INQUIRY INTO INCLUSION OF DONOR DETAILS ON THE REGISTER OF BIRTHS

Organisation: Donor Conception Support Group of Australia Inc.

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13th December, 2011

To The New South Wales Parliament Legislative Assembly Committee on Law and Safety INQUIRY INTO INCLUSION OF DONOR DETAILS ON THE REGISTER OF BIRTHS

Thank you for this opportunity to tell you about the views of the members of the Donor Conception Support Group of Australia.

We would like to let you know that should you wish to speak to members of our group we will be most happy to meet with you.

Yours Sincerely

Caroline Lorbach National Consumer Advocate Donor Conception Support Group of Australia Inc.



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

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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 siblings 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.

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

NSW Reference Group looking at reproductive technology

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- WA Reproductive Technology Council
- Victorian Infertility Treatment Authority

Achievements of the DCSG.

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.

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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 AID¹ 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 find 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."²

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:

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.

¹ AID Artificial Insemination Donor – the term by which donor insemination was known.

² David Gollancz a DI offspring in his fifties.

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.³

As part of the Victorian Law Reform Commission Final report on Art And Adoption (2007) the Victorian adoption agency Connections Adoption and Permanent Care Program 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.⁴

In 2008 the new Assisted Reproductive Treatment Act 2008 was passed through the Victorian Parliament and it included:

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

³ Page 142, Ch 14 Birth Registration Victorian Law Reform Commission - Assisted Reproductive Technology & Adoption: Final Report 2007

⁴ Ibid page 143

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 donortreatment 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 DCSG would like to congratulate the Committee on Law and Safety for holding this inquiry as it is a further step in the direction of all donor conceived people having the right to have identifying information about their biological parentage.

It is the strong view of the DCSG that birth certificates for donor conceived people should be a true indication of a person's biological parentage and so must show the names of a persons' donor/s. We believe that this could be achieved in much the same way as now being done in Victoria where a person on reaching adulthood and requesting a birth certificate will be told that further information is available to them on their birth.

The current system for recording donor information in NSW.

In NSW the Assisted Reproductive Technology Act (2007) was enacted at the beginning of 2010. This Act enabled any people conceived with donated gametes after 1st January 2010 the right to know the identity of their donor once they reach the age of 18. The Register that records this information is held in the Private Health Care Branch This Act gives no rights to people conceived with donated gametes before this date. So what this has created is to very distinct groups of people one with rights and one who has had rights denied. The information about the identity of their donors does in very many cases exist but this information is being kept secret from thousands of people a good proportion of whom are adults already.

There is also the voluntary register also contained within the Private Health Care Branch which allows donors and donor conceived people the opportunity to put their details down in order that a match might be made. No advertising has been done in regards to this register and with out extensive advertising and public education it will only be of help to a limited number of people.

The Private Health Care Branch had no experience with running a register, and certainly not ones of this importance. The people charged with organising the registers had no training and from our knowledge did not investigate the workings of other registers in other jurisdictions. The NSW Register has no counsellors available which is something that is absolutely necessary when dealing with birth origin information.

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 as 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 Report¹, 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

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.

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

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 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

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

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 McDonald⁵ 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

⁵ Margaret McDonald worked in adoption in NSW for 30 years as a case worker, a manager and an advisor to the state government.

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"⁶

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.

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

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

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

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 all who initiate them, and positive or acceptable by the majority of those who are contacted⁷.

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 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:

⁷ http://www.lawlink.nsw.gov.au/lrc.nsf/pages/R69EXEC

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.

"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?

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 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.

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

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.⁸

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—

(a) the welfare and interests of persons born or to be born as a result of treatment procedures are paramount;9

⁸ Pge 9 Ethical guidelines on the use of assisted reproductive technology in clinical practice and research 2007 NHMRC

⁹ Pge 8Victorian Assisted Reproductive Treatment Act 2008.

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 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:

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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.¹⁰

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.

¹⁰ http://portal.unesco.org/en/ev.php-URL_ID=31058&URL_DO=DO_TOPIC&URL_SECTION=201.html 19

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)?

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?

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 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:

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.

