Submission No 5

MANAGING INFORMATION RELATED TO DONOR CONCEPTION

Organisation: Donor Conception Support Group of Australia

Name: Ms Caroline Lorbach

Position: National Consumer Advocate

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DONOR CONCEPTION SUPPORT GROUP OF AUSTRALIA INC.

[redacted]

Website: www.dcsg.org.au
ABN: 57 033 493 921

To the Law and Safety Committee

Of the NSW Parliament.

Dear Committee Members, we would like to send our sincere thanks to the committee for the work that you have already done in the area of donor conception and birth certificates and for you continued interest in our issues.

Attached is our submission to the current inquiry and also an appendix with information relating to part of that submission.

The DCSG would be pleased to send representatives to speak with the committee if required.

Yours Sincerely

Caroline Lorbach

National Consumer Advocate

DCSG

[redacted]

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

It is a basic human right to know of one's origins. Every person should have a right of access to information about 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, *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.* [1]

It was discussions such as those that preceded the enactment of NSW legislation allowing 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*

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

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."[23]

Prior to the enactment of the NSW *Adoption Information Act (1990)*(AIA) adult adoptees who were not able to access information spoke 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 decisions made for and about them, and experienced this as a lack of control and self-determination over their own lives and futures. These feelings are mirrored in donor conception today.

We understand the controversial nature of retrospective information rights, and empathise with the fears of some clinics, some parents and some donors. 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.

Currently, because of destruction of some records or because some clinics will not attempt to contact donors, the only way that some donor conceived people can access information on their donor is to make a public plea for that person to come forward.

By 17, Geraldine had a lot of unanswered questions about her donor. "In reply to my inquiries to the Royal Hospital for Women, where I was conceived, I received a letter saying I was 'one of four live births'. I felt like a clinical statistic. They told me I have one half brother and two half sisters somewhere, all conceived and born in 1983.

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

"My donor is apparently blond, blue eyed, 5 feet 8 inches [173 centimetres], fair skin, average build, Caucasian and O+ blood type," she says. "I knew some other girls who were conceived at RHW and we compared our little descriptors and they were all the same. You couldn't get a more bland description if you tried."

Donors participating in early artificial insemination by donor programs in the '70s and '80s were routinely screened for infectious diseases and given a medical history, but the information was generally sketchy.

Today, screening is carried out for genetic disorders common in certain populations, such as cystic fibrosis in Caucasian donors, Tay-Sachs disease in Jewish donors and sickle-cell anaemia in those with an African background. Tests are available in Australia for about 300 genetic disorders, but it is not feasible to blanket-screen prospective donors.

However, it should be noted that couples who have their own biological children do not generally blanket screen each other, either.

"As with all of us there is a risk of heritable diseases, but donor-conceived adults have the fear of the unknown," says Hewitt. "Even where some families' records have been destroyed during the war, people growing up with their biological relations have the oral history of their extended family.

"One effect of not knowing my family medical history is that I am paranoid about my health. I put my hand up for any available health checks, because I don't have prior knowledge that would enable me to take preventative health measures.

"Donor-conceived adults will have needs in the future. Even if this is not imperative at 18, it will be when we have our first child or if we have a medical problem.

"Family medical histories of donors need to be updated regularly and held by a central

body. I don't think anybody else should be created until the laws are brought up to speed."[3]

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).[4]

Other donor conceived people have had to rely on luck to find information.

... suggested I contact a group she had found on the internet - the Donor Conception Support Group - for advice. They gave me some really helpful counselling and support, although I still couldn't come to terms with never knowing who my father was.

After some time, I was invited to one of their meetings to help lobby for a voluntary donor registry. It wouldn't help me because a register would not be retrospective, but I didn't want anybody else to go through the same experience as me.

The first person I saw at the meeting was a sperm donor called Peter Browne, who was hoping to trace his offspring - one son and one daughter. I had a strong, instant reaction to him.

