



PUBLIC HEARING

INVESTIGATION INTO ALTRUISTIC SURROGACY COMMITTEE

7 JULY 2008

12.40 – 1.15pm Child's rights to genetic information

Helen Kane, Infertility Treatment Authority Victoria
Administrator of oldest donor register in Australia.

The terms of reference list Issue for Comment No. 16 as "what rights should a child born through an altruistic surrogacy arrangement have to access information relating to his or her genetic heritage? Who should hold this information?"

Issue No.16 is therefore the focus of the comments I would want to make.

I am a social worker with extensive experience in the obstetrics, adoption, infertility, and access to information services in both adoption and donor conception, as a counsellor and administrator. For the past 2 years I have been the Manager of the Donor Registers Service at the Infertility Treatment Authority in Melbourne, and that position has involved both development of the service, and provision of counseling to people affected by donor conception.

The personal and professional statement that I would make, arising from my experience, is that all children have a right to know how they came to exist, how their family was created, and who was involved. I believe they have a right to access information relating to their genetic heritage, if they want to.

This rests of course on the knowledge of their origins, and that the information itself actually exists. I believe that the information itself has to be accurately recorded, be protected by law, and that clear information about both existence of the information, and the pathway to it, has to be readily available to all. This means the information system and process have to be good, and stand up well over time, and that the community needs to know about it.

THE VICTORIAN REGISTERS

The Infertility Treatment Authority has responsibility for the maintenance of four Registers and for provision of service to applicants to these registers under the provisions of the Infertility Treatment Act 1995. These are two Central Registers which record the births of children under the Infertility (Medical Procedures) Act 1984 and the Infertility Treatment Act 1995. These Registers record information about donors, recipient parents, and the person born, as a result of egg, sperm or embryo donation. There are also two Voluntary Registers, created in 2001, one which applies to births prior to legislation, and the other which applies to all births from the time of enactment of legislation in 1988.

In Victoria, over 1200 donors have provided eggs or sperm to help create over 4000 children since Central Registers were set up to record births from donor conception in 1988. Of these donors, over 700 are egg donors and over 500 are sperm donors.

People were generally unaware of the existence of the Registers, and their rights in relation to them. Parents and donors had had contact with infertility programs at the time of treatment, but were unlikely to know about the Registers at the Infertility Treatment Authority. It was also acknowledged that many donor conceived people would not know of their status.

2006 saw the creation of the Donor Registers Service, and the commencement of a 3-year "How to Tell" Campaign, to inform the public about the impact of the 1984 legislation, as that was the year that the first of the donor conceived people on the Registers became legal adults, which meant that they were able to seek information about the donor, or could be approached by the ITA as a result of an application for information from the donor.

The focus of the campaign was on parents who have donor conceived children, young adults who may wish to seek information or contact with their donor, and donors who may wish to seek information or make contact with a child.

We have provided assistance to parents wanting to tell their children, of all ages. We realized early in the campaign that it was difficult to engage people easily face to face, and so we placed a strong emphasis on developing information available through our website. This information is downloaded at very high rates, particularly the documents which talk about how to approach telling the child.

There have been more than 100 applications for information in the last 12 months. Families are applying to both Central Registers and the Voluntary Registers, wanting information about the donor, but some using the Voluntary Register in the hope that they can have contact with other families with children conceived with the same donor. Donors are predominantly using the Voluntary Registers, wanting to provide information to donor conceived individuals or their families.

We have had few CR applications by donor conceived people, partly because there are only around 500 who have reached adulthood, many of whom are likely to not know of their status. The other factor is simply developmental stages – in the

formation of identity, and a readiness to take risks to obtain information, a need to take active steps to find out is most likely to be as the young adult is moving into a permanent relationship and thinking about the creation of the next generation.

