

**LAW REFORM COMMITTEE OF THE PARLIAMENT OF VICTORIA**

**INQUIRY INTO ACCESS BY DONOR CONCEIVED PEOPLE  
TO INFORMATION ABOUT DONORS**

**SUBMISSION BY HELEN KANE**

**INTRODUCTION:**

My name is Helen Kane, and I make this submission as a private person. I am a social worker with many years of experience as a social worker in the adoption, infertility, access to information field (both adoption and donor conception), and in public health and private infertility clinics. I was the Manager of the Donor Registers Service at the Infertility Treatment Authority in Melbourne, from 2005 to 2009, when the changes in legislation led to the closure of these Registers, and the transfer of their functions to other bodies. I had previously managed Adoption Information Services in several private adoption agencies, and had been involved with the implementation of the 1984 Adoption Act in Victoria, which introduced access to information for adopted people, no matter when the adoption took place. It was retrospective, and was a clear and positive success, as long as it was accompanied with good counseling and linking services, which acknowledged the needs of all the people concerned. I was also involved, as a member of the Victorian Infertility Counsellors Group, with developing a model of practice for use with people wishing to access information in relation to donor conception, as a consequence of the 1984 Infertility legislation.

## **SUMMARY OF RECOMMENDATIONS:**

The major point that I would make is that all people created with the use of donated gametes have a right to know the truth of their conception, and the right to seek information about the donor or donors, and any other individuals created with gametes from that person. There is a right to know one's biological and social reality of identity.

All donor conceived individuals have a right to seek information, and current legislation which is based on when and where the conception took place is inherently discriminatory. Victorian law has created pre-88 rights, post 88 rights, post 2009 rights, in relation to knowing their genetic history and donor. Donor conceived people in Victoria have different rights from each other as a consequence, as well as different rights from non-donor conceived people.

All donor conceived people in Victoria should have the same rights to seek information about their donor, no matter when their conception occurred.

Both donors and parents have been poorly advised in the past, in relation to the need for openness and the needs of the child, and also their own needs to know more about the other. Poor advice and practice of the past does not provide justification for limiting the rights of all parties to seek information, or most particularly, for the donor conceived person to do so.

But to implement access to information rights requires consideration of the needs of all concerned. This means seeking to involve and inform people affected by an enquiry. If the donor conceived person wants identifying information about their donor, the latter requires the dignity and support to make their own decision about this, in the present. Any wishes expressed at the time of donation cannot carry over automatically, on the basis that the original advice was flawed, or indeed that no choice was given at the time. Donors were required, at certain points in the history of donor conception in this state, to swear that they would never ask, and would never be told, the results of the donation. Donors did not see counselors in this state until the 1984 legislation required this. There are questions, prior to that, about the "informed consent" of any donor.

What is required, if equality is acknowledged for all donor conceived people, is a system which has the capacity to locate information, confirm it, provide counseling, and provide an outreach/mediation service to the parties concerned.

It requires recognition of the rights of the donor conceived person to seek information, and for respect of the needs of the donor, as well as the family, to be involved in making decisions in the present, based on new circumstances.

## **TERMS OF REFERENCE**

- (a) **The legal, practical and other issues that would arise if all donor-conceived people were given access to identifying information about their donors and their donor-conceived siblings, regardless of the date that the donation was made.**

I believe that it is important that all donor conceived people possess the right to seek information which identifies their donor. That does not mean the automatic release of that information without the involvement of the donor.

There are practical issues which relate to the way that records have been kept in the past. Private doctors in their private practices, as well as doctors within public and private hospitals, have provided donor treatments since well before the 1940's, with a huge increase in the 1970's, and into the 1980's. There was enormous variation in the way that records were kept, but most importantly, they were not kept at all at times, or destroyed when medical practices closed down. Where records do exist, some are the property of the private doctor, some the property of the hospital where the treatment took place. There was no requirement that records be maintained, and sometimes they were destroyed. The records themselves can be unreliable – simple issues like misspelling the name of the donor, because there was no check done at the time, means that the chance of locating the person are minimized. It is crucial that information be checked and confirmed where possible, before any thought of releasing that information.

I believe that the donor conceived person has the right to seek information, and that the donor has the right to be contacted, and that his/her thoughts and wishes in relation to that in the present to be ascertained by the neutral organization providing the service overall.

- (b) **The relevance of a donor's consent or otherwise to the release of identifying information and the National Health and Medical Research Council's ethical guidelines on the use of assisted reproductive technology in clinical practice and research.**

Informed consent when donating gametes is the essential element required for the carry over of that consent into the present. It would be fair to say that no consent prior to 1984 would meet the criteria of informed consent in law. And many after that did not, as there was a wide misunderstanding, particularly amongst the medical profession, about the implications of the aspects of the 1984 Act which allowed all the individuals concerned to seek information about each other.

A decision to donate takes place at a point in time when it is perhaps not possible to consider future implications. There would not be many 26 year old men, for example, who can think ahead to how they might feel about the needs of the children conceived,

in another 20-30 years time, when the young person, or the parents, may be developing a need to know more. It has not been unusual, in my experience, to find that donors have wondered if there were children, and if there were, what were their lives like, and was there anything that they needed of them.