Something told me I had to speak to him, and I had a bizarre feeling we had a connection. When I introduced myself, I noticed I looked like him, but I told myself I was just being silly and clutching at straws.

[3] http://www.smh.com.au/news/health/theory-of-relativity/2005/09/01/1125302660799.html
[4] Letter to the DCSG from donor offspring "J"

Discovering that he had donated sperm in 1980-1981 made my heart beat faster - I was born in 1982 - but I told myself to put him out of my head. After all, the odds of him being my dad were literally millions to one.

Weeks later, I still couldn't put him out of my mind and asked the support group to ask Peter if he would agree to a DNA test. Looking back it seems absurd, but a sixth sense urged me to do it.

To my relief, Peter, an accountant, readily agreed - I think he had sensed a connection, too - and while we waited for the results he appeared on a television discussion about donors.

The presenter asked him: "What would it mean to you if you were to find your donor offspring?" Peter replied: "It would validate my whole existence." That comment really floored me, and I hoped against hope he was my real dad.

When, six weeks later, the social worker invited me to the hospital where I was conceived to give me the DNA results, I reminded myself they hadn't matched a single parent and child in the past 20 years of testing.

But that was about to change. Reading those magical words "99.9 per cent probability" changed my life in an instant. Peter - the stranger I'd bumped into by chance - was my natural father. It seemed incredible, but there was no way in the world our DNA would match so precisely if I weren't his child.

The social worker gave me Peter's phone number, but it took me several days to pluck up the courage to ring him. Despite hearing what Peter had said on TV, I think part of me feared rejection again.

When I finally phoned him, I said something like: "This is a bit weird, but I think you're my father" - to which he replied: "I know, I've been waiting for your call."

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. She had been informed by the clinic that no records had been kept at the time of her conception but that her donor was most probably 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 going relationship with my donor – I already have two loving parents.[5]

She received some lovely replies from many of the men wishing her luck in her search but she never found her donor.

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. One area of opposition to proposed changes surrounded donors & consent.

It is indeed true that most doctors and fertility clinics did require donors to sign anonymity agreements but our group has been contacted by donors who have stated that signing these documents was not an option; they signed them or they would not be considered suitable to donate. So anonymity was not necessarily requested by donors but by the medical profession.

[5] Letter given to the DCSG by donor offspring "R"

Further to the article in the weekend papers, I was a sperm donor during 1997-1998. Attached to the ……. Hospital in Melbourne, 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.[6]

Many clinics also had parents sign similar forms which stated that they would not try and seek out the identity of their donor.

In the early days neither donors nor parents received counselling or information on the long term consequences of donation. This brings up the question of whether the forms signed by both donors and parents were signed with informed consent.

I received no counselling, nor can I remember undergoing a medical check, other than completing forms outlining my medical details and history. I was given the assurance that my anonymity would be preserved which wasn't- and still isn't – a concern.[7]

And, of course, donor conceived people never had a chance to for a say in the nature of their conception; never signed any forms to say that they would not seek out identifying information about their donors.

There was also concern that allowing adoptees retrospective access to information would be a breach of a 'contract' entered into years before because privacy (and secrecy) was enshrined in The Adoption of Children Act, 1965. 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

[6] "P" DCSG written communication from donor.
[7] "PH" DCSG written communication with donor

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[8] 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"*[9]

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.*[10]

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

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

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

"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."[11]

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.[12]

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".[13]

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

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

[13] Letter from parent "C"

"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."[14]

"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."[15]

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

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

[14] 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.
[15] Jean-Marie Thevoz - Foundation Louis Jeantet de Medicine, Geneva, Switzerland. Pge 201 *"Creating the Child - The Ethics, Law and Practice of Assisted procreation"*

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. [16]

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.

[16] Letter from Parent "D" to DCSG

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.

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 heart 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. [17]

[17] Letter from Donor "P"

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 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 they 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?