We have developed clear service models in relation to both CR applications and VR Matches (the application by two related individuals to the VR). Counselling is a requirement in both models, but also the counsellor has the role of facilitator between the parties. This makes for a responsive, flexible service system, which enables people to reach arrangements that suit them, and in the instances where the outcome is not what was hoped for, the counsellor is able to provide counseling and support.

LESSONS FROM VICTORIAN EXPERIENCE

Part 1 of the issue – what rights should a child born through altruistic surrogacy arrangement have to access information?

1. individuals and families are complex, and the addition of issues such as infertility, non-biological parenting, difference in status between the parents in relation to this, and lack of information and connectedness to the biological parent, the donor, creates particular hurdles for them.
2. Parents have difficulties telling their children about how they were conceived. The things that get in the way are their own feelings about this, and their fear that their child will not accept them as their parents. In the past, silence on the issue has been presented as the best policy by the professionals involved in the infertility field – literally “get on with your lives as if there had been no donor”. But they also don’t know how to tell their children, they don’t know the words, they don’t know how to present the situation.
3. Altruistic surrogacy, like “known donor” implies close relationships between the adults involved, and an assumption that they will be able to deal with issues over time. Relationships change, families fall out, and at times the “known” is simply that they have found each other for this particular purpose, rather than having a developed relationship. They may all require access to information over time, that may not be directly accessible.

IN SUMMARY: The child ought to be aware of his or her genetic history, including that a surrogate was involved, because it simply is a basic human right. But ought to learn of this within the family, as part of being a family. They ideally learn this over time, with having a sense of “always having known”. This is the easiest for the parents as well, and allows for the child’s understanding to develop over time, and being addressed at the time.

People require information and support in relation to telling their children how their family was created. This is likely to apply to surrogacy, as it does to donor conception.

Part 2 of issue: who should hold this information?

1. The information has to be recorded, and recorded consistently. The clinic involved should keep records. Provision needs to be made for clinics closing, and what needs to happen to their records. Provision also needs to be made for services to their past clients. This should be addressed in legislation.
2. There ought to be a central authority, like the ITA, which maintains the information permanently, and which also has the power to ensure that the information is recorded, together with provision of appropriate services. It may be 30 years or more before a donor conceived person makes application for information about the surrogate, and the information must be there.
3. It is illogical to consider an information system for surrogacy, without this being within the context of access to information for donor conception. It ought to be a "one stop shop" situation of a program which maintains the records, in both areas, and provides services, like the ITA Donor Registers Service.
4. Surrogates ought to have the same rights as donors in regards to seeking information about the family or the child. All parties to the conception ought to have the right to seek information and/or contact in the future.
5. A baby who is born of a surrogate, no matter what state, is legally her child. So a separate issue is the matter of legal parentage. No matter what is the solution arrived at, there need to be clear pathways of information for the child. A solution which encourages secrecy would be working against the best interests of the child, but also the family.

OTHER MATTERS

1. There needs to be community education in relation to altruistic surrogacy, and clear information disseminated in relation to any change in law. There needs to be a process which moves away from secrecy, and places these particular families within the umbrella of diverse families.
2. The professionals working with families created in this way also need to be educated and aware of the issues that can arise in families. However, we also need to have a clear idea about what those issues are. This requires research, but also services like the ITA registers, which people use for their own needs, but in the process educate us about what it has been like for them, and what are the issues that have presented for them.
3. The education material and opportunities should be wide ranging and accessible. The "How to Tell" campaign, and the use of media, has been very successful in reaching people, and encouraging them to think about the issues, but the material on our website, the opportunity to talk by phone, or to meet with a counsellor, have been crucial, with the individuals themselves able to access the information that they need.

4. The numbers of surrogacy arrangements which result in a child is likely to be small. If a single point of maintenance of records and provision of services existed, understanding and development of appropriate services is more likely to occur than if they could only go back to the original service provider, i.e. the clinic, which may no longer exist. That understanding can then be fed back to the field, and to other professionals, such as family and individual counselors in the community. If this service was placed with a service relating to donor conception, it would be ideal.

