Submission to the Senate Enquiry into

"The past and present practices of donor conception in Australia"

on behalf of the Fertility Society of Australia and its sub-committees

- **The IVF Medical Directors Group**
- **Scientists in Reproductive Technology**
- **The Australian and New Zealand Infertility Counsellors Association**
- **The Fertility Nurses Association**

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All responsibility for the opinions expressed in this submission lie with the Board of the Fertility Society of Australia.

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The past and present practices of donor conception in Australia, with particular reference to:

(a) donor conception regulation and legislation across federal and state jurisdictions

(b) The conduct of clinics and medical services, including:

payment for donors

management of data relating to donor conception

provision of appropriate counselling and support services

(c) The number of offspring born from each donor with reference to the risk of consanguine relationships

(d) The rights of donor conceived individuals

Executive Summary

The Fertility Society of Australia (FSA) would like to make the following points to the Senate Enquiry

- We strongly support the rights of donor-conceived individuals to have access to identifying information about their genetic origins

- We support the present system of regulation of ART in Australia, involving a combination of state-based legislation and clinic accreditation to the Reproductive Technology Accreditation Committee Code of Practice by independent assessors.

- We have concerns about some State governments whose legislation limits access to fertility treatment in a discriminatory manner.

- We support the establishment of donor registries, both prospective compulsory registries and voluntary retrospective registries, including in those states, which do not presently have it.

- We are strongly opposed to **compulsory** retrospective registries as this would be a violation of agreements entered into, in good faith, with sperm donors who have made an altruistic donation to help other families have children.

- National legislation in this area would add significantly to the administrative burden of both government and clinics with little evidence that there would be benefit over the present State-based arrangements.

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- Introduction

Nowadays, there is widespread acceptance of the right of a donor-conceived individual to have access to identifying knowledge of their genetic parentage.

The Fertility Society of Australia is strongly supportive of the right of a donor-conceived individual to have access to identifying knowledge of their genetic origins and this principle is now enshrined in the practices and procedures of all our sub-committees, including the Reproductive Technology Accreditation Committee Code of Practice where the introduction in the latest version states:

"Fundamental to the delivery of ART services is that patients and their offspring remain the most important consideration in all decisions. Organisations aspire to deliver services in a manner that recognises patients' cultural and individual values and beliefs, upholds their dignity and privacy, and acknowledges the rights of children born through ART to know their genetic origins and health outcomes.

Modern infertility practice using donated gametes is therefore based on an understanding of the needs of donor-conceived individuals and the consequent principles of being open with all participants about future identification and the consequences that follow from that.

However, we fully recognise that this has not always been the case. Sadly, some of the infertility practices of the past have resulted in unforeseen long-term consequences for the individuals involved. The Fertility Society of Australia acknowledges the serious difficulties that this has caused in some cases and now seeks to make amends for the mistakes of the past through being at the forefront of the continuing evolution of practice in this area.

It is, however important to consider the historical context of past practices. At the time, anonymous donor insemination had the broad support in the community and was supported by the legal and ethical frameworks of the era.

A survey of New South Wales people carried out in 1984 as part of the investigative work for the NSW Law Reform Commission found that only 13% of those surveyed thought that donor-conceived children should have access to identifying information about their donor. In Victoria, The 1982 Waller Committee Report on Donor Gametes in IVF, recommended that "the use of known donors in donor gamete in IVF should be permitted, where both partners request it". In other words, anonymous donation was seen as the generally accepted practice. In 1984, the NSW law reform commission made recommendations that "our tentative view is that there are no persuasive reasons for creating a legal right in favour of AID children or any other person for access to identifying information about an AID donor or any other party to AID."

As recently as the mid 1990s, the 1996 NHMRC Ethical Guidelines in Assisted Reproductive Technology made no reference to the need for providing identifying information to donor-conceived individuals.

The principle of anonymity was therefore widely accepted in the early days of this treatment and it was on this ethical basis that doctors sought to provide assistance to the patients under their care by the best means available.

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It was only in the mid 1990s as the first offspring from donor conception began to grow up that the importance of identifying knowledge about their genetic antecedents has become clear to all of us. As these views have become more widely known and understood, the Fertility Society of Australia has been at the centre of changing clinical practice to reflect these needs. Fertility clinics have changed their donor recruitment practices and now recruit only gamete donors who are willing to have their identity released to the conceived individuals.