While a great many comparisons have been made between adoption and donor conception there is one fundamental difference; children are, for the most part, adopted because of tragedy or unintended mistakes but donor conceived people feel that their loss of information 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.

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

There has been much talk over the years about the "competing rights" of parents, donors and offspring in donor conception but we feel that it is not helpful to talk about "competing rights". All people involved in donor conception have a right to privacy and this should and can be upheld.

The protection of privacy works very well in adoption

In Victoria, Australia, the state granted adopted adults unconditional access to their

> original birth certificate retroactively with mandatory counseling.[18]

As in NSW there were many fears surrounding this move but as time went on these fears were not realized; approaches for information and/or contact were made with sensitivity for the feelings of the other party[19]

The DCSG feels strongly that donor conceived people should be given access to identifying information on their donors (where it still exists) and all parties should be given the ability to place contact vetoes on their files, as in adoption. In this way the privacy of all parties will be respected while still giving donor conceived people the ability to access information that is vitally important to a great many of them.

If donors wished it, the power to put contact vetoes in place would involve virtually no disruption to the lives of donors and their families.

Implementing retrospective legislation should go hand in hand with a public advertising campaign giving donors and donor conceived people the opportunity to revisit donor conception issues and put contact vetoes in place if that is what they wish.

In the adoption debate around Australia there was fears that a contact veto system may not work.

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*

[18] Does Opening Adoption Records Have an Adverse Social Impact? Some Lessons from the U.S., Great Britain, and Australia, 1953–2007 E. Wayne Carp, PhD Adoption Quarterly, Vol. 10(3–4), 2007 by The Haworth Press.

[19] GeraldMcPhee, MarilynWebster 1993, Marshall & McDonald, 2001; Swain, 1992.

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 all who initiate them, and positive or acceptable by the majority of those who are contacted[20].

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.[21]

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."[22]

The Contact Veto system in adoption has worked well for many years and participants have treated each other with sensitivity and respect. This experience would beg the question why would those involved in donor conception be any different?

[20] http://www.lawlink.nsw.gov.au/lrc.nsf/pages/R69EXEC
[21] http://www.communities.qld.gov.au/resources/childsafety/about-us/legislation/balancing-privacy-and-access.pdf
[22] McDonald, M., *Developments in Adoption Information Legislation in Australia.* Unpublished paper. Circa 1992.

While we acknowledge that some donors may feel apprehension about the retrospective release of their details it is often because of lack of information that they feel this way and for those donors a publicity campaign could go a long way to alleviating those fears.

Our group has met many donors over the years who are not afraid of contact:

My first donor child is due next month and if that child searches for me one day, I'll meet him or her[23]

In 1975 I donated at the…….. Hospital for ……. I have often wondered what happened and would be happy to correspond, possibly meet any offspring, or just provide mine and my parent's medical history.[24]

I decided that I would have been more than happy for any children (now young adults!) conceived as a result of my donations, to know something about me, their biological father, and even to make contact, should they desire.[25]

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

It is the opinion of the DCSG that donor conception records and access to these records should be managed by either an independent authority (as was the case in Victoria with the Infertility Treatment Authority) or by an agency such as Births, Deaths and Marriages. Further discussion of these issues is in the next few questions.

[23] "N" DCSG written communication with donor
[24] "R" DCSG written communication with donor
[25] "A" DCSG written communication with donor

One of the most helpful things that could be done to mitigate any possible problems would be a public advertising campaign that would provide information to all parties involved in donor conception, including information on legal issues, registers and counselling available.

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

The DCSG's preference is for an independent authority to be given the task of managing donor conception records and registers but if this cannot be done then our suggestion would be either the BDM or the Department of Community Services. As you are aware the Health Department currently manages the NSW donor conception registers within the Private Healthcare Branch. Our group is of the strong opinion that this is not the correct place for donor conception registers nor the place for facilitating birth origin information sharing.