HELEN KANE
MANAGER, DONOR REGISTERS SERVICE

3 July 2008



Investigation into Altruistic Surrogacy Committee July 2008

Background information and figures

The ITA has responsibility for maintenance of four Registers and for provision of service to applicants to these registers under the provisions of the *Infertility Treatment Act* 1995. These are two Central Registers which record the births of information under the *Infertility (Medical Procedures) Act* 1984 and the *Infertility Treatment Act*, 1995. Registers record information about donors, recipient parents and the person born as a result of egg, sperm or embryo donation. There are also two Voluntary Registers, one which applies to births prior to legislation, and the other which applies to all births from the time of enactment of legislation in 1988.

In Victoria, over 1200 donors have provided either donor eggs or sperm to help create over 4000 children since Central Registers were set up to record births from donor conception in 1988. Of these donors, over 700 are egg donors and over 500 are sperm donors.

Increasingly prospective parents are recruiting their own donor (egg or sperm donor).

Public education is required to provide information about the registers so that people are aware of their rights to apply for information and issues associated that. The ITA receives very few applications to the donor registers without publicity and is currently experiencing a 30% increase in applications as a result of a *Time to Tell* campaign.

When an application for information is made to the Central Registers, the ITA is required to locate and contact the person whose information is being sought, in order to seek consent to release identifying information. The ITA has been able to obtain approved access to the confidential Victorian Electoral Rolls, which means we are better able to ensure that the correct person is contacted, with protection of privacy.

Evaluation has shown that counselling is crucial for all parties involved in making an application and has an impact on decision-making in relation to linking between parties.

The Fertility Society of Australia's accreditation scheme (Reproductive Technology Accreditation Committee Code of Practice) for Australian ART units requires the following for clinics to be accredited:

S 9.13: Child's rights to know their genetic parents. The ART unit must provide appropriate counselling for recipients of donor gametes to ensure that they consider the issue of a child's future right to know their genetic background. The ART unit must advise patients that conception must only be facilitated in circumstances where the child can know their genetic parents.

However these are guidelines, clinics can close or be taken over by another business entity and contact details change over time. Clinics are not in apposition to use confidential electoral rolls or other mechanisms to check for current contact information for linking purposes and may not have developed expertise in dealing with these processes.

1984 Central Register

This Register was established under the *Infertility (Medical Procedures) Act* 1984. The management of the Register was handed over to the ITA when the *Infertility Treatment Act* 1995 was proclaimed. Information that identifies any person on the Register may only be released with the consent of the person to whom the information relates. Registrations continue to be made to this register in cases where the consent to donation of gametes was made before the 1 January 1998.

1995 Central Register

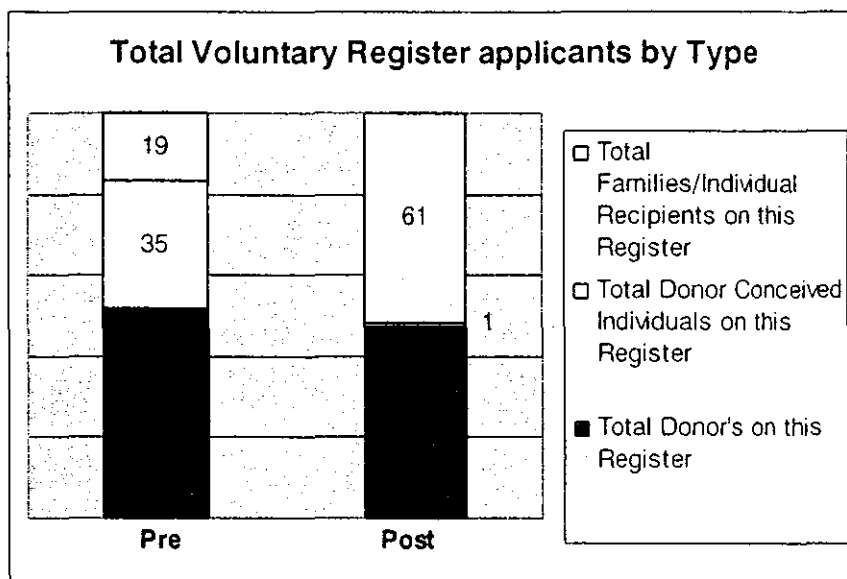
This Register allows access to identifying information by offspring when they turn 18 years. This right is conferred unconditionally, the donor consenting to the use of their gametes or embryos on the understanding that this information will be made available if requested. This Register includes all donors who have consented to the use of their gametes/embryos after 1 January 1998, the date on which the *Infertility Treatment Act* 1995 came into effect. If donors request identifying information about offspring aged 18 years or more, there must be consent from the offspring before information is released to the donor. If children are under eighteen years, parents may also apply for identifying information about the donor, consent would then be sought by the ITA from the donor concerned.