Recommendations:

- Birth certificate of donor conceived people should contain the identity of their donor/s – they should be a truthful record of their biological parentage.
- 2. Legislation needs to be amended so that all donor conceived people no matter when they were conceived will have the right to know the identity of their donor/s
- The donor conception Registers both compulsory and voluntary should be moved to another location – either an independent authority or to Births, Deaths and Marriages.
- 4. There needs to be a proper support service for donor conceived people, their families and donors. This service must include experienced counsellors.

"I found that talking to the clinic counselor did help. I don't know if it was because of any great advice that they gave me or simply that I was actually talking about the issues. My wife took a different approach: she read as many books as she could and contacted other couples in the same situation as us." 'J'

We don't live in a perfect world and our plans to have kids didn't go very smoothly. We had to make lots of happy compromises along the way. We always chose the option that gave us the next most natural way to conceive a family. I had always wanted to see my wife pregnant and embryo donation became our last option."

The counsellor helped us look at issues that we either hadn't thought about or hadn't wanted to look into more deeplysuch as how the child would deal with it. It was never an issue for us to keep it a secret, right from the start we decided our children had that right to know. It's an enormous responsibility to think that you're creating a life in this way and you just want to be sure that you're equipped to help them deal with the implications of it. 'J' Legislation regarding Donor Conception currently varies from state to state; some states have no legislation. The DCSG can provide information for each state and you can also contact the relevant authorities in each state:

ACT NSW NT QId SA Tas Vic	Minister for Health (02) 62050840 The NSW Registers (02) 9424 5953 http://www.health.nsw.gov.au/ hospitals/phc/art.asp Minister for Health (02) 9230 3463 Minister for Health (02) 9230 3463 Minister for Health (02) 9230 3463 Minister for Health (03) 8901 4161 Minister for Health [07] 3234 1191 SA Council on Reproductive Technologies (08) 8226-6048 http://www.sahealth.sa.gov.au go to health service—women's health—pregnancy & fertility Minister for Health (03) 6233 6752 Victorian Assisted Reproductive Treatment Authority (03) 8601-5250 www.varta.org.au/	AN AUSTRALIAN SUPPORT NETWOR FOR:	Families with donor children Adult Donor Offspring Donors - past or present Anyone Interested in Donor Issues
National H cil	ealth & Medical Research Coun-	Postal Address	PO Box 554 Seven Hills NSW 1730 Australia
a second and a second second	low the NHMRC Guidelines on As- ductive Technology . To download a	Email: dcsupport@hotn	ngil com
	hmrc.gov.au/guidelines/	Web: www.dcsg.org.au	
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The Donor Conception Support Group of Australia Inc. is a self funding organisation run by volunteers that has been in existence since 1993. Starting with a membership of 20, we have members around Australia & in many overseas countries.

Our membership is made up of people considering or using donor sperm, egg or embryo, those who already have children conceived on donor programmes, adult donor offspring and donors. We also have social workers, clinic staff, researchers & other interested people as members of the support group.

Unlike many other infertility treatments those using donor gametes continue to need support beyond the initial decision making and treatment. They need ongoing support as their families grow.

For those who have children, we provide the opportunity to meet other donor gamete families.

As children get older they sometimes feel the need to talk to another donor conceived person and we can put them in touch with other donor offspring.



Experiences of Donor Conception: Parents, Offspring & Donors through the years

A book written by Caroline Lorbach of the DCSG. This book explores the process of deciding to use donor conception, choosing a donor & discussing the decision with others – and considers the perspective of the donor alongside those of parents & offspring. It tackles difficult subjects such as disclosure & offspring's access to information. This book may be purchased from the DCSG \$45.00 incl postage (profits go to the DCSG) For further information contact:

> Caroline on dcsupport@hotmail.com or

Write to PO Box 554 Seven Hills NSW 1730

From 2011 our group will now be centred around our website which will provide members with a quarterly newsletter; useful information on donor conception, legislation, media articles personal stories, research papers etc.

WHAT WE OFFER

- Quarterly newsletter
- Social Days
- Consumer advocacy on issues relating to

donors, donor recipients and offspring

Membership Fees

Membership is FREE

To join go to www.dcsg.org.au; follow the prompts and fill in your details

Newsletters

Newsletters are electronic only; downloadable by members from our website (with a password which will be emailed to you when you join)

Professional Support

Members can refer to the website for professional organizations/counsellors who may be of help.