The Fertility Society of Australia

The Fertility Society of Australia is the parent organization for professionals in fertility healthcare in Australia and New Zealand. We are an open multi-disciplinary society with a number of sub-committees for individual professional groups, including the Australian and New Zealand Infertility Counsellors Association (ANZICA), Scientists in Reproductive Technology (SIRT), the Fertility Nurses Association (FNA) and the IVF Medical Directors group. We also run special interest groups dealing with the specific topics of pre-conceptional health, preservation of fertility for cancer patients and the co-ordination of controlled trials of fertility treatments.

In the context of donor conception, we are responsible for two important activities in the regulation of fertility treatment in Australia and New Zealand. The first is the accreditation of fertility clinics through our sub-committee, the Reproductive Technology Accreditation Committee (RTAC). This process is described in detail below. The second is supporting the National Perinatal Statistics Unit of the Australian Institute of Health and Welfare in the collection, assembly and reporting of comprehensive statistics on assisted reproduction in Australia and New Zealand. This process is described in detail below

Why do we need donor conception at all?

Donor sperm

Due to the dramatic developments in ART over the past two decades, successful conceptions can now be achieved from even tiny numbers of sperm, often obtained direct from a man's testis. This means that many men who would have previously had to use donated sperm to have a child can now successfully father a pregnancy using their own sperm. Therefore donor sperm is, nowadays, only needed in infertility cases where a man is unable to make any of his own sperm at all. This is usually due to genetic factors but occasionally environmental factors such as chemotherapy or radiation therapy may be involved.

In addition, some men may use donor sperm to avoid transmission of heritable disorders to their children. In more recent years, single women and lesbian couples have been able to use DI and IVF with donor sperm to have children.

Donor oocytes

Donor oocytes (eggs) may be used by couples where ovarian failure or declining ovarian function is the cause of infertility, poor oocyte quality has been identified in previous ART cycles, or the woman is a carrier of a severe genetic condition. Furthermore, couples who experience repeated treatment failure may be advised that their chance of becoming parents is higher if they use donor oocytes.

In a donor oocyte cycle, the woman making the donation is required to go through a full IVF cycle including injections, blood tests, internal ultrasounds and a procedure (often under anaesthetic) to have the oocytes collected ready for donation. Once the oocytes have been collected, they are combined with the sperm of the recipient's partner to create an embryo that is replaced in the womb of the recipient. Because of the demanding and invasive nature of oocyte donation, most oocyte donation in Australia is done between either friends or relatives and is done on a completely open, known donor basis and is very rarely used to create more than one family.

Donor embryos

For couples where both the woman and the man have problems relating to gamete production, donor embryos may be a treatment option.

Surrogacy

In a small proportion of infertile couples indeed, the woman has a uterine disorder and is consequently unable to carry a pregnancy. In order to have a child this couple will need to commission a surrogate to carry the pregnancy and give birth. Surrogacy is not included in the scope of this enquiry and will not be referred to further in this submission.

History of Donor Insemination in Australia.

Because of the lack of available treatment for male infertility, donor insemination (DI) using fresh sperm, unscreened and unmatched, has been practised in Australia since the 1950s. The services were revolutionised by the development of sperm freezing and banking, which allowed the screening and matching of donors. In 1980, Alan Trounson published a landmark paper to show that frozen sperm was as efficient as fresh in achieving pregnancies.

A number of "Artificial Insemination with Donor Workshops" (artificial insemination by donor was abbreviated as AID until 1984 when, to avoid confusion, the abbreviation was changed to the present form, donor insemination, DI) were established, with the first meeting in Melbourne in 1977. This was a multidisciplinary group including clinicians, nurses, scientists, and counsellors, and met annually. By 1981 there were over 100 registrants, and many of the doctors pioneering IVF at that time were also heavily involved with the AID Workshops

The group, at its annual meetings, began setting standards for DI treatment in Australia including aspects such as the technicalities of cryopreservation, the timing of insemination and insemination techniques as well as considering the social aspects of counselling and information collection and retention.

As there was no legislation relating to gamete donation at that time, the rights and responsibilities of donors were unsure, and the group started agitating for a formalisation of this. The first legislation was the Federal "Status of Children Amendment Act" . The Honourable Justice Austin Asche became interested in the legal aspects of DI, and talked the group through the issues.