Post 1988 Donor Treatment Procedure Information Register

This Register was set up under the provisions of section 82 of the *Infertility Treatment Act* 1995, and is known as the Voluntary Register. Anyone who has been involved with a treatment procedure since July 1988 may apply to this Register. The applicant may provide identifying information to be released to applicants, or may wish to lodge photos or messages and any other information which may be of interest to other parties associated with the donor procedure.

Pre-1988 Donor Treatment Procedure Register

This Register is also voluntary and allows people involved with donor treatment procedures before 1 July 1988 to register. This Register operates in a similar manner to the post 1988 Register, except that the donor code, which is the linking mechanism, has to be provided by the clinic with the consent of the person about whom the application relates.



Time to Tell Campaign

The ITA is currently engaged in a three-year campaign, *Time To Tell*, to inform the public about the impact of 1984 legislation, which was enacted in 1988. The legislation means that from July 1 2006, donor-conceived young adults can apply for identifying information about their donor once they turn 18. The donor can also apply for identifying information about the donor-conceived adult. Parents of younger children can apply for information on behalf of their children or decide whether to provide consent if a donor applies for information. However, the exchange of identifying information can only occur if both parties agree.

In making an application for information, contact can be initiated one step at a time. The ITA can facilitate an exchange of information in a non-identifying way to start the process.

By the end of this year **596** donor-conceived young adults will be affected by the legislation and can make applications.

The *Time to Tell Campaign* specifically targets:

- People who may have conceived a child using donated sperm or egg.
- Young adults who have turned 18 and who wish to make contact with their donor.
- Donors who wish to register information or make contact with a child.

Information on the donor registers and "how and when to tell" is available on the ITA's web site:
ITA web site: www.ita.org.au

Louise Johnson
Chief Executive Officer
Infertility Treatment Authority
3/7/2008



ITA

The Central Registers

Infertility Treatment Authority

Since 1988, the Victorian government has recognised that individuals born with the assistance of donor procedures have a right to information that will help them trace their biological origins. Donors consent to providing information at the time of their donation. This information is kept in the Central Registers.

What information is kept?

The Infertility Treatment Authority keeps a Register of children born from donated sperm, egg or embryo. To be included in the Register the donation must have been made in Victoria.

Information contained in the Central Registers is provided to the Infertility Treatment Authority by the treating clinic, after the parents have advised the clinic that a baby has been born as a result of the treatment.

The reliability of information supplied to the Authority will vary depending upon when the baby was born, the information held by the clinic, and the nature of the consent provided by the donor. In particular situations, the individuals concerned may wish to consider using DNA testing to confirm genetic links, and this can be discussed with the counsellor.

The Register contains information about:

- ❑ The donor (s), including contact details, date of birth, some physical characteristics (1984 only);
- ❑ The parents, including date of birth, contact details and information about the clinic where treatment was received;
- ❑ The child, including date of birth.

More extensive information about the donor is kept by the clinic, including details of physical characteristics of the donors.