Lobbying

The DCSG lobbies for legislation both federally & for those states who still do not have legislation (or legislation that needs improving).

Information

If you would like information on legislation, accessing donor information please drop us an email at dcsupport@hotmail.com

From 2011 our group will now be centred around our website which will provide members with a quarterly newsletter; useful information on donor conception, legislation, media articles etc.

How to join: go to www.dcsg.org.au; follow the prompts and fill in your details

Membership Fees

Membership is FREE

<u>Newsletters</u>

Newsletters are electronic only; downloadable

oy members from our website (with a passwordwhich will be emailed to you when you join)

Email

nformation and may also be able to put you in We are more than happy to answer any questions that donor conceived people have. Our group will share their experience in accessing touch with other donor conceived people Phone Unfortunately we are unable to provide a phone professional organizations/counsellors who may service. Members can refer to the website for oe of help.

<u>Lobbying</u>

federally & for those states who still do not have egislation (or legislation that needs improving) The group's roll in lobbying for legislation both will continue

Information

If you would like help in accessing information or conceived people please drop us an email at would like to get in contact with other donor dcsupport@hotmail.com Ŧ

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- Minister for Health (02) 62050840 The NSW Registers NSW ACT
 - (02) 9424 5953
- Minister for Health (02) 9230 3463
- Minister for Health (08) 8901 4161 Minister for Health [07] 3234 1191 Ż
 - SA Council on Reproductive QId SA
- [echnologies (08) 8226-6048
- Minister for Health (03) 6233 6752 Tas Vic
- Victorian Assisted Reproductive
- Ireatment Authority (03) 8601-5250 Reproductive Technology Council ٨A
 - 08) 9323 6642

Would you like to chat online to other donor conceived people? There are a number of forums that may be of interest to you including:

- http://australiandonorconceptionforum.org
 - http://health.groups.yahoo.com/group/ **DonorSiblingRegistry**

Experiences of Donor Conception: Parents, Offspring & Donors through the years:

considers the perspective of the donor alongside those of parents & offspring. It tackles difficult subjects such as disclosure & offspring's access to information. This book may be purchased from the DCSG \$45.00 incl postage (profits go to A book written by Caroline Lorbach of the DCSG. This book explores the process of deciding to use donor conception, choosing a donor & discussing the decision with others - and Caroline on 02 9624 5110 or Write to PO Box 554 the DCSG) For further information contact:



Come From? Where Did

found out that you were created from Donor Have you recently Conception?

Have you always known that you were created from donor sperm, egg never spoken to someor embryo, but have one created in the same way?

search for your birth origin information?

PO Box 554

Postal Address

Seven Hills

NSW 1730

Do you have a need to

Australia

Email: dcsupport@hotmail.com Web: www.dcsg.org.au

Last updated July 2011

Seven Hills NSW 1730



The Donor Conception Support Group of Australia Inc. is a self funding organisation run by volunteers that has been in existence since 1993. Starting with a membership of 20, we have members around Australia & in many overseas countries. Our membership is made up of people considering or using donor sperm, egg or embryo, those who already have children conceived on donor programmes, adult donor offspring and donors. We also have social workers, clinic staff, researchers & other interested people as members of the support group.

Unlike many other infertility treatments those using donor gametes continue to need support beyond the initial decision making and treatment. They need ongoing support as their families grow.

Our group has recognised the need for donor conceived people to have contact with others conceived in the same way. There are many donor conceived people within the group and that we are in regular contact with. They have many different experiences—some knew about their conception from a young age, some as teenagers while others didn't learn about their conception until adulthood.

"What was it like to be conceived through donor sperm? What is the emotional impact of our conception? It is frustrating to try and express the meaning of donor insemination to anyone who has not lived that life!"

THOUGHTS AND FEELINGS

"It's good to know that I am not alone and that there are others conceived just like me. What's wrong with wanting to know the truth about myself and my identity?"

Priscilla 35

"I learnt about my donor conception when I was nine, but many offspring were told at an older age in unhappy circumstances. Everyone has different experiences and I believe that it is beneficial for all donor conceived persons to share their stories and receive support and understanding?