In 1980, Carl Wood, John Leeton and Gab Kovacs edited the DI Handbook- "Artificial Insemination by Donor" with chapters written by Australian experts, recording in a book covering all aspects of treatment discussed at the annual workshops.

The group also started negotiating with the Department of Health to obtain some Medicare support for the costs of DI treatment, with some success.

In 1984 when Acquired Immuno Deficiency Syndrome (AIDS) came on the scene, anxiety arose that the virus may be transmitted through stored donor sperm. The possibility of this was subsequently confirmed in a sad case in New South Wales where a donor did infect three recipients. Treatment was suspended in November 1984, and under the auspices of the FSA, an advisory group was established who then worked with State Health Departments to establish guidelines for screening and quarantining of semen prior to its use for donation.

In the 1980s, the development of IVF in Australia led to the use of donated oocytes and donated embryos. While the same issues arise from donor oocytes as for donor sperm, of the balance between privacy of the donor and the rights of the donor-conceived individual, in practice, the issues were less pressing due to the fact that most oocyte donation has always been done on an known donor basis. Even where an anonymous donation has taken place, it is extremely rare for one oocyte or embryo donor to create more than one additional family from their donation(s).

(a) donor conception regulation and legislation across federal and state jurisdictions

There is broad public acceptance of the use of ART to treat infertility in Australia and ART procedures are subsidised by Medicare and the PBS. Infertile couples can access affordable ART services at some 70 fertility clinics around Australia. IVF procedures can only be performed in accredited fertility clinics but it is possible for donor insemination (DI) cycles to be performed in hospitals and private practices, Nowadays, however, the extent of this is very limited indeed.

There is no Australia-wide government body or legislation regulating the provision of ART services. However, all ART clinics are required to comply with state based legislation as well as having to satisfy the Code of Practice for Reproductive Technology Units developed by the Fertility Society of Australia's Reproductive Technology Accreditation Committee (RTAC).

State-based legislation

Four of the six Australian states have legislation which regulates ART in those states:

- The *Assisted Reproductive Technology Act 2007* (NSW) and the associated Assisted Reproductive Technology Regulation 2009 in New South Wales
- The *Assisted Reproductive Treatment Act 1988* (SA) in South Australia (also adopted by the Northern Territory)
- The *Assisted Reproductive Treatment Act 2008* (Vic) and the associated Assisted Reproductive Treatment Regulations 2009 in Victoria
- The *Human Reproductive Technology Act 1991* (WA) and the associated Human Reproductive Technology (Licences and Registers) Regulations 1993 in Western Australia

Eligibility requirements for access to ART services vary throughout Australia. In New South Wales, Victoria and Western Australia, access to ART services is broad, enabling any woman, regardless of relationship status or sexual orientation to have ART treatment. Hence, in these states single women and lesbian couples can use donor sperm or embryos in ART procedures. In contrast, South Australian law restricts access to ART to heterosexual married or de facto couples and single women who are medically infertile, whereas lesbian couples and single women who are not medically infertile are denied access. In all other states, eligibility for ART treatment is determined by individual clinics.

People wishing to have ART treatment in South Australia are required to sign a statutory declaration prior to commencing treatment to indicate that they do not have a criminal history that could impact on the health and welfare of a child to be born. Legislation introduced in Victoria in 2010 requires eligible women and their partners (if they have one) to undergo criminal record and child protection order checks prior to treatment and they are denied access to ART if they have convictions of violent or sexual offences or have had a child removed from their custody. Victoria is believed to be the first jurisdiction in the world to implement such rigorous checks as prerequisites for ART treatment.

NHMRC Ethical Guidelines

The Australian Federal Government, through the National Health and Medical Research Council (NHMRC), has issued Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research. It is a requirement of the RTAC Code of Practice that these ethical guidelines are followed and the independent RTAC assessors assess each ARC clinic for their compliance with these guidelines.

Commonwealth legislation

The 2002 Commonwealth Research Involving Human Embryos (RIHE) Act, Section 11 made it a criminal offence to use an embryo outside the body except at "an accredited ART centre"

11 Offence—use of embryo that is not an excess ART embryo

A person commits an offence if:

(a) the person intentionally uses, outside the body of a woman, a human embryo that is not an excess ART embryo; and

(b) the use is not for a purpose relating to the assisted reproductive technology treatment of a woman carried out by an accredited ART centre, and the person knows or is reckless as to that fact.