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

There are a number of shortcomings in the current service model for the donor conception registers in NSW including problems with accessing counselling services as the current Register provides no counselling and no proper referrals for counselling nor support services.

This means that when people make applications to have their details placed on the Voluntary Register no counselling is available. If a person applies for identifying information and is told that this information is not available to them (there may be many reasons for this denial) there is no counselling or support available to them.

The issues surrounding donor conception are not short lived and for some they may be affected for many years; there is no capacity for ongoing counselling within the current system.

Because of these shortcomings the DCSG would recommend a standalone body would be the best service model as it can contain most of what is needed for the support of those involved in donor conception within a "one stop shop". Proper training can be given to those managing the body and these people can also draw on the decades of experience that a group like the DCSG has.

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

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 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.

Clinics do provide more support, post conception, 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."

While our group has found a great many excellent counsellors working in clinics we do need to make people aware they are in the employ of the industry and are also, not specifically trained in the area of birth origin information.

Currently the only referral that the NSW Registers give for counselling is to refer people to the ANZICA page on the Fertility Society of Australia website[26]. On searching through the pages on the FSA website that are linked to this initial page it is possible to find contact details for the committee members of ANZICA; so not all fertility counsellors are listed. Apart from this problem there is an additional even greater problem; these counsellors are "fertility" counsellors; they are not birth origin counsellors so may well not be the best place to send people who are dealing with issues of identity, access to information or relationship issues.

There is also a need for support and counselling in the area of telling children.

One of the most important roles the DCSG has 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 in talking to their own children about donor conception. 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.

The support that the DCSG gives has become more limited in recent times as we have no funding and so cannot have anywhere near the capacity for support that an organisation such as the Victorian Infertility Treatment Authority may have.

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) which is funded by the Benevolent Society; these are apart from the smaller adoption organisations such as

[26] http://www fertilitysociety.com.au/anzica/

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.

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

One of the most important areas of support is that of being able to access the experiences of people living with the long term consequences of donor conception. The DCSG has fond over many years that people really do want to learn from each other; be they, parents, donor conceived people or donors; they want to hear the good stories and the bad. It is very important that any formal support service set up to help those involved in donor conception makes use of the real-life experiences.

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

Living in the real world we understand that there is not a never-ending supply of funding available so our suggestion is that services should be funded by a combination of government, ART clinics and individuals. The only provision we would make is that no donor conceived person should be prevented from accessing the services because of lack of money.

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

The DCSG would strongly suggest that support should be provided by the same organisation that manages the registers i.e. a standalone body..

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

Firstly there is an important point to be made: Fertility clinics create two different types of records those for the donor and those for 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 their own using Freedom of Information because they have no records.

All records wherever they are currently held must be given permanent protection; in donor conception these records are the equivalent of true birth certificates.

> *All records of my existence in the programme had been destroyed in 1983 – for very questionable reasons (paranoia?). In retrospect it can be said that the future needs – psychological/emotional etc for all offspring had been given zero consideration. Shame on all of us.*[27]

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.

Donor conceived people are, for the most part, very realistic about the fact that records pertaining to their donor may be minimal or even no longer in existence. What they need is access to whatever does still exist and the recognition of their need for this information.

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.

[27] "PB" DCSG written communication with donor

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.

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.

The parent above made a statutory declaration as part of an investigation by the NSW Health Care Complaints Commission against a doctor who was fined for not keeping accurate records but still allowed to keep practicing.[28]

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

[28] See attached appendix for documents relating to this case.

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." [29]

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.

> *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.* [30]

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. The Fertility Society has made no moves to try and take up the records of medical practitioners who have retired.

[29] Cleo 21. Marie Claire Magazine "Secrets & Lies, Donor daughters searching for the truth" 2005
[30] Letter from Doctor to offspring "J"

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.

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

The records of clinics that close must be taken up by the authority or government department that operates the donor registers in NSW.

