know how or where to begin. I guess I'm scared in a way to tell her as she may not approve (sic0 of it and hate me as we have a very close relationship (sic).*[72]

One of the most difficult things that some parents find is how to get information about their child's donor especially when the clinic does not appear to support the request.

> *I know it's very personal but I heard on the grapevine that you may have 'identifying information' on your eldest daughter and that she may be able to obtain it later on.*
>
> *I don't know if this is exactly true or not but if you could let me know either way I would appreciate it. I feel that we are all in the same boat and that if we can help each other out we are doing good for each other. Swapping information on how to approach organizations, departments etc is the only way to go. I would like to, if possible get that information for my daughters one day and if not, at least they may be able to obtain it one day. They of course are pre-register.*[73]

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[72] See appendix 24 for full letter

We also have adult donor offspring accessing our group, most have found us through searches on the internet.

> *Three years ago when I was 18 my mother told me I am the result of a donor conception program. I have little knowledge about it and or if I am able to find the donor this is why I am writing to you. I do have doubts that the information about my donor no longer exists as it was 21 years ago but I am hopeful I might be able to be more informed with options on how to locate this person. The only information I have is I was conceived at …….. Hospital at …….. in February – March and this person had donated before and was successful in pregnating (sic) another couple. Could you please send or contact me with some information on your group or whom I should get in contact with who can help me on my quest.*[74]

> *I don't really know who you are and this is a very personal subject but I thought I would take a chance.*
> *I'm 21 and I was just told that my "father" isn't really my biological father. Actually I was conceived by a donor……… I think that I just really need to talk to someone who is in the same boat as If you know about any children of donors could you help me out?*[75]

Talking to donor conceived people is not easy, they are looking for information which will answer so many questions that they have, they are looking to complete their identities and apart from our group there is no where else for them to go.

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[73] See appendix 25 for full letter
[74] See appendix 26 for full letter
[75] See appendix 27 for full letter

As we have said before some donor conceived people take things one step further by going to the media either to help with the search for their own donor or to try and further the case for changes to donor conception practices.

> *Well the two interviews are over & it's very normalizing & also humbling to see so many other adults like myself "stripping naked" in front of the public eye in order to get the same point across. (ie. That records need to be kept, Drs monitored by some one other than themselves, we should never be lied to, & we should have access to info – relatives etc).*[76]

Over the years some parents have been able to exchange letters with their child's donor. This has occurred because of many reasons:

- some parents have decided that they needed to be in contact with the donors in case clinics destroyed records
- some parents have wanted to be able to have their child's questions answered.
- Some parents just wanted to thank the donors.

The first parents to ask clinics to forward letters did not find the request was received that well, as we stated before with the request for donor information most clinics did not understand the need for communication with donors.

While some clinics have ended up handling the passing backwards and forwards of letters very well not all have.

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[76] See appendix 28 for full letter

The following extracts are from a letter that an egg donor and her husband wrote to our group. The husband and wife had made a decision that the wife would donate eggs to two couples. She wanted to be a known donor and the clinic arranged for her to meet the recipients before egg pick up.

> *2 pregnancies resulted from the 1st implants. One pregnancy succeeded with a little girl born in January this year. The other couple are pregnant again after a 2nd attempt. We wait with interest.*
> *The 1st couple sent me a scanned photo of the little girl, but the clinic has decided to deny contact with the couple, stating that it is better for all of us this way. We have no idea what the couple think of this because we are unable to speak with them. (Husband) & I wrote a letter (through the clinic) saying that we were pleased that they now have their long-awaited child….. but we would always be open to contact if that is what they wanted.*[77]

Not long after this they received a letter back from the clinic, it read in part:

> *The Clinical management committee met today to discuss how best to clarify the uncertainties that have arisen in the process of your anonymous egg donation*[78]

The letter went on to discuss the arrangements of identity being confidential and that there would be no contact till the child was 18. This was not exactly the way the egg donor had remembered the discussion with the clinic before she agreed to donate. The clinic letter also said:

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[77] See appendix 29 for full letter

[78] Ibid

> *The committee has considered carefully your desire for ongoing contact with the recipient couples, photos, and news of their child's progress. Whilst sympathetic to your sincere interest in the ongoing progress of any children conceived using your donated eggs, we feel it is in the best interests of all parties that we adhere to the pretreatment agreement, which protects the privacy of all concerned……*
> *For this reason we have decided not to forward your letter requesting further communication with the new parents, nor will we facilitate any further contact.*[79]

The couple finished their own letter to us by saying

> *In conclusion, we never wanted to intrude on the couples lives – what we have sought is simply news of their success. I am sure that you would agree that it would seem unnatural to go through the rather intensive process of egg donation and not want to know that it was all worthwhile, that we have made a truly positive contribution to the lives of 2 other couples.*[80]

In 2007 when the NSW Assisted Reproductive Technology Act was being debated in parliament a similar case was raised about a parent who was in communication with her daughter's donor.

> ***Tony Stewart (Member for Bankstown)**: Also, I refer to a constituent by the name of Melinda Harrington. Melinda has a child Marnie, who was born 5½ years ago following an anonymous sperm donation at the Royal Princes Alfred Hospital.*

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[79] Ibid
[80] Ibid

Melinda stated:

> *For several years, letters were exchanged between the sperm donor and myself, passed on via the Fertility and Andrology Sections at respective hospitals.*

That is fair enough.

> *I discovered that, sadly, the sperm donor father of Marnie [she says] had been unable to have children with his [own] wife despite years of trying. Then, in 2006, I received a card via the fertility unit from the sperm donor informing me that he had at last had a son with his wife. The card included a photo of the newborn babe.*

This woman needs to know this important history and what her child needs to know of her donor-conceived sibling.

> *I replied to the happy news. Unfortunately, the Andrology unit had made a decision in the interim not to forward any more letters between donors and recipient families. This decision was made following a situation where a recipient family identified their donor and made contact. I might add that this contact was well received between all parties and is still positive in nature.*
>
> *Despite our best efforts, the Andrology Unit absolutely refuses to budge on this issue: they refuse to allow any contact between parties, even where that exchange of letters has been friendly and positive in nature.*
>
> *Further to this they refuse to let my donor know that I have responded to his letter and card from last year.*
>
> *The donor does not know about the progress of his own child. She*

> *goes on:*
>
> *They stated that if he rings them they'll let him know there are letters there on file for him from me.*
>
> *But they cannot show him the letters. What a ridiculous situation in the twenty-first century. This is an individual situation but it is repeated hundreds of times over, particularly later on when siblings want to know about their real identity and who their birth father is, not because they want to take any legal action or because of legal ramifications but simply because, as I said at the outset of my contribution, they need to have an understanding of the genetic health issues they may confront later in life or they need to know of their chances of meeting a half-sibling at some stage during their life.*[81]

Unlike adoption there are no proper support systems for recipient parents, their children nor for donors. Clinics do provide more support than they used to but it is haphazard, dependent on what individual clinics are prepared to do and unfortunately this appears to be often subject to how much money a clinic is willing to spend on supporting families who are no longer "paying customers." Clinics also do not have the expertise in the ,long term effects of donor conception that our group does. The final question in this section might be "Is it ethical to provide donor conception procedures without proper support?"

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[81] http://www.parliament.nsw.gov.au/Prod/parlment/hanstrans.nsf/V3ByKey/LA20071114

Payment of Donors

The DCSG would like to see the end of ‘payment’ of donors. The Prohibition of Human Cloning Act 2002 has made it illegal to pay for human reproductive tissue in Australia

> ***21 Offence—commercial trading in human eggs, human sperm or human embryos***
> *(1) A person commits an offence if the person intentionally gives or offers valuable consideration to another person for the supply of a human egg, human sperm or a human embryo.*
> *Maximum penalty: Imprisonment for 15 years.*
> *(2) A person commits an offence if the person intentionally receives, or offers to receive, valuable consideration from another person for the supply of a human egg, human sperm or a human embryo.*
> *Maximum penalty: Imprisonment for 15 years.*
> *(3) In this section:*
> ***reasonable expenses**:*
> *(a) in relation to the supply of a human egg or human sperm—*
> *includes, but is not limited to, expenses relating to the*
> *collection, storage or transport of the egg or sperm; and*
> *(b) in relation to the supply of a human embryo:*
> *(i) does not include any expenses incurred by a person*
> *before the time when the embryo became an excess*
> *ART embryo; and*
> *(ii) includes, but is not limited to, expenses relating to the*
> *storage or transport of the embryo.*
> ***valuable consideration**, in relation to the supply of a human egg,*

> *human sperm or a human embryo by a person, includes any inducement, discount or priority in the provision of a service to the person, but does not include the payment of reasonable expenses incurred by the person in connection with the supply.*[82]

The NHMRC Guidelines mention the prohibition of trading in human gametes and embryos as listed in the Prohibition of Cloning Act but also states:

> *17.21 Respect the donors of gametes or cells used to form embryos by means other than fertilisation*
> *17.21.2 There should be no payments or other inducements for the donation of gametes, gonadal tissue or cells for research that is subject to these guidelines. The reimbursement of reasonable out-of-pocket expenses associated with the procedures is acceptable. In research to which these guidelines apply, reimbursement does not cover compensation, including compensation for time.*
> *17.23.3 There should be no trade in human foetal gametes, gonadal tissue or cells.*[83]

The guideline sees fit to reinforce the ban on the trade of human gametes and the ban on the payment of donors but only in respect to gametes & embryos which are being used for research.

There is no definition in either the guidelines or the Cloning Act of what is considered to be reasonable expenses.

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[82] http://www.comlaw.gov.au/comlaw/Legislation/ActCompilation1.nsf/0/A5C8B715DBE6173ECA257528000E1F35/$file/ProhibHumanCloningforRep2002_WD02.pdf

[83] Pge 76 NHMRC *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* 2007

The FSA also does not know what constitutes "valuable consideration." They have states in their July 2009 RTAC Technical Bulletin:

> ***Obtaining donor sperm outside Australia and New Zealand***
> *Several people have asked about the legal position of importing donor sperm from commercial sperm banks or units that reimburse donors differently to units in Australian and New Zealand.*
> *Whether or not importing donor sperm is legal depends on whether the 'reimbursement' to the donor constitutes valuable consideration under Australian law or New Zealand law. There is no known legal ruling on what constitutes valuable consideration in this context in either country. Accordingly, neither FSA nor RTAC can offer an opinion on this point. Units should seek independent legal opinion that takes into account the type and amount of 'reimbursement' given to the sperm donor by the sperm bank.*[84]

It is interesting to note the difference in how clinics approach sperm donations as compared to egg donation.