Lauren 31

This flyer is a way to help others, that includes health professionals, offspring and families to understand the issues surrounding donor conception."

Nicky 42

A lot of the pain of being a DI adult is similar to the experience of Adoptees. There has been a growing understanding of the consequences of adoption, but not a clue about DI. This group provides a start to help DI people understand themselves and begin to educate the outside world."

Louise 43

"Someone told me 'I am the descendant of my ancestors and I am the ancestor of my descendants', and I thought, 'Yeah, but I have 50 percent ghosts as ancestors—that's no small thing!' I am glad to know my DI friends feel the same way. There is so much for us to talk about, compare and aim to change with regards to the silence surrounding our rights and our identities. The denial is bound to hurt us and make us feel angry, but we have strength in numbers."

Jo 35

"When I first discovered the truth about my DI conception I didn't know of a single person in my situation. I felt like freak of the week. Some of my best support comes from the other side of the world... Thank heavens for e-mail. I didn't know it was normal to feel angry at being cheated out of knowing my biological family."

Christine UK

"Making contact with other DI adults for the first time was incredible—I realised I wasn't the only person in the world with such an unconventional set of identity issues. For the first time I could compare my feelings to other peoples and find that they were normal—I was no longer such an unusual case!"

Rebecca 31

"Upon meeting a group of offspring I felt a connection with others like me. I felt an instant rapport."

How You Can Really Help....

If, after reading this information sheet and discussing your decision with friends and family, you still want to donate your gametes, that will be terrific. But whatever you do, don't simply leave your gametes at the clinic!

As a first step, it is important that you leave information about yourself that both parents and the child can have access to. Medical history is important, but so is information about your personal history, your personality and talents, and how you feel about the donation. You can leave a letter, and even a photo, at the clinic at which you donate. It is also important that you are open to a possible request for information, and maybe even contact, at some time in the future. To do this, it will probably be important for you to tell special people in your life about the donation, and the possibility that you have genetic offspring who may need some information and/or contact with you at some time. Make sure that you leave enough identifying information with the clinic to enable you to be found in the future. If you feel uncomfortable about having a number of genetic offspring. then you may wish to ask the clinic at which you donate to limit the number of pregnancies which arise from your donation.

Getting Support

It's possible that you don't know anyone else who has donated gametes. You may think you don't know any parents whose children were born using donated gametes, or any people who were themselves conceived using donated gametes. You might have thought this would be an easy decision, and now realise it isn't. If that has been a painful realisation, take heart in the knowledge that it is an important one, and you are now much better equipped to make, and live with, this important decision.

Creating a life, and a family, is a powerful and generous act.

It is important that you get as much information as you can about the consequences of your decision. Talk to people about your decision. If you feel you can't, that may be a sign that donation isn't right for you. A secret as enormous as this will be hard to bear for a lifetime, and may prevent you from fulfilling your responsibilities to your genetic offspring. Other donors, adult people who were conceived using donated gametes, and parents whose children were conceived using donated gametes, may be able to help you to make a decision that is right for you, and those who will be affected by your decision. If you don't know people with these personal experiences, contact the Donor Conception Support Group of Australia. They can help potential donors of sperm, ovum and embryos, and can give you important insight into the complicated issue of gamete donation.

It is very important that you don't rush your decision. Take time to make a well-informed decision that you feel you can live with for the rest of your life. A decision that you feel will have positive implications for those who will be affected by it. The Donor Conception Support Group is for anyone involved in donor conception from donors to families to medical professionals, counsellors etc., and anyone with an interest in the area. Please ask your clinic for a flyer about the group or contact:

The Donor Conception Support Group of Australia Inc. PO Box 554 Seven Hills NSW 1730 Website dcsg.org.au Email dcsupport@hotmail.com

Last updated July 2011



Not My Child...

An information Sheet for Potential Gamete Donors. You are reading this information sheet because you are currently considering donating sperm, ovum or embryos to assist an infertile person or persons who wish to conceive a child. You may have a very personal reason for wanting to help others in this way, and perhaps even know the people you want your donation to help. You may simply want to "help others", or share your good fortune as a parent, and not know or care who will benefit from your donation. The decision may seem a simple and uncomplicated one.