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

The only way this can be done is by legislation to prevent tampering and destruction and this legislation must be accompanied by severe penalties for non-adherence.

Further Discussion:

The principles of medical ethics have always spoken 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 in the past (and still, for the most part, today) 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, and also legislation, in the case of donor conception must consider the child that is being created.

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 any 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 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.[31]

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.

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.

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

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)?

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?

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. [32]

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.

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

[32] 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

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.*[33]

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*

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

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.[34]

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

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

the truth concerning such a fundamental issue as her/his genetic background?[35]

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

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.[36]

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. [37]

[35] Ibid.
[36] DCSG written communication with Donor "D"
[37] Ibid

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DX: 22808 GLADESVILLE
TELEPHONE: (02) 9879 6799
FACSIMILE: (02) 9816 5307
www.nswmb.org.au

Our Ref:
Your Ref:

12 July 2001

[redacted]

[redacted]

Dear [redacted]

Professional Standards Committee – Dr [redacted]

I refer to the Professional Standards Committee Hearing convened on 14 and 15 March 2001.

The Committee considered a complaint that Dr [redacted] had been guilty of unsatisfactory professional conduct and/or professional misconduct within the meaning of sections 36 and 37 of the Act, in that he had demonstrated a lack of adequate knowledge, skill, judgement and/or care in the practice of medicine and/or improper or unethical conduct.

The particulars of the complaint which relate specifically to you, were as follows:

1. In September 1990 the practitioner implanted Patient A (Ms [redacted]) with three embryos created from donated ova. The practitioner failed to make and preserve appropriate records of the donor of the ova.

The Committee was reasonably satisfied that Dr [redacted] failed to make and preserve appropriate records of the donor of Patient A's (Ms [redacted]) ova as good medical practice at the time required.

The Committee was reasonably satisfied on the balance of probabilities, that Dr [redacted] was guilty of unsatisfactory professional conduct within the meaning of section 36 of the Act in that he has engaged in conduct which demonstrates a lack of adequate knowledge, judgment and care in the practice of medicine.

That decided to reprimand Dr [redacted] and imposed a fine of 30 penalty units (representing an amount of $3,300) on [redacted]

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Health Care Complaints Commission

Investigation Report

Complainants	:	**Mrs** [redacted]
Respondent	:	**Dr** [redacted]
File nos.	:	[redacted]
Date	:	**10 May 2000**

BACKGROUND

Dr [redacted] works with her husband Dr [redacted], an obstetrician gynaecologist at [redacted] Fertility Centre, [redacted]. In September1990 Dr [redacted] implanted Ms [redacted] with three embryos created from donated ova. Dr [redacted] is also a respondent to this complaint, however this investigation report deals only with the complaint concerning Dr [redacted].

Ms [redacted] said that she had approached the [redacted] Fertility Centre to obtain information about the donor of the ova which were used to conceive her seven-year-old twins in 1990. She spoke to the counsellor, [redacted], who said she would look up the files and lab sheets for the day and to make an appointment with her to discuss it. The appointment was on 10 November 1998. Ms [redacted] said she was told that there were no records for her or the donor, that they had been destroyed, even though ten years had not yet passed. She was asked why she wanted the information and Ms [redacted] replied that it was for medical, genetic, hereditary and other reasons, so [redacted] advised that she would consult with Dr [redacted] and Dr [redacted]. On 13 November 1998 [redacted] telephoned Ms [redacted] to advise that her files had been found in archives and that "descriptive information" from the files would be sent to her by mail. However, on receipt of the letter, it contained descriptive information about Ms [redacted] which she had provided for the purposes of matching with a donor. On inquiring with [redacted] the next day, Ms [redacted] was told that records of the donor were not kept "in those days" as everyone was anonymous. It was only the recipient who gave their characteristics.

Ms [redacted] had an an interview with Dr [redacted] on 4 December 1998. Dr [redacted] did not provide any information about the donor of the ova.