On Monash IVF's website they clearly mention how much sperm donors will be paid

> ***Compensation for Reasonable Medical and Travel Expenses***
>
> *An allowance of $90 per donation is payable to cover reasonable traveling expenses, car parking, time off work etc, however this is paid in three amounts.*
> *Initially, $400 is paid by cheque after the fifth donation. This is to cover the time you spent in counseling, medical consultation and for the first 5 donations.*
> *A further $200 is paid after the tenth donation.*
> *Finally, you will receive a final $300 payment when the 6 month*

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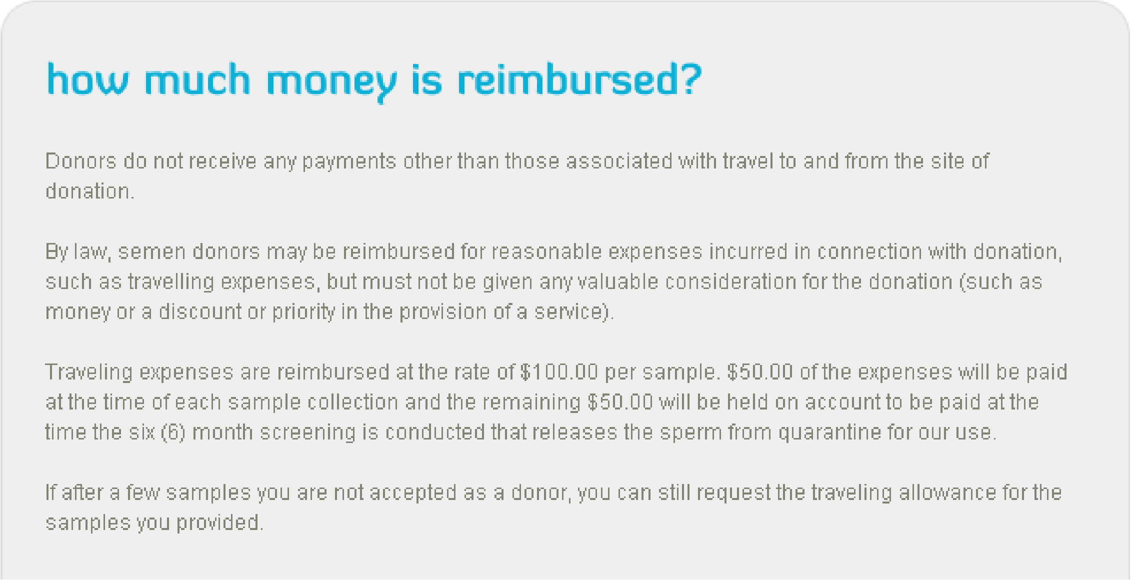
[84] http://www.fertilitysociety.com.au/wp-content/uploads/20090706-rtac-technical-bulletin-number-2.pdf

> *quarantine blood tests have been finalized, and the donated sperm is available for use.*[85]

But when you look at their egg donors page there is absolutely no mention of egg donors being paid for anything.

Fertility First in Sydney have only this year commenced an online advertising campaign to try and draw more sperm donors



how much money is reimbursed?

Donors do not receive any payments other than those associated with travel to and from the site of donation.

By law, semen donors may be reimbursed for reasonable expenses incurred in connection with donation, such as travelling expenses, but must not be given any valuable consideration for the donation (such as money or a discount or priority in the provision of a service).

Traveling expenses are reimbursed at the rate of $100.00 per sample. $50.00 of the expenses will be paid at the time of each sample collection and the remaining $50.00 will be held on account to be paid at the time the six (6) month screening is conducted that releases the sperm from quarantine for our use.

If after a few samples you are not accepted as a donor, you can still request the traveling allowance for the samples you provided.

[86]

We would suggest that if sperm donors are being paid travelling expenses of $100 per sample, then they are, in just about all cases, going to have a reasonable amount of money left over and to us this would definitely constitute payment.

Concept Fertility in Western Australia also mentions payments to donors

---

[85] http://www.monashivf.com/default.asp?action=article&ID=21695

[86] http://donatedontwaste.com.au/whats-in-it-for-me/reimbursement/

Your contribution will bring happiness to infertile couples

SPERM DONORS

Urgently required

Between 18-50 years of age and of all nationalities

You will be reimbursed with $75 per donation

All approaches will be kept strictly confidential

Please call Dr Peter Burton on (08) 9382 2388 to discuss
or email pete@conceptfert.com.au

Your contribution will bring happiness to infertile couples

EGG DONORS

Urgently required

Between 18-35 years of age and of all nationalities

You will be reimbursed with $200 per donation

All approaches will be kept strictly confidential

Please call Dr Peter Burton on (08) 9382 2388 to discuss
or email pete@conceptfert.com.au

[87]

The amounts listed above would again, in just about all cases, more than cover any travelling costs incurred by a donor so they do constitute financial gain.

In 1996 there was an advertisement placed by a Sydney clinic in the Sydney Morning Herald. Our group complained to the Central Sydney

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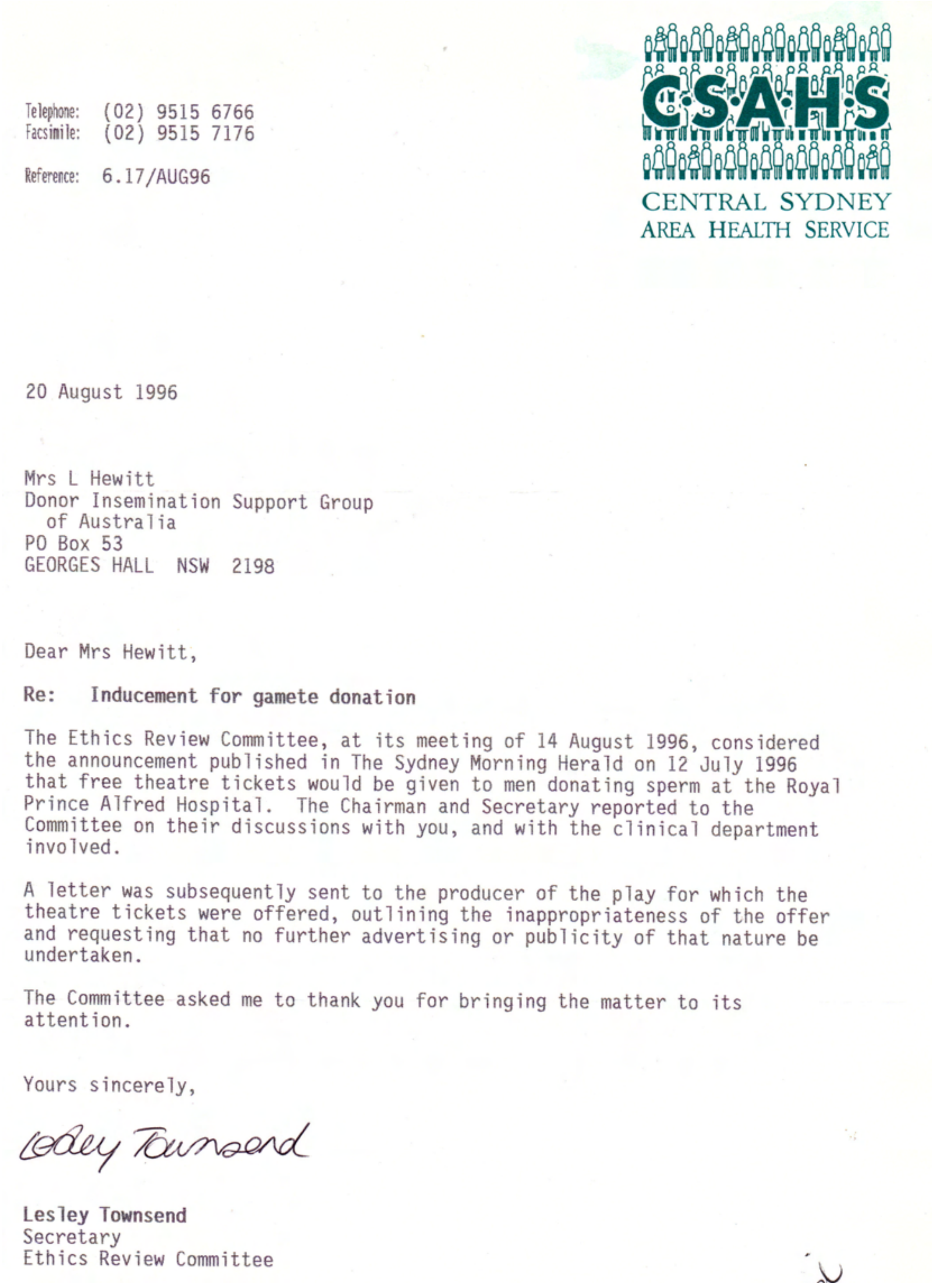
[87] http://www.conceptfert.com.au/eggdonors.html

Area Health Service about the use of inducements to get sperm donors and the advertisement was eventually withdrawn.



Telephone: (02) 9515 6766
Facsimile: (02) 9515 7176

Reference: 6.17/AUG96

CSAHS
CENTRAL SYDNEY
AREA HEALTH SERVICE

20 August 1996

Mrs L Hewitt
Donor Insemination Support Group
of Australia
PO Box 53
GEORGES HALL NSW 2198

Dear Mrs Hewitt,

Re: Inducement for gamete donation

The Ethics Review Committee, at its meeting of 14 August 1996, considered the announcement published in The Sydney Morning Herald on 12 July 1996 that free theatre tickets would be given to men donating sperm at the Royal Prince Alfred Hospital. The Chairman and Secretary reported to the Committee on their discussions with you, and with the clinical department involved.

A letter was subsequently sent to the producer of the play for which the theatre tickets were offered, outlining the inappropriateness of the offer and requesting that no further advertising or publicity of that nature be undertaken.

The Committee asked me to thank you for bringing the matter to its attention.

Yours sincerely,

Lesley Townsend

Lesley Townsend
Secretary
Ethics Review Committee

In 2004 an Australian clinic started an advertising campaign in Canada to recruit donors.


[88]

Fertility clinic launches working holiday plan

Canadians answer call

Paula Beauchamp
health reporter

CANADIAN students could fly into Australia on sperm donor "holidays" and pocket a trip worth $7000 for their trouble.

Authorities have given a green light to the plan after a six-month investigation, in a bid to overcome a domestic sperm drought.

Reproductive Medicine Albury advertised the two-week trips Down Under through a University of Calgary newspaper in December.

Under the plan, students would donate sperm every second day while enjoying a Murray River holiday in Albury-Wodonga.

The holiday package, valued at $7000, includes return airfares, accommodation for two weeks and a daily allowance of $150.

"We have advertised locally but with little success and for that reason find it necessary to search further from our own region," the ad in the sports section of *The Gauntlet* read.

"We have many women and couples whose hopes of having children may never be fulfilled due to the severe shortage of sperm donors."

The clinic has since been inundated with responses — from as far afield as Ukraine and Russia.

National Health and Medical Research Council licensing committee chairman Professor Jock Findlay said the plan was investigated to ensure it didn't amount to "trading in sperm".

Under the Prohibition of Human Cloning Act it is illegal to commercially trade in human sperm. NHMRC investigators found the offer did not breach the law.

"If the clinic was going to pay more than the bare expenses necessary that would have posed a problem," Professor Findlay said.

SPERM DONORS NEEDED

WE WILL PAY

- Return Air Fares to Australia
- Two Weeks Accommodation
- Daily Allowance

- You will need to be over 18 and under 40 years of age
- Available every second day to produce a semen sample
- Available to attend two compulsory counselling sessions
- Mentally fit, healthy—able to pass a medical assessment
- Able to pass compulsory blood tests for HIV/hep B+C
- Willing to be registered as an identifiable donor *(we cannot accept anonymous donors)*
- We are a fully accredited infertility clinic on the southern border of N.S.W.
- We have many women and couples whose hopes of having children may never be fulfilled due to the severe shortage of sperm donors. We have advertised locally but with little success and for that reason find it necessary to search further from our own region.

IF YOU ARE INTERESTED
fax: 011 61 2 6041 2118
email: rasmuson@reproductivemedicine.com.au
our website is: www.reproductivemedicine.com.au
Check out our region at: www.albury-wodonga.com/docs/t.htm

Pay day: the advertisement.

"Investigators found this offer amounted to reimbursement for legitimate expenses."

Professor Findlay said it wasn't NHMRC's role to approve or allow the IVF initiative, but to establish whether it breached the law.

Melbourne visitor, Canadian backpacker Steve Greatrex, yesterday welcomed the offer.

"I know heaps of guys who'd do this," he said, before asking for the IVF clinic's contact details for friends.

"I know guys who really want to come to Australia. But what's so special about guys from Calgary?" the 25-year-old from Ottawa asked.

It is believed RMA chose Calgary because one of its gynecologists came from the city and could organise necessary health checks.