You are to be congratulated for your desire to help others in this special way. However, if you do make the decision to donate, this will have an important impact on the people who receive your donation, on the person who is born as a result of your donation, and even on you.

About Gamete Donation	How Gamete Donation Affects Children and	The Impact of Your Decision to Donate
	FamiliesAnd Donors	At the second se
Donor Insemination, or DI, has been practiced for many years in Australia. In Vitro Fertilisation (IVF) fechniques have also al-	It was once believed that adopted children would not want or	consider in your decision about whether or not to donate your
lowed women to donate ovum (or "eggs") and couples to donate	need information about their "birth" parents, if the adoption was a success. It was even believed that children who were adopted	gametes. No one is more important than the person who will be created: your genetic offspring, but your own feelings are yerv
In the midst of all this technology, it can be easy to forget just	would be better never knowing of the adoption. It was also thought that birth parents didn't care about, and would be better	important too.
exactly what is being done. The donation of sperm, ovum or	never knowing about, the child who was adopted. In short, eve- ryone should just get on with life and forget about the adoption.	Take some time to consider how you might feel about your do- nation in years to come. One or more people may come to exist
enunyos is not the same as the domation of numeys, invers, and hearts	The adoption was an "event" that had happened, not a process that would continue to have an effect on the individuals	as a result of your donation. They will genetically be your chil- dren, although legally, and socially, they will be the children of
A whole person will be created. And not just a newborn baby,	and families involved.	the parents to whom you are donating your gametes. They may eventually have children who will be your genetic grandchildren
eenager, then a young adult, and eventually a parent and	Some people would prefer to believe that people born using	Vou have a special and indiscutable link to any child you helped
yrandparenn ni misine, own ngin.	donor, to whom they are genetically related. They would proba-	to create, and therefore some very special responsibilities which
This person, and his/her family, will have the same needs as other individuals and their families. The need to be safe and	bly be better off not even knowing the truth of their conception. The donors won't want or need to know how their offspring are	no one else can assume on your behalf.
secure. The need to be loved. The need to be treated with re-	ranng, because they are indurien children . The donation of the sperm over a pathway was just something that once hap-	can you inagine now donor onspring might rear to wonder about who they may look like where they get their talents and
		personality traits from, what their genetic family history is and
Not rour ching	We now know that it is normal and healthy for adopted people to want to know the truth of their origins, and to need information	why you donated, and if you cared about their future?
oriality your sperify, ordiff or enlarges allows for the creation of a person who will be cherished by people who have longed for a child. You may rightly say that the child who is created is	about their genetic history. We now know that adoptive parents want and need this information too.	How would you feel if your genetic offspring needed a lifesaving bone marrow transplant from you in the future? Or felt a desper- ate need to meet with and talk to you, even if just once?
not your child, even thought he or she is geneucally your on- spring. That the parents who raise the child will be the parents in every sense.	We also know that birth parents often think of the child they gave up for adoption, want to know if he/she is well and happy. They don't want to take over parenting the adopted person but	Can you imagine how it must feel for parents of children with all these questions? Will these parents be able to answer their chil-
All parents will tell you that it is the challenges and trau- mas of parenting, not just the "birthing", which creates strong	Both possible and offenzing of families created using compte	Low would vou monored if one day in the future vou wore
bonds between parents and children. Most adopted people and heir adoptive parents have strong, positive feelings about adop-	donation are increasingly stating that they also want and need to have information about the gamete donor.	asked to meet with your genetic offspring and his/her parents? Your answer may depend on whether you keep your donation a
and children don't need to share genetic material to love and be committed to each other.	We now also know that many donors think of the child that was	secret from important people in your life, or not. It may also de- pend on how many genetic offspring arise from your donation.
However, more than one hundred years of adoption experiences in this country has faught us that genefics are important too.	has questions about them. Most donors don't expect that they will feel this way, but find the donation, and the growing child or chil-	At this time, it may seem easier for you to focus on the creation of a healthy baby for loving people who have longed to be parents.
	goes on.	If you don't feel comfortable with the responsibilities of donation, then don't ignore them. Don't donate!

All of this is normal.