Date of successful donor ova implantation	Sept 1990
Date of first request for donor information:	3 November 1998
Date of complaint:	19 November 1998

ISSUE FOR INVESTIGATION

The issue for investigation arising from the complaint is the failure to make and preserve records of the donor of the ova

INVESTIGATION

During the course of the investigation the following documents were obtained by the Commission

1. Statutory declaration from Ms [redacted] dated 18 November 1998.
2. Report from Dr [redacted] undated, received 15 January 1999.
3. Report from Dr [redacted] undated, received 21 January 1999.
4. Peer review report dated 1 January 2000.
5. Combined s.40 submission from Dr [redacted] and Dr [redacted] dated 28 March 2000.
6. References (published before 1990):
   a. *Statement on Human Experimentation, Supplementary Note 4.* National Health and Medical Research Council, 1982.
   b. *'Standards as a Guide to the Code of Practice'*, Fertility Society of Australia, 1986.
   c. *Code of Practice.* Reproductive Technology Accreditation Committee, 1988.
   d. *'Reproductive Technology: Record Keeping and Access to Information; Birth Certificates and Birth Records of Offspring Born as a result of Gamete Donation'.* National Bioethics Consultative Committee, August 1989.

TIME LINE OF PUBLISHED CODES OF CONDUCT IN RELATION TO THE ISSUE FOR INVESTIGATION

The standards of practice relating to the issue in this complaint have evolved substantially since 1982. A major challenge in this investigation has been to establish the standard of practice which existed in 1990 when [redacted] was implanted with the ova. Selected quotes from the published codes of conduct are represented on a time line along with the events identified in the complaint.

1982 — National Health and Medical Research Council (NH&MRC)
'Statement on Human Experimentation, Supplementary Note 4'

"Every centre or institution offering an in vitro fertilization (IVF) and embryo transfer (ET) program should have all aspects of the program approved by an institutional ethics committee (IEC). The IEC should ensure that a register is kept of all attempts made at securing pregnancies by these techniques. The register should include details of parentage..."

1986 — Fertility Society of Australia (FSA)
'Standards as a Guide to the Code of Practice'

"A permanent record must be kept of all procedures identifying the patients, donors and recipients of all gametes involved in fertilisation and embryo formation..."

June 1988 — Reproductive Technology Accreditation Committee (RTAC)

'Guidelines to the Code of Practice for Units using In Vitro Fertilisation and Related Reproductive Technologies'

"A permanent record must be kept of all procedures identifying the patients, donors and recipients of all gametes involved in fertilisation and embryo formation..."

August 1989 National Bioethics Consultative Committee
'Reproductive Technology: Record Keeping and Access to Information; Birth Certificates and Birth Records of Offspring Born as a result of Gamete Donation'.

"...there is consensus... that information relating to parties involved in donor gamete programs must be kept and maintained".

"...the right to explore and discover biological origin has a corollary, namely that information should be kept, particularly when that may be the only available information source for offspring".

[The National Bioethics Consultative Committee recommends that...] *"Both existing and future information and records concerning offspring conceived as a result of gamete donation should be kept indefinitely".*

Sep 1990 Ms [redacted] - Donor ova implanted

10 Nov 1998. Ms [redacted] told, "donor records were destroyed".

13 Nov 1998. Ms [redacted] told, "donor identity was never recorded".

4 Dec 1998 Dr [redacted] tells [redacted] "no records found".

INFORMATION FROM DR [redacted]

In her report received on 15 January 1999, Dr [redacted] states,
"...In 1990, [redacted] Fertility Centre had a policy of complete anonymity regarding all donor gametes and embryos. No donor identifying information was recorded or kept. Accordingly, no records were destroyed since such records were not made. Only non-identifying characteristics of patients receiving donor gametes/embryos were available. We changed this policy in June 1997 and now keep donor and recipient details..."