IVF doctor Scott Giltrap said RMA would run another donor recruitment drive locally before putting the Canadian plan into play.

Victorian and NSW IVF clinics have seen sperm donor numbers dwindle in the past five years.

Fertility Society of Australia spokesman Professor Peter Illingworth said laws allowing children to know the name of donor parents at age 18 had sparked the drought.

"I'm really defeatist about it," he said. "We are now unable to treat many couples, especially those from a background where the stigma of open sperm donation is too much."

But Infertility Treatment Authority CEO Helen Szoke said it was difficult to attract donors even if donor registers weren't kept.

"We have to look at the consequences. What are the rights of a child born of donor sperm? They didn't have any say. They didn't give consent," she said. "We need to think about new ways to encourage people to donate."

Monash IVF and Melbourne IVF said donor numbers had dropped.

Ballarat IVF spokeswoman Katrina Dowling said the clinic had never had any sperm donors.

She hoped a recent advertising campaign for donors would prove successful.

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[88] heraldsun july 9 2004

As you can see by the article the NHMRC investigated the payment of donors in this way and decided that it did not breach the Prohibition of Human Cloning Act. Considering that no proper definition has ever been given on what actually does constitute payment or inducement we do not know how they came to this decision. It amazes our group that this could ever not have been considered to be inducement and payment.

> *As a result of this newspaper campaign which was picked up by Australian newspapers the Albury clinic got a sudden influx of Australian donors.*
>
> *After several years of failing to raise enough donors in Australia, despite advertising widely, Reproductive Medicine Albury found the intense publicity about its other-side-of-the-world sperm search last year delivered a new batch of homegrown donors.*
>
> *Not to be outdone by Canadian donors, it seems, Australian men reacted to the campaign as a point of pride. "It was a bit of, 'What? Isn't Australian sperm good enough, then?' " says Dr. Scott Giltrap, director of the fertility centre.*
>
> *Dr. Giltrap is a big believer in the any-publicity-is-good-publicity credo.*
>
> *Because of the sufficient domestic response, the clinic hasn't yet had to follow through on its Canadian candidates, but the campaign, and the grim medical reality behind it, is not a joke at all to the clinicians and*

> *their patients.*[89]

Apart from the fact that the donors would be paid there was also the problem of any children born from these donors being put in the situation of having to try and get information about their biological heritage from another country.

The Fertility Society's own Code of Practice state:

> *the fact that donors will receive no financial gain, consideration or similar benefit for their donation.*[90]

Consider that in Australia we do not consider it necessary nor acceptable to pay for blood donations or bone marrow donations. We would consider it immoral to offer money to families who after the death of a loved one donate their loved one's organs so why do we pay for sperm and egg donations? Some psychologists have suggested that payment for sperm donors is a way of 'divorcing' them from their donations. Once bought from them it is someone else's concern and they can go away and forget about it. But as we have shown donors do not forget. Even though we have had donors tell us that they donated partly for the money we have also had donors tell us that they never cashed the cheques given to them by the clinics for their donations.

The articles about the recruitment of donors from Canada and the ones below also show that even though clinics are constantly blaming the lack of donors on legislation if clinics find the right way of appealing to people

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[89] http://www.canada.com/nationalpost/news/story.html?id=8b5bbf63-ebd5-4962-92f7-5c504ed24bcf&k=79732

[90] http://www.fertilitysociety.com.au/wp-content/uploads/20080924-rtac-cop-final2.pdf

there will always be a supply of donors who are also willing to be identified to donor conceived people.

Again we demonstrate this with another example of a clinic going to the media about the lack of donors then promptly having men come forward.

December 21, 2009

TASMANIA'S Health Minister Lara Giddings has called on the state's men to help end the state's sperm drought.

The Sunday Tasmanian reported that Tasmania was down to its last four sperm donors and for the first time in the program's 35-year history women will have to go on a waiting list.[91]

December 27, 2009 07:14am

TASMANIAN men have risen to a call to donate sperm.

The Sunday Tasmanian last week reported that the state's sperm bank had almost run dry because of fewer men donating and more demand from interstate women.

The sperm bank is down to its last four donors and, for the first time in the program's 35-year history, waiting lists will be introduced next

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[91] http://www.couriermail.com.au/news/national/tasmania-down-to-last-four-sperm-donors/story-e6freooo-1225812423991

month.

Tas IVF director Bill Watkins said last week there had been a rush of men calling to find out more about becoming a sperm donor. "We've had a huge response to the story," Dr Watkins said. "About 30 calls and so far seven have booked follow-up appointments.[92]

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[92] http://www.themercury.com.au/article/2009/12/27/118221_lifestyle.html

Consanguinity

Our group consensus on this point was that one donor should be allowed to donate to no more than 5 families including the donors own family.

We also feel that donors should be given a choice of a lower number than this if they so desire.

- Western Australia has put a limit of 5 families from any one donor.
- NSW has put a limit of 5 families from any one donor, including the donor's own family.
- Victoria has a limit of 10 families including the donor's own family
- France puts a limit of 5 children and
- Austria allows donors to help create children in only 3 marriages or co-habitations.

What are the chances of a consanguineous marriage between people born from donated sperm, egg or embryo?

The majority of donors will naturally choose to donate at a local clinic for ease of access and of course the majority of people attending a clinic will do so for the same reasons. This can result in both donors and recipient parents having children growing up in the same area. There is a chance that related children may attend the same primary school. Later they will go on to high schools which draw their students from a much wider area thus increasing the chances of half siblings meeting each other. The chances at tertiary education level are even higher.

The ABC Four Corners programme discussed this issue with a clinic doctor.

JANINE COHEN: Professor Douglas Saunders, the former head of Obstetrics and Gynaecology at Sydney University, and now chair of the fertility industry's licensing body, has himself attracted criticism. Four Corners has obtained a copy of a letter written in 1997 where a family complains to Professor Saunders about his own clinic. The patient said she'd discovered her donor contributed to at least 11 families although she'd been promised the clinic's limit was 10. Professor Saunders wrote back - "We are mindful of legislation in other states, but you would appreciate fixing a legal number is fraught with difficulties."

PROF. DOUGLAS SAUNDERS, RTAC CHAIRPERSON: Well, this is because of some states have got a small population like Tasmania where...

JANINE COHEN: But this letter is about your own clinic. Why is it a problem at your own clinic?

PROF. DOUGLAS SAUNDERS: It was tied up with the fact some people wanted to have another child within the same family with the same donor.

JANINE COHEN: But then why do your RTAC guidelines work if you say 10 families? If you can't stick to the guidelines or to the rules why should anyone else be able, expected to be able to?

PROF. DOUGLAS SAUNDERS: Ah, I don't...

JANINE COHEN: Do you think...

PROF. DOUGLAS SAUNDERS: Well, we can only try, we can only try.

JANINE COHEN: You can only try. Do you think, given instances like this, is RTAC the right body to be the watchdog over the industry?

PROF. DOUGLAS SAUNDERS: I believe it has worked well over the years and I still say this. There has, there is no evidence that harm has been caused over the years.

JANINE COHEN: How would we ever know? There's no records. How would we ever know?

PROF. DOUGLAS SAUNDERS: Yes. Yes.

JANINE COHEN: Many donor-conceived adults want an independent authority to monitor the industry. Four Corners has spoken to a former RTAC member who supports this claiming the licensing body is often ineffective.

JANINE COHEN: This former RTAC member of your own committee says that there's often corporate amnesia when they come to inspecting clinics. That the real records... The truth isn't always declared.

PROF. DOUGLAS SAUNDERS: Well, we do our very best. We are human. And we are not policemen. And, ah...

JANINE COHEN: But isn't that just the point - you're not policemen. Shouldn't there be an independent watchdog...? [93]

---

[93] Australian Broadcasting Corporation Four Corners Transcript Janine Cohen's report, "Secrets of the Fathers". 24/10/2005. http://www.abc.net.au/4corners/content/2005/s1489657.htm

> "The possibility of the excessive use of the same donor, the danger of consanguinity dictates that a donor should not be allowed to be the father in more than ten cases. If the donation is taking place in a very restricted area, then even this figure may need appropriate reduction"[94]

How many half siblings can a person born from donated gametes have? To answer this we need to look at some real life examples. We have created a graphic of a young man born from donor insemination who has allowed us to use his picture and personal information to show you the number of half siblings that he is related to[95]. The information on the number of half siblings was given to his parents by the clinic they attended. As you can see in the appendix the grapfic only lists the number of half siblings that the clinic is aware of; if parents chose not to tell the clinic of a pregnancy or birth then it would not be recorded (in Victoria it is part of their 1995 legislation that parents are required to report births of donor conceived children).

The Federal *Marriage Act 1961* states:

> Part III—Void marriages
>
> (2) Marriages of parties within a prohibited relationship are marriages:
>
> (a) between a person and an ancestor or descendant of the person; or

---

[94] Gian Carlo Di Renzo & Gaetano Caserta - Centre of Prenatal Medicine, University of Perugia, Italy & Emerlendo V. Cosmi - Il Institute of Obstetrics & Gynaecology, University of Rome, Italy. Pge 33 *"Creating the Child - The Ethics, Law & Practice of Assisted Procreation"* Edited by Donald Evans.

[95] See appendix 30

(b) between a brother and a sister (whether of the whole blood or the half-blood).

The federal Marriage Act prohibits the marrying of full and half siblings but the government allows a practice to continue which not only allows for the chance of this to happen but increases the chance by allowing so many children to be born from one donor.

The following are the records provided to the DCSG by a donor who donated at a number of clinics in Sydney. As you can see the number of donations is very large covering 13 years. The early donations up to 1984 would have been 'fresh' donations used for only one insemination per donation but after 1984 all semen was frozen for quarantine purposes; this meant that semen could be divided and one donation could be used for at least 6-12 inseminations.[96] The donor does not know how many children have been born as a result of his donations.