Two Registers

Two Registers exist. These cover births occurring under the jurisdiction of separate acts of Victorian Law.

The **1984 Central Register** is established under the provisions of the Infertility (Medical Procedures) Act 1984. This Register includes all of those births from 1 July 1988 and where the donor has consented to the use of their sperm, eggs or embryos before 1 January 1998.

The **1995 Central Register** is established according to the provisions of the Infertility Treatment Act 1995. This Register includes all births from where the donor has consented to the use of their sperm, eggs or embryos after 1 January 1998.

Slight differences exist in relation to the Rights of the parties involved in Donor procedures. Please refer to '*Differences between the Registers*'.

Who will have access to the Information?

Both the parents and the person born are able to access the non-identifying information about the donor whenever they wish. This can be sought from the clinic where they received treatment.

Should the inquiring party/ies require information about the donor that identifies that person, you have the right to request identifying information about the donor. This is done by writing to the Infertility Treatment Authority. However, the Infertility Treatment Authority is only able to release identifying information about the donor, if they have the Donor's consent in writing, and counselling is provided to both parties before the release of information.

Infertility Treatment Authority

Level 30, 570 Bourke Street Melbourne Victoria 3000

Telephone 61 3 8601 5250 Facsimile 61 3 8601 5277 Email ita@ita.org.au Web www.ita.org.au

Donors are also able to access the non-identifying information about the recipients who have used the sperm, eggs or embryos, and non-identifying information about the children who were born as a result of a donation.

If the donor(s) wishes to have identifying information about the person born as a result of their donation or their parents, then they must also write to the Authority. The Authority then must seek the consent of the parents or the child if they are over the age of 18 years. The Authority would seek consent as follows:

- ❑ If the child is under 18 years of age, the parents must consent to the release of any identifying information on the child;
- ❑ If the child is 18 or over, they must first consent to the release of any identifying information. The consent of the parents is no longer required.

In both instances, the donor(s) will be required to have counselling, and counselling is offered to both the parents and the child, if consent is given and information is to be released. There is no requirement to give consent.

Differences between the Registers

Once a child on the 1995 Central Register turns 18, they can automatically receive information from the Central Register. Any other release of identifying information may only be undertaken with the consent of the person about whom the information relates.

The Voluntary Register

The Infertility Treatment Authority also has a Voluntary Register which allows the voluntary exchange of information for those people involved with treatment since 1988.

You can join the Voluntary Register by completing an application form.

Application is completely voluntary. On the form you will be asked how any match or request of information should be handled. For example, you may only want to pass a message onto the donor (s) or you may wish to provide the donor (s) with information that will identify you. This Register allows the voluntary release of information between parents and donors, or half siblings over the age of 18 years, or their parents. However, you can give as little or as much information as you wish.

When the Authority receives an application to join the Voluntary Register we check to see if there is a matching link. If there is we will contact you in writing to let you know and to check again whether you want to proceed with the release of information.

More Information?

If you want to clarify anything in this document, or discuss any other matter in confidence, associated with the registers and your information, please contact the Authority. All enquiries will be dealt with confidentially.

Support groups

Donor Conception Support Group of Australia

This is a national self funded organisation, run by volunteers, which aims to provide support to those contemplating use of donor gametes or embryos, to existing parents and to children themselves.

DCSG Australia

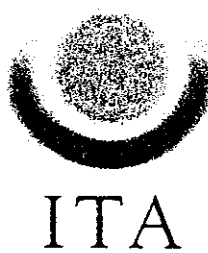
P.O. Box 53

Georges Hall NSW 2198

Tel: (02) 9793 9335

Email: dcsq@optushome.com.au

Website: www.dcsq.org.au



The Voluntary Register

Creating opportunities to exchange information

Infertility Treatment Authority

In the past it was often difficult, if not impossible, for children born with the help of donated sperm, eggs or embryos to get information about their biological heritage. There was a widely held view that the offspring were better off not knowing.