In her Section 40 submission dated 28 March 2000 Dr [redacted] states,
"In 1997-98... the clinic decided that it was in the best interests of its confidential donors to deny the existence of records.
R.T.A.C. makes regular accreditation visits. During these visits, RTAC physically checks over record keeping systems. In fact, the complainants had sent letters to RTAC and the following visit, they [RTAC] specifically checked all record keeping.
In a letter to [the Commission] *on 22 October 1997 Dr [redacted] stated that the clinic maintained records."*

INFORMATION FROM DR [redacted]

Dr [redacted] submitted a report received on 21 January 1999 which was identical to Dr [redacted] report received on 15 January 1999.

Dr [redacted] co-signed the Section 40 submission dated 28 March 2000.

INFORMATION FROM THE PEER REVIEWER

The peer reviewer is moderately critical of Dr [redacted] departure from an acceptable standard of practice concerning her failure to record identifying information about the gamete donor.

The peer reviewer is also moderately critical of Dr [redacted] departure from an acceptable standard of practice concerning her failure to record non-identifying information about the gamete donor.

INFORMATION OBTAINED FROM PUBLISHED SOURCES

The Commission obtained the following information published prior to 1990 about standards of practice in relation to making and preserving records of a gamete donor:

'Statement on Human Experimentation, Supplementary Note 4',1982
National Health and Medical Research Council

'Standards as a Guide to the Code of Practice', 1986
Fertility Society of Australia

'Guidelines to the Code of Practice for Units using In Vitro Fertilisation and Related Reproductive Technologies', 1988
Reproductive Technology Accreditation Committee

'Reproductive Technology: Record Keeping and Access to Information; Birth Certificates and Birth Records of Offspring Born as a result of Gamete Donation', 1989
National Bioethics Consultative Committee

DISCUSSION

Dr [redacted] responses to the Commission are contradictory. She indicates in her report received on 15 January 1999 that donor records were not made, but she indicates in her s.40 submission on 28 March 2000 that donor records were made. Dr [redacted] has provided no donor information, neither identifying nor non-identifying, to Ms [redacted]

In addition Dr [redacted] admits to the Commission that the clinic denied the existence of donor records to recipient patients when the records did in fact exist.

It appears that Dr [redacted] has not breached the *Human Tissue Act 1983* because that legislation covers only male gametes (semen) not female gametes (ova). However, Dr [redacted] should not have set her own standards for maintaining donor records without approval of an institutional

ethics committee.

The peer reviewer is moderately critical in relation to this complaint. Dr [redacted] conduct contravenes published codes of conduct in existence in 1990.

Dr [redacted] has not argued in her defence that Ms [redacted] was not her patient, nevertheless it appears that Dr [redacted] responsibility for Ms [redacted]'s care and treatment was quite remote. Thus, despite the weighty public interest in this complaint the Commission has not recommended to the Medical Board that this complaint be prosecuted as professional misconduct or unsatisfactory professional conduct at a disciplinary hearing.

CONCLUSION

Dr [redacted] has provided a brief response to the complaint and a brief Section 40 submission..

There is a significant public interest in the Commission dealing effectively with this complaint because of the *"...stark exception that the most populous Australian State has yet to enact any legislative controls in the area of assisted reproduction..."* [1]. In the absence of strong prescriptive legislation that exists in other states, the people of NSW depend on medical practitioners adhering to existing codes of ethics. At stake are the important rights and opportunities of persons born as a result of assisted reproductive technology treatment to discover their genetic parentage.

The public interest is twofold. Offspring of donor conception have interests and rights in relation to information about their genetic parents. This was made clear in a report by the National Bioethics Consultative Committee to the Australian Health Ministers published in August 1989. Secondly, there is a public health issue which arises from destroying records of genetic parentage. This is made clear by the National Health and Medical Research Council in *Ethical Guidelines on Assisted Reproductive Technology* published in 1996. Records should be adequate to:

1. Enable linkage studies with other health data eg. registers such as cancer and congenital abnormalities.
2. Facilitate outcome studies of assisted reproductive technology procedures.