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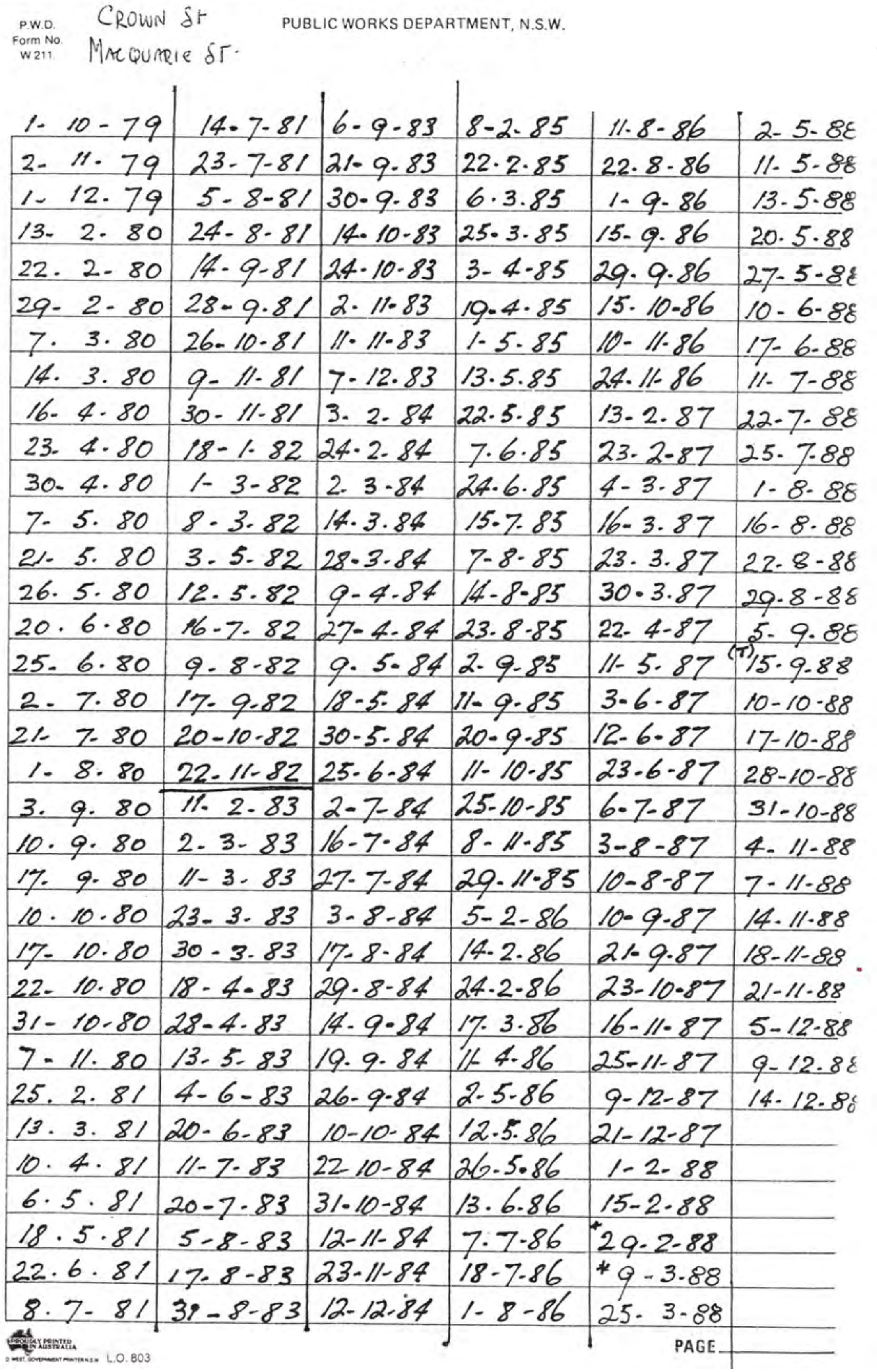
[96] Fertility Potential of Individual Sperm Donors
Hesham G. Al-Inany, GerardA.J. Dunselman, JohnC.M. Dumoulin, JacquesW.M. Maas, JohannesL.H. Evershttp://content.karger.com/ProdukteDB/produkte.asp?Aktion=ShowPDF&ProduktNr=223845&Ausgabe=225050&ArtikelNr=10082
And also: Recruitment of sperm donors: the Newcastle-upon-Tyne experience 1994–2003 S.Paul1,2, S.Harbottle1 and J.A.Stewart1,3
http://www.oxfordjournals.org/eshre/press-release/freepdf/sperm_donors354.pdf



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(17)

(318)

This donor was married with children of his own when he first donated fresh semen in 1979. He told our group that clinic staff had never asked him if he had donated at another clinic. He also said that it had never been mentioned on any form that he had signed. He said that he was curious about any possible children. He realised that not all records would have been kept. He is willing to have a blood test so that clinics could match up his information with any offspring.

This donor was part of the ABC Television 4 Corners programme entitled "Secrets of the Fathers" in 2005. The interviewer also spoke to Dr Straun Robertson a doctor who ran a private clinic in Sydney but it now retired.

JANINE COHEN: This man has no idea how many children he's helped create. He donated sperm 318 times from 1979 to 1992. Four Corners obtained a copy of his personal records detailing where and when he donated. He agreed to do an interview on the proviso he wasn't identified. So you donated 318 times. How many offspring do you think there could be out there?

ANONYMOUS DONOR: I wouldn't have a clue.

JANINE COHEN: Throughout mostly the 1980s this man donated 270 times at Dr Straun Robertson's clinic. He says he did it for some pocket money, to support his wife and four daughters, as well as to help infertile couples.

JANINE COHEN: I know times have changed but knowing what we know now, is that risky business taking that many donations from one man?

DR. STRAUN ROBERTSON: Ah... Yes.

JANINE COHEN: You wouldn't do it now?

DR. STRAUN ROBERTSON: No.

JANINE COHEN: Why do you think you did it then?

DR. STRAUN ROBERTSON: I presume that we were unaware that the numbers were building up over time.

JANINE COHEN: As well as donating at Dr Straun Robertson's practice, this man donated at six other clinics. At the Royal Prince Alfred Hospital he donated 13 times and three boys were born as a result. He also received a letter saying there could be more on the way. At the Royal Hospital for Women in Paddington he donated nine times. [97]

The DCSG wrote to the FSA to try and get some help on what could be done to help the adult donor conceived people coming to see us who were trying to get information from Dr Robertson. The FSA did write and ask Dr Robertson whether he had files on the donors and if he could provide information to donor conceived people.

---

[97] Australian Broadcasting Corporation Four Corners Transcript Janine Cohen's report, "Secrets of the Fathers". 24/10/2005. http://www.abc.net.au/4corners/content/2005/s1489657.htm

How could the sort of figures mentioned in the Four Corners programme impact on donor conceived individuals and their parents and the donor's own children?

> *Lucinda, who has known about her DI conception (using an anonymous donor) since she was 13, says that the prospect of 'falling in love or having a sexual relationship with a possible half-brother just freaks me out'. Sexual relationships between unwitting siblings concerned parents and offspring.* [99]

Barry Stevens, a documentary filmmaker, is in his fifties and was conceived with sperm from an anonymous donor; he fully understands what it is like to not know who you are related to.

> *It is not just health. There are also issues of consanguinity which are fed by anonymity. The less one knows about the donor, the more likely it is that one might meet and marry someone who is his or her half-sibling or even, conceivably, biological father. This may seem extremely unlikely, but remember that people do cluster in groups. Like- minded people tend to get to know each other, and sometimes they get to know each other because they have had treatment in the same place.*
> *I know of two cases where the people's children play together. Both*

---

[99] *Australian Journal of Emerging Technologies and Society Vol. 2, No. 1, 2004*
Genetic Connection And Relationships In Narratives Of Donor-Assisted Conception
Maggie Kirkman NHMRC Post-doctoral Research Fellow at the Key Centre for Women's Health in Society

> *the mothers and children do not know but I actually do know — through a quirk of fate — that the mothers have the same donor.*[100]

The stresses of growing up are known to us all but add to that the stress of inadvertently having a relationship with a half sibling. This can foster emotional insecurities when seeking out and forming intimate relationships.

Donors also worry about the dangers of their own children meeting and forming relationships with half siblings.

> *There is a danger here, albeit a small one, and this is that one of my children should meet and fall in love with one of my "unknown" children. Should this happen and they wished to marry and have their own children a tragedy could eventuate as they would be marrying within the forbidden degree of kindred and this would of course be incestuous, with all the dangers inherent is such a liaison. It has, I believe, happened twice already in the United States, and this is of course only the reported cases. It may have happened an unknown number of times and gone undetected.*[101]

It seems that if, as a country, we have a way of trying to prevent this from happening then we should be doing everything in our power to prevent it from happening.

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[100] Proceedings of the Standing Senate Committee on Human Rights Canadian Government Issue 10 – Evidence Barry Stevens, Founding Member, Alliance of People Produced by Assisted Reproductive Technology

[101] See appendix 31 for full letter

One of our members who was conceived over two decades ago by donor insemination has talked about the worry that she might be related to someone she forms a relationship with. She told us that she had a friend at high school and after knowing each other for three years they found out that they were both conceived by donor insemination. She wondered what might have happened if this friend had formed a relationship with her brother. They could have had the same donor. What might have happened if that friend had been a male?

These are very genuine concerns that some doctors try to push under the carpet with comments such as: Even if a man and a woman who are half siblings form a relationship and have children there is still only a very small chance of any problems with the resulting child.

We see that there is incredible risk of harm to all concerned. The discovery that one is having a relationship with a half sibling would be devastating. For donor conceived individuals to have to spend time wondering about their possible relationships provides them with a great deal of stress. This stress could easily be alleviated by all offspring being given the information that they need.

We have heard with dismay from more donors than we would like who have donated at more than one clinic. These donors are just men who wanted to help infertile couples, or were encouraged by the payment being made. They were not asked if they had donated at another clinic and were not made aware of the implications of doing so.

Michael telephoned us after reading an article about Lauren and her feelings about not knowing anything about her donor. He told us that he had donated at 2 Sydney clinics approximately once a week for 5 years. He is interested in what has happened to his donations. He joined our group so that he could keep up to date with changes in the area of reproductive technology and any changes to legislation.

Steven donated at 3 Sydney clinics in the early 1980's. Both his father and uncle have been diagnosed with prostate cancer. He felt that the families who had conceived children from his donations should be told this. He says that he would make himself available for possible contact with any children when they get older. He has sent a letter to each of the clinics at which he donated. This letter contains updated information, photos of himself at the time of donation and current ones. He has asked that this letter be made available to any offspring who ask the clinic for information about him.

Consanguinity has been a major concern of both recipient parents and donor offspring. As we have mentioned previously offspring do worry if they are perhaps forming relationships with people who are also donor conceived persons or the children of a donor's own relationships. The setting up of a Federal Register would limit the offspring from any one donor and could also be used by donor offspring to establish who their half and full siblings are.

Regulation

In the domain of reproductive technology there is a long-standing tradition of self-regulation. Physicians have regulated their activities in accordance with their own understanding of what constitutes responsible practice. Up until very recent times the practice of donor conception has been for the most part a result of this self-regulation.

Clinics in Australia are governed by peer group regulation under the control of the Reproductive Technology Accreditation Committee (RTAC) which is a sub-committee of the Fertility Society of Australia. To enable a clinic to continue to receive Medicare funding it must be checked and accredited by RTAC. Does RTAC send a report of what it has found at each clinic to the government or can a member of the public or a past consumer see these reports? We asked RTAC; this was their reply:

> It is required that RTAC provides each ART unit with a report after an assessment.
> There is a confidentiality agreement between each unit and RTAC as defined in the Code of Practice.
> The Deed of Agreement in the Code of Practice states that the report is for the sole purpose of consideration for accreditation and is not to be used for any other purpose.
> RTAC does supply a copy of the report to legislative authorities in some states of Australia where the legislation requires units to be RTAC accredited such as ITA in Victoria.
> In New Zealand the HART legislation requires units to supply their RTAC reports to the govt. No reports are supplied by RTAC directly to govt or

to the FSA or NHMRC.

RTAC does report regularly to FSA about accreditation matters in a general way such as a list of units that have been visited and accredited. The RTAC section within the FSA website lists the ART units and their accreditation status and this is updated fairly regularly and will be updated again very soon.

RTAC unit reports are not public documents mainly for confidentiality reasons.

In 2007, the FSA decided to introduce independent (third-party) certification of ART clinics as the basis for licensing and accreditation. They asked JAS-ANZ (joint accreditation system of Australia & New Zealand) to work with them to develop and organize a new RTAC accreditation scheme.

JAS-ANZ accredits CABs (conformity assessment bodies – also known as CB) who will then be employed by the clinics to check that they are adhering to the RTAC Code of Practice. Below is a simplified flowchart of how accreditation of fertility clinics works according to the RTAC Code of Practice.

The organisation contacts a CB and then submits an application for certification to the CB.

⇩

Primary audit conducted by the CB against all aspects of *the Code.*

⇩

Final report, including any corrective actions undertaken, submitted to RTAC with recommendations for licence.

⇩

RTAC reviews the report and recommendations and makes the decision to grant or not grant a Licence.

⇩

RTAC sends licence to the ART unit. RTAC contacts ART unit if licence is not granted.

As we can see from this chart RTAC has the final say on whether a clinic is accredited and RTAC is made up of people who work in the industry and one consumer representative that is the nominee of an organisation which is funded partially by the FSA and industry bodies.