Today we know that many beneficiaries of donor procedures wish to have the opportunity to find out about the donors, and that many donors also wish to know about the offspring created with the assistance of their donation.

Since 1988, the Victorian government has recognised that individuals born with the assistance of donor procedures have a right to information that will help them trace their biological origins. Donors consent to providing information at the time of their donation. This information is kept in the Central Registers.

However this does not help individuals born with the assistance of anonymous donations made before 1988.

The Voluntary Registers have been created to:

- Help those people involved before 1988 to find information
- To facilitate a voluntary exchange of information for those people involved with treatment since 1988

The registers are called the Pre-1988 and the Post-1988 Voluntary Register.

People who can use the Voluntary Register include:

- people born as a result of donor treatment procedures;
- descendants of offspring of donor treatment procedures;
- couples who have had a child through these procedures;
- donors who have provided sperm, eggs or embryos;
- relatives of any of the groups of people described above;
- people who wish to establish whether they were born as a result of a donor treatment procedure; and
- biological siblings of offspring of donor procedures.

Information from the Voluntary Register will only be provided in line with the instructions given by the applicants to the Register.

How can I join the Voluntary Register?

You can join the Voluntary Register by completing an application form. The forms are available at www.ita.org.au or by phone or post. There are different forms for recipients, parents, donors and siblings. As well as your details, you will be asked how any match or requests for information should be handled. For example: you may only want us to give access to information that does not identify you; or you may want us to provide contact information that will allow you to meet.

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The donor code is the key piece of information that allows the Authority to link the names of recipients and donors. If you don't have a donor code we will make every effort to identify it either from:

- the Central Registers that have been established since July 1988, or
- the records that were kept by the treating clinic or doctor prior to 1988.

If you are under 18 years old then your request must be made by your parents.

What will happen if a match is found?

Every time we receive an application to join the Voluntary Register we check to see if there is a matching link. If there is we will contact you in line with the instructions you provided when you joined the register.

How likely is a link to occur?

The Authority is actively promoting the Voluntary Register to encourage people to join. As the Register grows, the chance of a link increases. However, many early donations were made in a climate of secrecy and anonymity so there are no guarantees that a link will be made.

Where a donor code is not available, it may not be possible to identify matching applications. Pre-1988 procedures are the hardest to link as the record keeping provisions of clinics have changed significantly, from a time when the purpose was to protect the anonymity of the donors and families, to the current practices. This means that records may not always be

complete, and that it may not be possible to identify a donor code.

Where a person is deceased, and therefore not able to provide consent to access information from their medical records, the applicant will be notified.

Is there someone I can talk this through with?

Yes, we encourage you to seek counselling and we have a counsellor on staff who is available to talk to you at no cost.

Further information about the operation of the Registers can be obtained by contacting the Authority.

Support groups

Donor Conception Support Group of Australia

This is a national self funded organisation, run by volunteers, which aims to provide support to those contemplating use of donor gametes or embryos, to existing parents and to children themselves.

DCSG Australia
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Georges Hall NSW 2198

Telephone: (02) 9793 9335
Email: dcsg@optushome.com.au
Website: www.dcsq.org.au

The Voluntary Register is more correctly known as the Donor Treatment Procedure Information Register.

There are in fact two registers:

The first covers all people who were involved with a donor procedure since 1 July 1988 and was established under the provisions of Section 82 of the *Infertility Treatment Act* 1995.

The second is the Pre-1988 Donor Treatment Procedure Information Register, which was established under the provisions of Part 7A of the *Infertility Treatment (Amendment) Act* 2001. It includes all people who were involved with a donor procedure before 1 July 1988, the date of proclamation of the *Infertility (Medical Procedures) Act* 1984, which established the 1984 Central Register.

The application form that you should use will be labelled according to your role in treatment (either Donor, Offspring or Recipient Parent/Relative). You should choose the form based on your involvement.