Maximum penalty: Imprisonment for 5 years.

The RIHE Act defined accreditation as follows

accredited ART centre means a person or body accredited to carry out assisted reproductive technology by:

(a) the Reproductive Technology Accreditation Committee of the Fertility Society of Australia; or

(b) if the regulations prescribe another body or other bodies in addition to, or instead of, the body mentioned in paragraph (a)—that other body or any of those other bodies, as the case requires.

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Reproductive Technology Accreditation Committee

The Reproductive Technology Accreditation Committee was established in 1987 as a sub-committee of the Fertility Society to visit and accredit fertility clinics according to the Reproductive Technology Accreditation Code of Practice, which had been written the previous year. The purpose of the code is to set minimum standards for fertility clinics providing ART services in Australia and New Zealand and to promote continuous improvement in the quality of care provided to people who undergo treatment.

For most of the last twenty-five years, RTAC has performed inspection visits to each fertility clinic every three years. At each visit, a multi-disciplinary team, chaired by either the RTAC Chair or Deputy Chair, attended, checked the quality system of the unit, reviewed a selection of case-notes and interviewed patients of the unit. At the end of this visit, a report would be issued stating whether accreditation of the clinic had given for a further three years.

Significant revisions to the RTAC Scheme

In 2007, RTAC a new, and radically different system for certifying fertility clinics. These changes were made for several reasons – difficulty in finding sufficient highly experienced volunteers who had time for the many peer review visits, the challenge of auditing to professional standards by volunteers with limited auditor training, the concern that peer review could be seen as subjective, and limited input from external stakeholders other than patients.
Under the new system, the RTAC Code of Practice (Attachment 1) was reframed into auditable criteria and their accompanying measures. . There are 13 Critical Criteria focus on the safe and effective delivery of ART services, including adherence to the NHMRC Ethical Guidelines and a set of strict criteria for the management of donated gametes. The Critical Criteria are audited annually and the five Good Practice Criteria, including the quality management system, are audited over a three year cycle.

To create the new RTAC auditing scheme, the FSA engaged the Joint Accreditation System of Australia and New Zealand (JAS-ANZ), the government-appointed accreditation body for Australia and New Zealand that has responsible for providing accreditation of conformity assessment bodies (CABs) in the fields of certification and inspection. With input from a variety of stakeholders now represented in the RTAC Technical Committee, JAS-ANZ wrote the RTAC Scheme (attached) based on international accrediting guidelines.

Thus the new system combines the RTAC Code of Practice, which describes what to audit with the RTAC Scheme, which describes how to audit.

ART units engage a CAB to undertake the audits. The audits are carried out by certified professional auditors with no connection to the ART sector. Auditors often use a Technical Expert to assist them. There are conflict of interest rules to ensure auditors and technical experts are independent of the organization being audited.

The Scheme rules are overseen by the RTAC Technical Committee which includes representatives from key stakeholders in fertility care in Australia, including the Commonwealth Department of Health, NHMRC, the State governments, Health funds, consumers, certification bodies, and others.

In addition, the Fertility Society of Australia has worked closely with State Governments to ensure a smooth interaction between State accreditation visits and RTAC. The RTAC

Code of Practice and the RTAC Scheme Rules are public documents that are available on the internet at: http://www.fertilitysociety.com.au/rtac/

(b) The conduct of clinics and medical services, including:

payment for donors

Payment of donors in any form, beyond legitimate expenses incurred in making the donation, does not take place in Australia. It has long been contrary to the RTAC Code of Practice.

Under the Commonwealth Prohibition of Human Cloning Act, 2002, Section 23 states that

23 Offence—commercial trading in human eggs, human sperm or human embryos
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(1) A person commits an offence if the person intentionally gives or offers valuable consideration to another person for the supply of a human egg, human sperm or a human embryo.
Maximum penalty: Imprisonment for 10 years.
(2) A person commits an offence if the person intentionally receives, or offers to receive, valuable consideration from another person for the supply of a human egg, human sperm or a human embryo.
Maximum penalty: Imprisonment for 10 years.

shortage of donors

Compared with overseas countries, there is a serious shortage of gamete donors in Australia.