RTAC includes FSA expert representatives from all specialty areas of ART, including reproductive medicine, nursing, counselling and reproductive biology. It also includes representation from the fertility consumer organisation ACCESS.
Membership of RTAC is as follows:

- *Chair (appointed by the FSA Board)*
- *Deputy Chair (appointed by the FSA Board)*
- *Nominee of ACCESS*
- *Nominee of Australian New Zealand Infertility Counsellor's Association (ANZICA)*
- *Nominee of Fertility Nurses of Australia (FNA)*
- *Nominee of IVF Medical Director's Group.*
- *Nominee of Scientists in Reproductive Technology (SIRT)*

RTAC reports annually on certification of organisations to the FSA board.[102]

> *As part of their registration fee all patients at Queensland Fertility Group pay for a one year's membership to ACCESS.*[103]

The executive director of ACCESS is also an ex officio member of FSA's board of directors. The FSA has at various times also provided finding to ACCESS including in 2001 $125,000 and in 2000 $123, 372.[104]

Comments about the accreditation of clinics have been made in the past in the Federal Parliament. Senator Brian Harradine spoke about the monitoring of fertility clinics within the discussion of the Research Involving Embryos Bill in 2002

> *Senator Harradine: I suggest that we really need to have a response from the minister which shows how she and the government are to ascertain what sort of outside monitoring provisions for the ART body—that is to say, the accredited ART centres—are required. These should not be provided by the Fertility Society of Australia, because they are an interested group.*[105]

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[102] http://www.fertilitysociety.com.au/wp-content/uploads/20080924-rtac-scheme-final4.pdf

[103] http://www.qfg.com.au/support-groups.html

[104] FSA Financial Report for the Year ended 30 June 2001

> *Who gives that accreditation? None other than the industry itself. If we have a look at the definition of `accredited ART centre' on page 6 of the bill, it says:*
>
> ***accredited ART centre** means a person or body accredited to carry out assisted reproductive technology by:*
>
> *(a) the Reproductive Technology Accreditation Committee of the Fertility Society of Australia...*
>
> *It is the industry; it is not an independent organisation at all. I want to ask the minister: what supervision is made of the body that gives this accreditation? You have this in the legislation; how do we know whether we should put all of our confidence into the hands of that accreditation committee when there is no legislation or other independent authority involved?*

He spoke again at a later time within the same debate

> *Is not the Fertility Society of Australia, in effect, an IVF industry body? I would be obliged if the minister could show me where it is not an industry body. In fact, isn't it true that the Reproductive Technology Accreditation Committee is a committee of the Fertility Society of Australia? If you have a look at that disinterested body—this*

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[105] Senator Harradine
http://parlinfoweb.aph.gov.au/piweb/view_document.aspx?id=1944533&table=HANSARDS

> *gatekeeper appointed by the government; it is to be imported into the bill by the government and it is going to end up in an act of parliament, so that is why I am raising this—it is to be appointed as the appropriate independent body to grant accreditation to IVF centres. This is a very important area because it means that this organisation, which is an industry body, can virtually give carte blanche approval to research activity on human embryos and that matter does not have to then go to the licensing committee.*
>
> *In my description of the Fertility Society, I include the consumer representative. There is a consumer representative on the body of the Fertility Society, but guess what? That organisation, called Access, is 70 per cent funded by the industry. That came out of the information that was brought to the committee. I think that Senator Bishop asked various questions at that time and it was revealed that the consumer representatives are from an organisation which is 70 per cent funded by the IVF industry.* [106]

Senator Harris was most distressed about this topic as well.

> *It is quite alarming that the Bill came into parliament without any provision for parliamentary oversight of the review process.* [107]

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[106] http://parlinfoweb.aph.gov.au/piweb//view_document.aspx?TABLE=HANSARDS&ID=1944533

[107] SENATE Official Hansard No. 15, Thursday, 5 December 2002 Research Involving Embryos Bill 2002

It was decided through these discussions that an amendment to the RIHE Bill would be accepted. This amendment in Section 19(3) set up the NHMRC Licensing Committee which is required to table six monthly reports in either House of Parliament on or before 30 June and 31 December each year, and at any other time as required by either House of Parliament. The reports must include information about both the operation of this Act and licences issued under the Act.[108]

The DCSG is saddened that this is required of a licensing committee which is dealing with embryos that will, in all likelihood never become living persons, but that when it comes to the lives of donor conceived people it is considered acceptable for the fertility industry to regulate itself and accredit itself and make no reports to Federal Parliament.

Within the RIHE Act it also states that:

> *(2) The Minister must appoint the members of the NHMRC Licensing Committee.*

and

> *(3) Before appointing a member, the Minister must*
>
> *(c) be satisfied upon receipt of a written declaration by the member proposed to be appointed that the member proposed does not have a direct or indirect pecuniary interest in a body that undertakes uses of excess ART embryos, being an interest of a kind that could conflict with the proper performance of the member's functions.*

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[108] http://www.nhmrc.gov.au/embryos/index.htm

The DCSG feels that the membership of RTAC, which is made up solely of people earning money from the fertility industry, has a serious conflict with its ability to perform its functions.

Our group has spent a great deal of time trying to understand exactly how the process of clinic accreditation works but this has been difficult considering the number of conflicting opinions and explanations we have received over the years. Our first example is from the Federal Government's Independent review of Assisted Reproductive Technology in 2006. This states that RTAC accreditation is not mandatory, that the creation of people by donor insemination may be provided in unaccredited units.

> *While RTAC accreditation is not a mandatory requirement for facilities that provide ART services in Australia, those facilities using embryos are required to be RTAC accredited under the Research Involving Human Embryos Act, 2002. Where no legislation exists in a state or territory to regulate the provision of ART services, the default position for regulation is voluntary accreditation with RTAC. RTAC is funded by, and draws its membership from relevant health care providers.*
>
> *If ART facilities are not RTAC accredited they may still provide ART services – other than IVF – in accordance with the various acts listed above. There is no mechanism in place to monitor the practice of non RTAC accredited facilities providing non IVF services such as IUI. The quality of service provision in these facilities is thus unknown. The*

> *introduction of national, mandatory accreditation would ensure that IUI is practiced to measurable and safe standards, reducing the risk of adverse health outcomes.*[109]

One of the key recommendations of this review was that:

> *both clinicians and patients would benefit from national accreditation of ART practices, underpinned by evidence-based guidelines;*

This was supported by Associate Professor Bernadette Tobin, Director of the Plunkett Centre for Ethics, who has sat on many review panels covering assisted reproductive technology. She claimed at the Sydney hearings of the Review, and in a submission, that RTAC does not monitor compliance with ethical guidelines and that this is a gap in the system; she said

> *The Fertility Society of Australia's Reproductive Technology Accreditation Committee does not monitor compliance with ethical guidelines … Nor do individual Human Research Ethics Committees: they are too busy, and their membership is not appropriate for monitoring compliance with ethical guidelines. There is, thus, a significant gap in the arrangements for monitoring the compliance of IVF clinics with ethical guidelines.*[110]

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[109] Report of the Independent Review of Assisted Reproductive Technologies 2006

[110] *Associate Professor Bernadette Tobin, Plunkett Centre for Ethics, Australian Catholic University (Submission LRC550)*
http://www.nhmrc.gov.au/research/embryos/review/_files/lrc_report_part_b_19dec05.pdf

In 2005 we wrote to the NHMRC to ask them was the accreditation process was and whether anyone in the government was overseeing the process. We were forwarded to the NHMRC Centre for Health Advice, Policy and Ethics and were informed by the then Acting Executive Director that in order to be accredited clinics had to comply with the NHMRC guidelines and that monitoring of compliance was the responsibility of RTAC.[111]

We then wrote to the then Chair of RTAC and also asked him about compliance with NHMRC guidelines. response stated that the relationship between the RTAC accreditation process and the implementation of the NHMRC guidelines was different to that expressed by . suggested that clinical practice could vary from the guidelines where the unit's ethics committee had considered an issue and decided that a different ethical approach to that specified in the NHMRC guidelines should be followed. He then went on to say that RTAC did not inspect units based on particular clauses in the NHMRC guidelines[112].

The 1999-99 RTAC Annual Report also mentions non-compliance with the NHMRC guidelines.

> ***Donor Services***
>
> *Provision of identifying information on the donors to the offspring has been policed by RTAC as part of the NHMRC Guidelines on Assisted Reproductive Technology 1996.*
>
> *(Section 3.1.5. Children bo0rn from the use of ART procedures are entitled to knowledge of their biological parents. Any person, and his or*

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[111] See appendix 32 for full letter.

[112] See appendix 33 for full letter

> *her spouse or partner, donating gametes and consenting to their use in an ART procedure where the intention is that a child may be born must, in addition to the information specified in this section, be informed that children may received identifying information about hem). However this has not been uniformly complied with because of different state laws and concern about the impact on donor recruitment. RTAC accepts that a Centre's Ethics Committee could indicate that the Centre need not comply with the NHMRC guidelines.*[113]

We asked about one particular section of the NHMRC Guidelines,

> *6.1.3 Working with relevant professional organisations, clinics should use forums for public information to encourage people who were donors before the introduction of these guidelines, and those previously conceived using donated gametes, to contact the clinic and register their consent to being contacted by their genetic children or genetic siblings and half-siblings, respectively.*[114]

We asked when clinics would be starting to implement this guideline. The response was that this was also an implementation issue and that we should raise it with RTAC.

We did raise this with stated that the FSA would be considered a relevant organisation.

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[113] See appendix 34 for Annual report

[114] NHMRC *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research2007.*

In a later letter[115] informed us that they were leaving the encouragement of past donors to come forward to an ABC Four Corners programme. This programme never eventuated and no clinic has ever used any forums for public information to encourage past donors to come forward. The DCSG would have thought that our group would have been one of the best places to start contacting past donors as we have had extensive contact with donors over the years but our group has never been approached to help with any advertising campaign by the FSA or any clinic except for one, the Royal Hospital for Women in Sydney. This public clinic is the only clinic in Australia that has set up its own voluntary register and to launch it they worked with a DCSG family who had children from that clinic. The register has had very limited success because of lack of a proper advertising campaign due to lack of money.

The National Health & Medical Research Council Ethical Guidelines on the use of assisted reproductive technology in clinical practice and research were reviewed and amended in 2007 mainly as a result of the Research Involving Embryos Act. These guidelines state:

> *6.13.1 When approached by a person who was conceived using donated gametes and who now seeks identifying information about his or her genetic parents, the clinic should examine the consent form of the gamete donor and proceed as follows:*
>
> *If the consent form does not include permission for release of identifying information (because the donation was made before the introduction of these guidelines and the gamete donor has not come forward in response to the public information campaign outlined in*

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[115] See appendix 35 for full letter

> *paragraph 6.1.3), the clinic should make an appropriate effort, consistent with the original consent document and the privacy rights of the donor, to contact the gamete donor and obtain his or her consent to the release of information.*

This guideline is assuming that there was a public information campaign to encourage past donors to come forward. We reiterate, this has never happened. How is it that the government has allowed clinics to ignore their responsibilities to donor conceived people as outlined in the NHMRC guidelines?

Rights of donor conceived people

The principles of medical ethics speak about non-malfeasance and doctors are supposed to ask themselves the question: will this decision or course of action cause physical, psychological or social harm?” The problem is that doctors treat infertile people and that is their focus. But infertility treatment, especially donor conception treatment, is qualitatively different to other medical treatment. Its aim is to create another person and so medical ethics in the case of donor conception must also consider the child that is being created.

There has also been a tradition of relating primarily to the interests of the adult parties.

There have been some changes in attitudes happening in recent years.