The Commission finds that Dr [redacted] conduct was a departure from acceptable standards of practice.

The Commission makes the following adverse comments to Dr [redacted]:

1. She failed to make and preserve appropriate records of the donor of the ova.
2. She participated in a policy of denying the existence of donor records to patients when she knew the clinic in fact had possession of those records.

---

[1] Szoke, H. 'Regulation of Assisted Reproductive Technology. The State of Play in Australia' in Freckelton, I., Petersen, P. Eds. *Controversies in Health Law*. Federation Press, Sydney, 1999. p.251.

File Nos: 98/01493-2
Contact : [redacted]

HCCC
HEALTH CARE COMPLAINTS COMMISSION

[redacted]

Dear Mrs [redacted]

Re. Complaint concerning Dr [redacted]
Outcome

I refer to your complaint concerning Dr [redacted] in relation to her failure to provide information about the donor of ova used in her treatment.

The Commission has concluded the investigation of this complaint and has consulted with the Medical Board on the outcome. The complaint has been substantiated and the Commission has made adverse comments to Dr [redacted] pursuant to s.39(1)(d) of the Health Care Complaints Act. Please find attached a copy of the Investigation Report.

The adverse comments are as follows:

1. She failed to make and preserve appropriate records of the donor of the ova.
2. She participated in a policy of denying the existence of donor records to patients when she knew the clinic in fact had possession of those records.

The Commission finds that these actions were a departure from acceptable standards of practice. The peer reviewer stated that Dr [redacted] conduct would invite the disapproval of the general body of her colleagues. unsatisfactory

Although the Commission has made adverse comments to Dr [redacted] about making and preserving donor records, the Commission has been unable to determine conclusively whether or not records of your ova donor do exist.

is it because she hasn't broken the law

The file on this matter has now been closed. Please note that if you are not satisfied with the outcome of the investigation, you can request a review by the Commission. Any request for review should be in writing and should specify the reason for a review.

The Commission is keen to receive comments on the handling of its complaints. The enclosed questionnaire relates to various aspects of our work, and the contact you had with the Commission. We would appreciate you taking the time to answer the questions and return the survey to the Commission in the reply paid envelope provided. It would be helpful if you would put your name on the survey. However, if you prefer to answer

Level 4, 28-46 Foveaux Street, Surry Hills NSW 2010 • Postal Address: Locked Bag No. 18, Strawberry Hills NSW 2012
Email: hccc@hccc.nsw.gov.au • DX 22508, Surry Hills
Telephone (02) 9219 7444 • Facsimile (02) 9281 4585 • TTY (02) 9219 7555

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Our Ref:
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12 July 2001

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I refer to the Professional Standards Committee Hearing convened on 14 and 15 March 2001.

The Committee considered a complaint that Dr [redacted] had been guilty of unsatisfactory professional conduct and/or professional misconduct within the meaning of sections 36 and 37 of the Act, in that he had demonstrated a lack of adequate knowledge, skill, judgement and/or care in the practice of medicine and/or improper or unethical conduct.

The particulars of the complaint which relate specifically to you, were as follows:

1. In September 1990 the practitioner implanted Patient A (Ms [redacted]) with three embryos created from donated ova. The practitioner failed to make and preserve appropriate records of the donor of the ova.

The Committee was reasonably satisfied that Dr [redacted] failed to make and preserve appropriate records of the donor of Patient A's (Ms [redacted]) ova as good medical practice at the time required.

The Committee was reasonably satisfied on the balance of probabilities, that Dr [redacted] was guilty of unsatisfactory professional conduct within the meaning of section 36 of the Act in that he has engaged in conduct which demonstrates a lack of adequate knowledge, judgment and care in the practice of medicine.

That decided to reprimand Dr [redacted] and imposed a fine of 30 penalty units (representing an amount of $3,300) on [redacted]