Where there is any uncertainty about the donor being aware that he or she may be contacted in the future, they should be approached, to seek consent, when and if the donor conceived person applies for information. This requires a skilled counselor to make the approach, but also requires skilled administrative and search staff, to confirm information, carry out searches, and locate the correct person.

**(c) Any practical difficulties in releasing information about donors who provided their gametes before 1 July 1988, because in many cases records are not available either because the procedure was carried out privately or records were not stored centrally.**

I have referred to the difficulties associated with this in the previous reference (b). I would add that the question of the existence of records ought not to stand in the way of all donor conceived people exercising their right to attempt to find out. There is no argument for limiting the rights of all because some will be disappointed in their search.

It is necessary, however, to attempt to locate and protect all information from the past, and to employ expert staff able to carry out a search for records, with a legislated right to request information held in a variety of places, not all covered by legislation of any kind at the time, or in the present.

It is self evident that if information does not exist, it cannot be released. But explanation, and associated counseling services, is required in such circumstance. One of the greatest issues for the people concerned is the secrecy and stigma associated with donor conception, and the failure to treat the information with respect within the treatment programs would appear to reflect this. Honest information about the failure to maintain information is imperative.

DNA testing has been used to identify if a donor is likely to be the biological father of a donor conceived person. This is the only option where there is uncertainty about records, or where they do not exist. This must always be accompanied by skilled counseling.

**(d) The options for implementing any changes to the current arrangements, including non-legislative options.**

When the 1984 Adoption Act was implemented, with the inclusion of retrospective rights of adult adopted people to seek their birth certificates and information which identified the circumstances of their adoption, there were several distinct steps.

The first step was extensive publicity about the changes, and dissemination of information about how this translated into action. There were a number of private adoption agencies already acting in the spirit of the new Act, and making contact with birth parents, on the basis that they needed to be informed that there were options available to them in the present. There was a model of service already in place which recognized the sensitivities of all parties, and was able to move with these parties at their pace. These practices were then translated into the method of practice with the Act itself. What was different was the vast numbers of people seeking their information. There had been many adoptions since 1928, in Victoria, but there had been an assumption that not many adopted people would seek their information. This was not the reality – once people could apply for their information, many did so.

Because of the legal process for registration of birth, and adoption, there were always records of some kind, if only the original birth certificate and the court records from the legalization of the adoption. There was certainty about the identity of the people concerned, and it was very rare for the information contained in these records to be false. With that firm base, it was possible to act to seek contact with other parties.

What was essential was a practice of involving all the parties as required, and moving at their pace. This included exchange of non-identifying information, which helped decision making about proceeding to closer contact, or not. But it was the people themselves who made those decisions, not an agency or a law which denied them the right to even consider this. Social workers provided the counseling and outreach/mediation services to support this process.

The infertility program at the Women's Hospital, now as Melbourne IVF, developed a practice in relation to assisting donor conceived people conceived prior to the 1984 legislation to seek contact with their donor. This has been highly successful, and demonstrates that it is possible to do this in a way that acknowledges the needs of all, even when legislation does not exist to guide the process.

**(e) The impact that any such changes may have on the donor, the donor-conceived person and future donor programs.**

The change which will impact on all of the parties to a donor conception is the freedom to seek information if they wish. They can choose for themselves, when and if, they will seek information, and will make their own decisions about how they might respond to the request of another party to that conception.

There will be disappointments and distress at times, to find there are no records, to find that the other party cannot be located, or to have the other party choose to refuse contact or release of information. It is essential that counseling be an integral part of any service which manages such requests.

Future donor programs will learn more about what it means to the people concerned, and will hopefully recognize the need to respond, both by providing good processes and

information at the time of donation and treatment, and to store information in an accessible manner, for the purposes of future access to this.

**(f) The impacts of the transfer of the donor registers currently held by the Infertility Treatment Authority to the Registrar of Births, Deaths and Marriages.**

It is a very difficult path for a donor conceived person to seek their information. It is fraught with a number of personal and emotional issues to be dealt with. The new process associated with application for access to information to the Registrar has fractured the service, made each section, information, education, records, counseling, release of information, contact with other parties, separate from each other.

Such a complex system, which reduces the possibility of a person exercising their legal rights, reduces those rights overall. A series of barriers and impediments reduces the possibility of a person making their way successfully through to achieve the goals they may have. These rights become very hollow if it becomes impossible, or unreasonably difficult, to exercise those rights.

**(g) The possible implications under the Charter of Human Rights and Responsibilities Act 2006.**

The Charter of Human Rights and Responsibilities Act 2006, under S.8, recognizes the right to recognition as a person, the right to enjoy their rights without discrimination, and the equality of all people under the law.

The donor conceived person, under these conditions, has the right to know the means of their creation, and the people who were involved in their creation. This is so, no matter when or where this creation occurred. It is unreasonable that a donor conceived person born in 1980 has different rights from a person born in 1990.

The limitation that might be put on this, as part of s.8, is that there is such variation in understanding about the future implications of donation and creation of children from donated gametes, that there must be services associated with management of applications and release of information which enable the people directly concerned to have clear information in the present about the options, counseling to deal with issues arising, and facilitation of release of information, both identifying and non-identifying.

**HELEN KANE**

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