> *2.5 In these guidelines, AHEC has recognised that the welfare of people who may be born as a result of the use of ART is paramount.*[116]

> ***5 Guiding principles***
>
> *It is Parliament's intention that the following principles be given effect in administering this Act, carrying out functions under this Act, and in the carrying out of activities regulated by this Act—*

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[116] Pge 9 *Ethical guidelines on the use of assisted reproductive technology in clinical practice and research 2007 NHMRC*

> *(a) the welfare and interests of persons born or to be born as a result of treatment procedures are paramount;*[117]

Unfortunately these attitudes only apply prospectively. There has to be a review of what was done in the past and mistakes have to be fixed.

It is a basic human right to know of one's own heritage, it is a right that most adults take for granted. Some may argue that many people in today's society do not know a part of their heritage for a variety of reasons, however their right to seek information is not denied to them through any legislative or regulatory framework.

Some donor conceived people will be interested in accessing their genetic information while others will have no interest. In all the years that our group has been in existence we have met a great many adult donor conceived people some have wanted to access donor information while others have not but one thing they have all had in common is that they all felt that they should have the right to access information.

The DCSG believes that it would be a grave injustice if <u>any</u> donor conceived person is denied this basic human right to seek information about themselves.

If you say that a donor conceived person cannot have access to information on biological parents then you are saying that they are different and will be treated differently by the very nature of their conception and birth. This is discrimination; the type of discrimination that

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[117] *Pge 8Victorian Assisted Reproductive Treatment Act 2008.*

was supposed to have been done away with decades ago with the advent of adoption legislation.

In October 2005 the UNESCO Universal Declaration on Bioethics and Human Rights was accepted by the United Nations. It has a number of clauses that apply to donor conception:

> Also recognizing that decisions regarding ethical issues in medicine, life sciences and associated technologies may have an impact on individuals, families, groups or communities and humankind as a whole,
>
> Also bearing in mind that a person's identity includes biological, psychological, social, cultural and spiritual dimensions,
>
> **Article 10 – Equality, justice and equity**
>
> The fundamental equality of all human beings in dignity and rights is to be respected so that they are treated justly and equitably.
>
> **Article 11 – Non-discrimination and non-stigmatization**
>
> No individual or group should be discriminated against or stigmatized on any grounds, in violation of human dignity, human rights and fundamental freedoms.[118]

Australia has ratified a number of important international conventions. The two most important ones that apply to donor conceived people are the International Convention on the Rights of the Child and the International Covenant on Civil Rights. Both of these tell us that donor conceived people who are actively being denied access to information on their biological parents are being discriminated against.

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[118] http://portal.unesco.org/en/ev.php-URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html

The International Covenant on Civil and Political Rights

Article 26

All persons be guaranteed equal & effective protection under the law against discrimination on any ground such as race, colour, sex, language, religion, or other opinions, natural or social origin, property, ***birth*** *or other status.*

Ratified by Australia 2 September 1990

United Nations Convention on the Rights of the Child

Article 7

1. The child shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and. as far as possible, the right to know and be cared for by his or her parents.

2. States Parties shall ensure the implementation of these rights in accordance with their national law and their obligations under the relevant international instruments in this field, in particular where the child would otherwise be stateless.

Does this apply to donor conception? The UNICEF Implementation Handbook (2002) for the Convention on the Rights of the Child clearly states that it does.

Implementation Checklist Article 7

Does domestic law and administrative practice ensure that the *identities of children's parents (including genetic parents, birth mother and caring parents) are accurately recorded and preserved?*

Do children have the right to know from the earliest date possible the truth about the particular circumstances of their parenting (for example by adoption or by an artificial form of conception)?

<u>Do all children, including adopted children and children conceived by artificial forms of conception, have the right to know, as far as possible, who their genetic parents are?</u>

Is refusal of this right limited only to the grounds that refusal of information is necessary to protect the child from a likelihood of harm or is necessary to protect the child's parent from a likelihood of harm?

When children are refused the right to know parentage, are they able to reapply at a later date?

There are countries, such as Austria, that have given donor offspring the right to learn the identity of their donor based on this article of the Convention on the Rights of the Child. (*Reproductive Medicine Act* of Austria states that a person conceived following sperm donation has the right to learn the identity of his/her genetic father on reaching the age of fourteen)

Article 2

1. States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without

> *discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.*
>
> *2. States Parties shall take all appropriate measures to ensure that the child is protected against all forms of discrimination or punishment on the basis of the status, activities, expressed opinions, or beliefs of the child's parents, legal guardians, or family members.*

This article provides for protection against discrimination. As others have argued it could be claimed that withholding information from a donor-conceived person about his/her genetic origins and who they are related to (half siblings) could be discriminatory. [119]

> ***Article 3***
> *1. In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.*

The Victorian Assisted Reproductive Treatment Act 2008 states that the best interests of the child are paramount.

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[119] Anonymity in donor-assisted conception and the UN Convention on the Rights of the Child The international Journal of Children's Rights 2004. Eric Blyth Professor of Social Work University of Huddersfield UK

> ***5. Guiding principles***
>
> *(a) the welfare and interests of any person born or to be born as a result of a treatment procedures are paramount;*

PRIMARY AND PARAMOUNT, these are words that are used in a great many documents that are concerned with assisted reproductive technology including the NHMRC guidelines on the use of assisted reproductive technology (2007). These words are telling us that the welfare of donor conceived people should be considered as more important than all others.

The DCSG firmly believes that to withhold information about identity, medical histories and relationships from people conceived by donated gametes is not treating their interests as paramount or as a primary consideration; in fact it is treating them in quite the opposite way, withholding from them rights that the rest of us accept as our due.

One donor conceived person expressed it like this:

> *I feel access to our genetic information, medical history and indeed family is so obviously necessary that I can barely cope with talking to anyone who thinks differently. DI offspring are the only current group of people who are denied this right due to the convenience of everyone other than themselves.*[120]

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[120] Let the Offspring Speak The Donor conception Support Group Of Australia Inc.1997 ISBN 0 646 32494 2

All the adult offspring in our group feel that donor offspring should have access to identifying information on their donors. Because of the importance of this to them they feel that it should be a right mandated by law.

I, personally, have nothing against assisted conception procedures. I believe it is tragic to see couples live without their one desire - children. What I believe is that in the past the procedures should have been conducted in a far more organised, insightful and compassionate manner. The community should be learning from the mistakes they made with the denial of birth information to adoptees, not making them all over again. This issue is not going to go away, it is going to escalate. Mark my words, Nikky and I are only the first of many who will come forward seeking information and answers from the doctors.

Lauren, a 21 year old conceived by d.i.

I attempt to over compensate for the loss of half my identity by holding on to the hope of one day finding out who my father was or is...and by harassing my mother to write down all she can remember about her childhood, her brothers and sisters, grandparents, parents, aunties, great aunts...I'm always searching for similar personality traits and interests in an attempt to affirm who I am and why I am what I am....

My sense of identity wavers from time to time and often I think how I'll feel when my mother dies....as she is my only immediate biological link.... I think I'll feel very alone...solitary...and I wonder how that will impact on my own relationships...both with men and with my own children, when I have them. I also wonder how my children will feel, not

> *being able to know a quarter of their biological heritage.*
>
> *These are a few of the reasons why I believe children conceived through donor insemination should be able to have access to information about their biological fathers and even better, to have contact with them if both parties agree to it. It would eliminate questions, anxieties, fantasies and wasted energy....*
> *Nicky, a d.i. offspring in her* 30.s.

> *I can't believe that intelligent, well-educated people wouldn't think that this information is important to me.*
> *A 30 year old conceived by d.i.*[121]

> *Regardless of whether knowing one's genetic heritage does or does not cause serious psychological problems, is it fair to deprive a DI child of information that other children assume is theirs by right? Is it fair to deny that child, and future adult, the right to know the truth concerning such a fundamental issue as her/his genetic background?*[122]

Many parents have only come to understand the needs of donor conceived people after they have had their own children.

> *My children may just be satisfied to not know him or thy might want to know his name or see him from a distance, or they might like to meet*

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[121] The above quotes are all from "*Let The Offspring Speak"* Donor Conception Support group of Australia, 1997.

[122] Ibid.

> *him, or simply shake his hand and say thanks. I strongly feel that this should be their natural right like any other child, why should they be kept in the dark? We are all guilty of not thinking about how this will affect the children conceived through donor insemination. Why is it that they are the only group of Australian children that currently have no rights? Why isn't their (sic) legislation in place to keep all records of donor and children information, including health, current address and dead or alive information. Why should they be denied the right to know?*
>
> *I contacted the clinic and asked for more information on the donor, they provided me with some more non-identifying information, I have asked if they could give me his name and current address but they said they can't, as identifying information about the donor is anonymous. Since then (16th July 2002) I wrote to the ……...Clinic asking them to get in contact with the donor to ask him is (sic) he would consider making himself available to meet my children when they come of age if they so wish and if he could provide us with any updated medical information about himself or family history etc. As you will see from my letter I thought that it was the law for all identifying information to the (sic) anonymous but now know that there is now (sic) laws/legislation protecting the rights of donor children and that it is mearly (sic) the clinic rules. They say they have no current address for him, have no idea where he is and will make no attempt to find him.* [123]

One family felt so strongly about their children's right to know that they wrote a letter to the Age newspaper.

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[123] See appendix 36 for full letter

> *My husband and I fully support our children's need to know their genetic and medical histories if they should at any time want to.*
> *No one person owns genetic or medical history, not the donors and definitely not the medical profession.*
> *To deny a human being their right to medical and genetic history is a denial of human rights under the United Nations Charter that Australia is a signatory to. Are the guardians of genetic information prepared for litigation in the future?*[124]

There are huge numbers of recipient parents who support the need for a federal register to store and give access to information.

> *I support the establishing/disclosure of a registry for D.I. children similar to the current adoption register (with the possibility of a veto from either party concerned: either the child or the donor). This information <u>should</u> be retrospective. Children should have access to D.N.A. information that could be important both to the child but perhaps also to their children – so many discoveries are happening at the moment in this developing field of science eg. Recent discovery of the gene responsible for some forms of breast cancer that are genetically linked.*
>
> *I think it is important for children to have information about their genetic parent, and their sense of identity otherwise a child will have so many unanswered questions about how/why they are the way they are !!*[125]

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[124] See appendix 37 for full letter
[125] See appendix 38 for full letter

One of the sperm donors who has been a member of our group for many years wrote in 2002.

> *In this day and age, any hospitals, clinics, and donors or couples who participate in this program without providing identifying information for the resulting children are, in my opinion, putting their own needs and insecurities first. Put simply, a moral obligation exists to give donor conception offspring the option to trace their own biological origins. Sooner or later, these kids will suspect or want to know the truth about themselves, for themselves. In all honesty, who wouldn't. Deliberately withholding information from someone, child or adult puts them at a distinct unfair advantage.*[126]

He finished his letter with a comment from one of his own children (who do know that he was a donor).

> *When I asked my daughter how she would feel if someone withheld crucial information from her, she replied "Pissed off". I think that says it all.* [127]

This donor conceived person supports the need for a National Register as do so many other people.

> *I completely support the efforts to make a national inquiry into Donor Conception and feel that we need to take the awareness of Donor Conception to a higher level.*
> *I'm sure so many people think that this kind of stuff doesn't happen to them; they know next to nothing about the topic and wouldn't have*

---

[126] See appendix 39 for full letter
[127] Ibid

> *given any consideration to the implications of Donor Conception on the child and the child's family.*
>
> *I was one of those people. I didn't know anything about the topic and never thought I would need to. Sometimes I wonder if I had have known that this could have been possible, I could have handled the situation better when I found out.*
>
> *I never thought it would be this hard to get some basic information about my origins when it should really be a human right.*[128]

The denial of such rights of access to one group, i.e. donor conceived people, within the broader community can have severe adverse affects on their perception of themselves and their position in the world. We are concerned that denial of such rights purely on the basis of their date of birth has produced a minority group afforded less rights than those of their younger counterparts.

With this Inquiry the Australian Government has the chance to enact world leading legislation which will give all donor conceived people the right to knowledge of their biological heritage no matter when they were born.

---

[128] See appendix 40 for full letter.

Executive Summary

Legislation

Donor conception is so qualitatively different to other forms of assisted reproductive technology that it needs separate legislation that deals with the long term effects of family creation using donated sperm, eggs or embryos.

National Register

- That the Federal Government legislates to set up a National Donor Conception Register independent of service providers that will store the identity of gamete and embryo donors, recipient parents and donor conceived people past and present.
- That the Register be maintained by an Authority set up by the Federal Government.
- That service providers must notify the Authority of all treatment procedures that use donated gametes and embryos.
- There must be compulsory notification by the service providers of all births (where known) from donated gametes and embryos.
- That parents be encouraged to also inform the Authority of all births from donated gametes or embryos.
- That the notification of births be linked to the Registers of Births, Deaths and Marriages so that Birth certificates of donor conceived people will have an appended note available only to the donor person which gives information about the nature of their conception.
- All records, where they still exist, of past gamete and embryo donations plus treatments with donated gametes should be compulsorily acquired by the Authority as these records contain the

identity of donor conceived people that cannot be obtained any other way.

- All records that will be stored on the Authority Register must be kept in perpetuity.

Access to Information

- All donor conceived people no matter when they were born should be able to access identifying information on their donor (if this information is still in existence) through the Authority Register.
- While donor conceived people should have the right to access identifying information about their donor a veto system akin to that used in adoption should be available to prevent unwanted contact between parties.
- Donor conceived people who need to use DNA testing to obtain a match with a donor because of the destruction of records must not incur a charge for this service.
- Donor conceived people and the children of the donors (in their own families) should be able to access, as of right, the year of birth and sex of all other of their half/full siblings (full in the case of embryo donation).
- Donor conceived people, their half siblings (full in the case of embryo donation) and the children of the donors (in their own families) should be able to share information or make contact with each other on a voluntary basis through the Authority Register.

Support & Counselling

- Counselling must be a mandatory part of entry onto a donor conception programme.

- The Authority must make counsellors available to all people requesting information from the Register. In the event of making contact for the first time, counseling should be made compulsory.

Awareness

- The Authority must conduct nationwide campaigns to:
  - Advertise the Register
  - Encourage past donors to come forward
  - To encourage parents to tell their children the truth about their conception
  - Raise awareness of donor conception.

Regulation

- Accreditation of service providers must be conducted by a licensing committee independent of the service providers. This committee must be accountable to the Federal Parliament.

Limit on Number of Births from Donated Sperm, Eggs and Embryos

- The number of families allowed to be created from one donors must be limited to no more than 5 including the donor's own family.

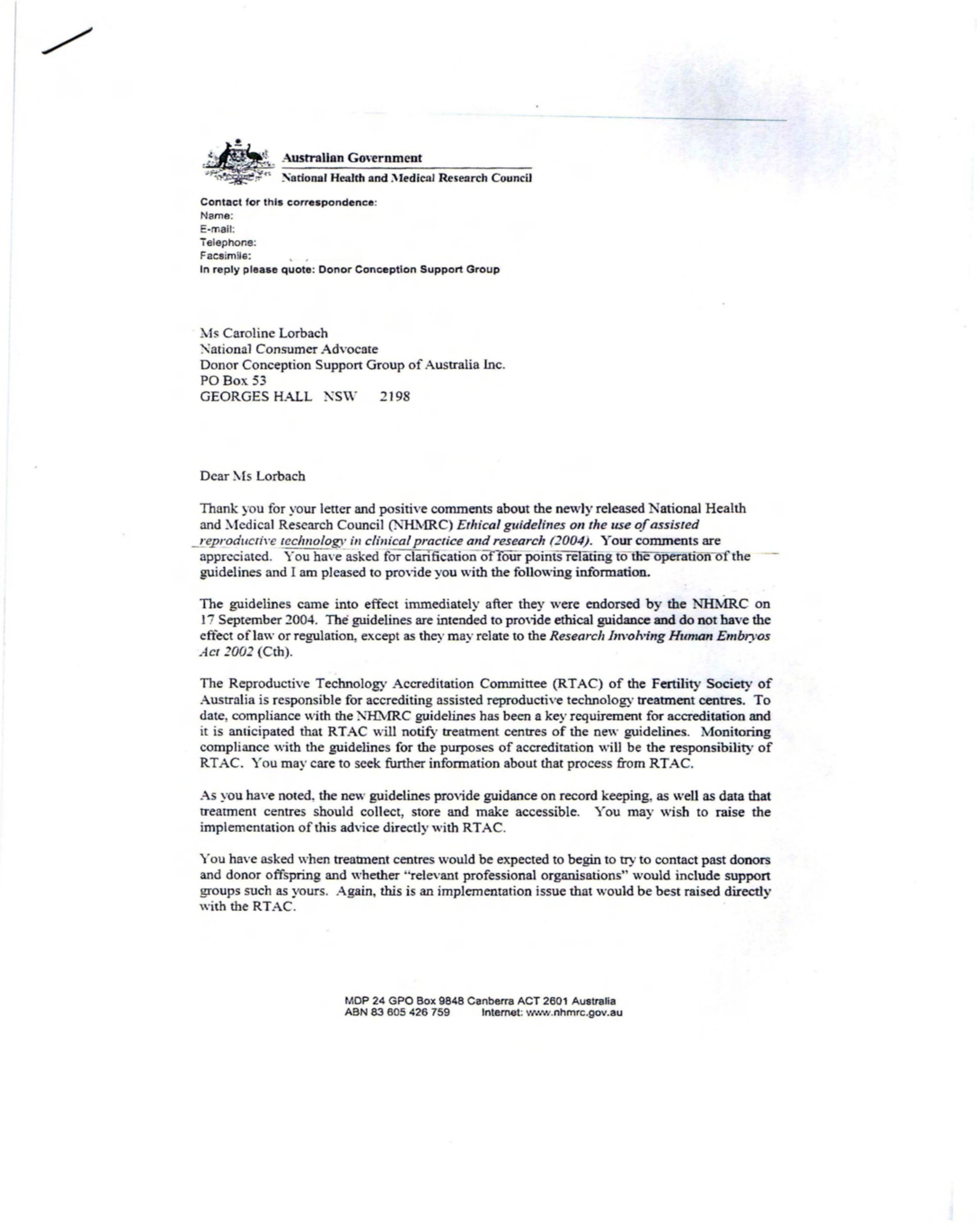
Payment of Donors

- Donors must be truly 'donors'. Reimbursement for travel expenses or parking may be allowed. The definition of reimbursement must be defined.

Appendices

Appendices 1-31	**Confidential**
Appendix 32	**Attached**
Appendix 33	**Attached**
Appendix 34	**Confidential**
Appendix 35	**Attached**
Appendices 36-40	**Confidential**

Appendix 32



Australian Government
National Health and Medical Research Council

Contact for this correspondence:
Name:
E-mail:
Telephone:
Facsimile:
In reply please quote: Donor Conception Support Group

Ms Caroline Lorbach
National Consumer Advocate
Donor Conception Support Group of Australia Inc.
PO Box 53
GEORGES HALL NSW 2198

Dear Ms Lorbach

Thank you for your letter and positive comments about the newly released National Health and Medical Research Council (NHMRC) *Ethical guidelines on the use of assisted reproductive technology in clinical practice and research (2004).* Your comments are appreciated. You have asked for clarification of four points relating to the operation of the guidelines and I am pleased to provide you with the following information.

The guidelines came into effect immediately after they were endorsed by the NHMRC on 17 September 2004. The guidelines are intended to provide ethical guidance and do not have the effect of law or regulation, except as they may relate to the *Research Involving Human Embryos Act 2002* (Cth).

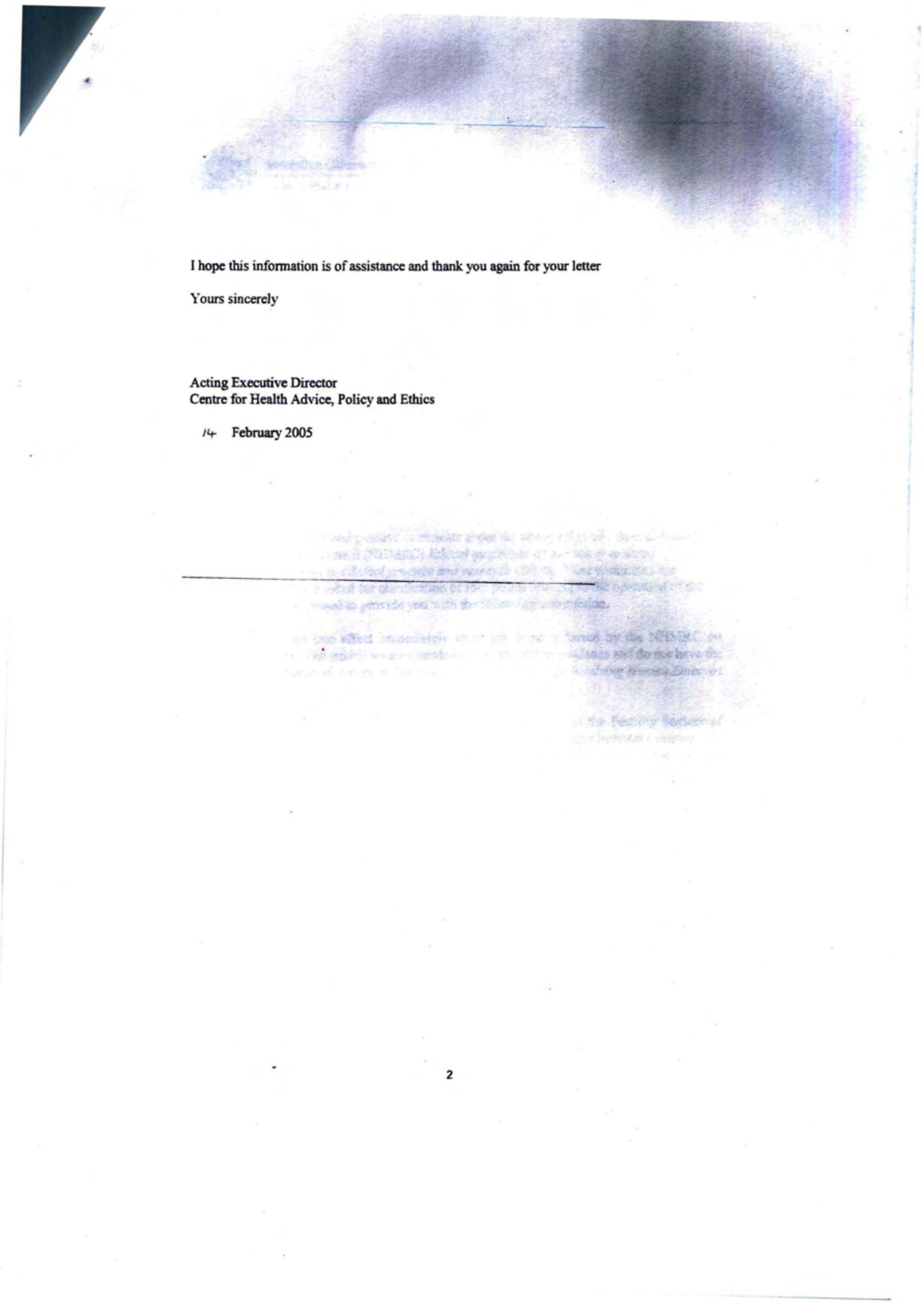
The Reproductive Technology Accreditation Committee (RTAC) of the Fertility Society of Australia is responsible for accrediting assisted reproductive technology treatment centres. To date, compliance with the NHMRC guidelines has been a key requirement for accreditation and it is anticipated that RTAC will notify treatment centres of the new guidelines. Monitoring compliance with the guidelines for the purposes of accreditation will be the responsibility of RTAC. You may care to seek further information about that process from RTAC.

As you have noted, the new guidelines provide guidance on record keeping, as well as data that treatment centres should collect, store and make accessible. You may wish to raise the implementation of this advice directly with RTAC.

You have asked when treatment centres would be expected to begin to try to contact past donors and donor offspring and whether "relevant professional organisations" would include support groups such as yours. Again, this is an implementation issue that would be best raised directly with the RTAC.

MDP 24 GPO Box 9848 Canberra ACT 2601 Australia
ABN 83 605 426 759 Internet: www.nhmrc.gov.au

Appendix 32



I hope this information is of assistance and thank you again for your letter

Yours sincerely

Acting Executive Director
Centre for Health Advice, Policy and Ethics

14 February 2005

Appendix 33

The Fertility Society of Australia
-- REPRODUCTIVE TECHNOLOGY ACCREDITATION COMMITTEE
c/o Waldron Smith Management, 61 Danks St, Port Melbourne, Vic 3207

9th June, 200

Ms Caroline Lorbach
National Consumer Advocate
Donor Conception Support Group of Australia Inc.
PO Box 53
GEORGES HALL, NSW, 2198

Dear Ms Lorbach,

Re: Questions related to NHMRC Ethical Guidelines.

Thank you for your letter of 29`i' May, 2005 regarding implementation of the *NHMRC Ethical guidelines on the use of assisted reproductive technology in clinical practice and research (2004).* Your letter includes a response from the NHMRC to questions you have posed.

There are a number of issues raised in the letter. In order for me to give my committee an adequate opportunity to discuss the questions I will not be able to provide any specific answers until after our next meeting in late September. RTAC only has two committee meetings each year. I am keen to obtain some comments from other members particularly the consumer representatives from ACCESS.

In order for me to expedite the distribution for discussion it would be helpful if you could forward an electronic copy of your letter as an email attachment to the RTAC Secretariat. The address is You should use this address for all communication with RTAC wherever possible.

In the interim you should note that it is my opinion that the relationship between the RTAC accreditation process and the implementation of NHMRC guidelines is different to that expressed by

RTAC's terms of reference are to set standards for ART units, document these in the Code of Practice (2005) and ensure units comply with this COP. The latest version of the COP (2005) states:

1.18 Ethical guidelines

> The activities of ART units in Australia, whether therapeutic or experimental, must be directed by relevant guidelines. Those published by the NHMRC include the *National Statement on Ethical Conduct in Research Involving Humans* (NHMRC 1999; referred to in this code as the NHMRC National Statement) and the NHMRC *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* (September 2004; referred to as the NHMRC ART Ethical Guidelines). NHMRC guidelines can be found at the NHMRC website.
>
> The NHMRC ART Ethical Guidelines are to be followed by all ART units in Australia. Practice that varies from those guidelines will only be permitted where:
>
> - the unit has prepared a quality assurance proposal for the proposed variation; and
> - the unit's HREC has considered the issue in detail and provided written direction that an alternative ethical approach to that specified in the NHMRC guidelines is to be followed.

Appendix 33

1.19 Ethics committee oversight

> Every ART unit must have all relevant aspects of its program monitored by the appropriate ethics committee of the hospital or the institution concerned.
>
> In Australia, the ethics committee must be an HREC, properly constituted according to the NHMRC National Statement.
>
> The ethics committee must be informed of substantive changes in clinical practice and ART procedures.

So RTAC expects units to follow the NHMRC guidelines and the unit's respective ethics committee is assigned as the monitoring agent. It is mandatory for each unit to have an NHMRC approved ethics committee and all units sign a deed of agreement (Attachment H) with RTAC that states they abide by the Code of Practice.

You can see from these statements that RTAC does not inspect units based on particular clauses in the NHMRC guidelines. RTAC has no input into the framing of the NHMRC guidelines and it cannot make any alterations to these guidelines. You are already aware that in general the guidelines do not have the effect of law or regulation. I will be writing to to ensure she is aware of the responsibilities of RTAC as I see them.

With respect to the question of "relevant professional organisation", I believe that he Fertility Society of Australia (FSA) falls under that umbrella and I will bring this matter to the attention of the President of the FSA.

Similarly, the question of the collection of data on donor sperm use by insemination and outcomes will be brought to the attention of the FSA. Currently there is no national data compiling as there is for IVF and related techniques. RTAC does not administer the NPSU/ANZARD process.

I look forward to receiving an electronic version of the letter for distribution to my committee and will reply again later in the year after the next RTAC committee meeting. I will also forward a copy of your correspondence to the FSA.

Yours sincerely,

Chair - Reproductive Technology Accreditation Committee

Appendix 35

Reproductive Technology Accreditation Committee (RTAC)
c/o Waldron Smith Management, 61 Danks St, Port Melbourne, Vic 3207

17th October 2005

Ms Caroline Lorbach
National Consumer Advocate
Donor Conception Support Group of Australia Inc.
PO Box 53
GEORGES HALL, NSW, 2198

Dear Ms Lorbach,

Re: Questions related to NHMRC Ethical Guidelines.

Earlier in the year I wrote in reply to your letter of 29th May, 2005 regarding implementation of the *NHMRC Ethical guidelines on the use of assisted reproductive technology in clinical practice and research (2004).* At that time I indicated that the matter would be discussed at our committee meeting in September.

The meeting was held in Sydney on Tuesday 20th September, 2005 and there were 15 members plus myself present. There was some time spent in discussion of the matters you presented.

The committee agreed with the general issue that formed the basis of my earlier response that RTAC has a responsibility to ensure all accredited units are informed of the NH&MRC guidelines and that these are followed by each unit with monitoring by their local ethics committee. It is a compulsory requirement under the revised RTAC Code of Practice (COP version 2005) that the local ethics committee is registered with the NH&MRC and RTAC is strictly applying all of the compulsory action clauses.

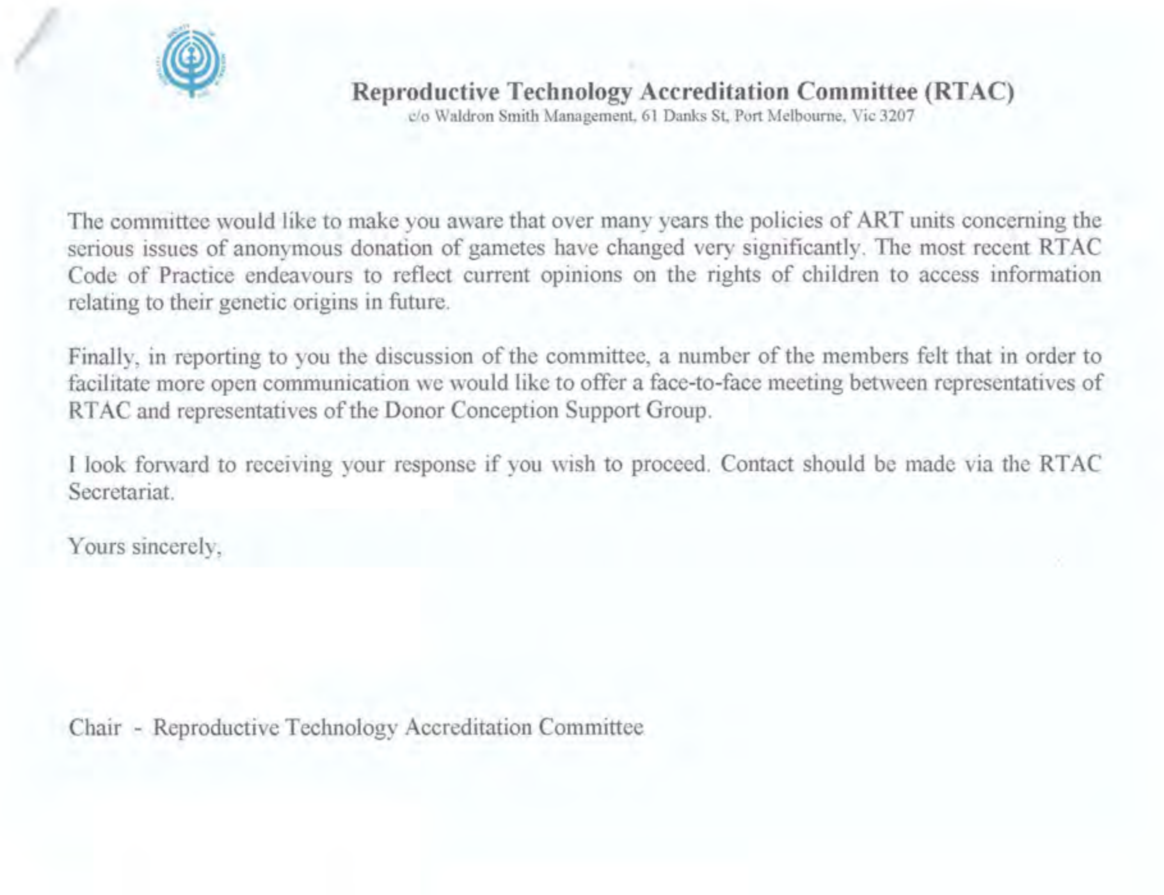
As I have previously stated, RTAC's terms of reference are to set standards for ART units, document these in the Code of Practice (2005) and ensure units comply with this COP. The latest RTAC Code of Practice was released in February 2005. ART units have until 2006 to fully comply with these requirements. Investigation shows that ART units are implementing changes to address issues relating to donor identification. As many donors are required to undergo further counselling and consenting, this process will take some time thus the allowance for implementation. I understand from the Secretariat that you have been supplied with a copy of that document.

The issues you have raised are mostly in response to the NH&MRC guidelines. These guidelines have been implemented from 2004. With respect to the collection of data on treatments using donated semen (both by insemination and IVF) the information I previously supplied was incorrect. All accredited ART units are required to supply such data to ANZARD and again this is a compulsory action for RTAC accreditation. The data are being collected and statistics related to donor semen insemination appear in the ANZARD data report of the National Perinatal Statistics Unit (NPSU) from 2002. These can be viewed at the following website: www.aihw.gov.au/npsu/

With respect to the question of "relevant professional organisation", the Fertility Society of Australia (FSA) has been informed and I understand that recently it was suggested to the TV program "4 Corners" by , the President of the FSA, that the issue could be positively handled in a specific program that they are preparing. It is hoped that this show may encourage people who donated in the past to come forward and offer to update their non-identifying information or supply identifying information to ART units or regulatory bodies like the Infertility Treatment Authority in Victoria.

The COP does have a clause regarding the payment of donors for their gametes or embryos and we are unaware of any units that pay inducements other than for reimbursement of donors' expenses in attending and donating. As identifying information about donors must be retained either at units where treatment takes place or at units where the material was originally donated, we believe the previous practice of importing semen where the identity of the donor is obscured has ceased.

Appendix 35



Reproductive Technology Accreditation Committee (RTAC)
c/o Waldron Smith Management, 61 Danks St, Port Melbourne, Vic 3207

The committee would like to make you aware that over many years the policies of ART units concerning the serious issues of anonymous donation of gametes have changed very significantly. The most recent RTAC Code of Practice endeavours to reflect current opinions on the rights of children to access information relating to their genetic origins in future.

Finally, in reporting to you the discussion of the committee, a number of the members felt that in order to facilitate more open communication we would like to offer a face-to-face meeting between representatives of RTAC and representatives of the Donor Conception Support Group.

I look forward to receiving your response if you wish to proceed. Contact should be made via the RTAC Secretariat.

Yours sincerely,

Chair - Reproductive Technology Accreditation Committee