Donors may be recruited by the ART clinic and be unknown to the recipient or recruited by the recipient and known and, in some instances, related to the recipient.

The requirement to only use donors who are willing to provide identifying information to any offspring and broadened access to treatment, to include single women and same-sex couples in certain states, has led to a shortage of sperm donors in some clinics. Occasionally, couples recruit their own sperm donor, either through social networks or advertising.

Occasionally oocyte donors are recruited by ART clinics and are unknown to the recipient couple. However, due to the shortage of women who are prepared to donate oocytes to someone they do not know, most recipient couples rely on a friend or a relative to agree to donate oocytes, or attempt to recruit an oocyte donor through advertisements in local newspapers or via the Internet.

There is a real shortage of embryos available for donation. At the end of the legal storage time limit for frozen embryos (five years in most states), couples are required to decide the fate of frozen embryos that they are not intending to use. Most couples donate these embryos to research or choose to have them discarded and only 10-15% of couples donate their embryos to another infertile couple. Common reasons for discarding rather than donating frozen embryos is the perception of the embryo as a potential child and sibling to existing children and the risk of being contacted by a child born as a result of the donation in the future.

management of data relating to donor conception

There are two aspects to management of the data relating to donor conception: the central reporting of deidentified information to a central repository and the collection and retention of private identifying and medical data about all participants in a donor treatment programme.

Central reporting

The RTAC Code of Practice requires all ART clinics in Australia and New Zealand to provide detailed information to the Perinatal and Reproductive Epidemiology Research Unit at the University of NSW, which is affiliated to the Australian Institute of Health and Welfare's National Perinatal Statistics Unit (AIHW NPSU). The data provided is required to provide specific, de-identified, information about every donor insemination cycle and every IVF treatment cycle carried out in every Unit. These data include details of the age of the participant, the source of the sperm, the number of eggs collected, the resulting embryos and whether or not a pregnancy occurred.

Treatment and pregnancy outcome data are compiled by the AIHW NPSU and published in an annual report. The 2007 report can be accessed at http://www.preru.unsw.edu.au/PRERUWeb.nsf/page/art13. In 2007, approximately 52,000 ART treatment cycles were performed in Australian fertility clinics and over 10,000 children were born as a result, accounting for 3.1% of all Australian births that year. Of the treatment cycles performed in 2007, 1,800 were embryo transfers with donated oocytes or embryos resulting in 300 births, around 2,200 were DI cycles resulting in 250 births and 52 were surrogacy cycles resulting in 7 births. Donor procedures accounted for approximately 7.5% of all ART procedures in 2007.

Collection and storage of private identifying and medical information

Under the RTAC Code of Practice, all clinics performing treatment with donated gametes are now required to collect and store detailed identifying information about the health and family genetic history of all persons donating gametes.

Under the RTAC Code of Practice, Clinics are required to maintain all records to gamete donation in storage indefinitely.

Clinics are required to obtain informed consent from all donors to provide the recipient with all non-identifying information that is relevant to the future health of either the recipient of a future donor-conceived individual.

Clinics are required to obtain informed consent from all donors to provide all donor-conceived individuals who have reached adulthood with identifying information about the donor.

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Donor registers

The four states with legislation (New South Wales, Victoria, Western Australia and South Australia) have all established compulsory prospective donor registers. These registers allow the prospective registration of all births taking place in a registered fertility clinic that involve a conception from donated gametes. This ensures that identifying information about donor conception is placed in a secure place to ensure that donor-conceived children can later have access to identifying information about their origins. In the future, individuals conceived from donated gametes will be able to access this information to gain information about their genetic origins.

The Fertility Society is supportive of the establishment of prospective donor registers in those States and Territories that do not currently have them.

The Fertility Society is also strongly supportive of the establishment of voluntary registers, whereby we encourage men and women, who have been anonymous gamete donors in the past, to voluntarily make their contact details available to the individuals who have been conceived as a result of their donation. Our experience has been that when they have been successful, these voluntary arrangements have worked very well for both the donor-conceived individuals and the donors involved.

However, we think it would be quite wrong to now compel the donor, through retrospective legislation, to release of his identifying information. These men, and to a lesser extent women, previously agreed, in good faith, to donate sperm to help another family on the basis of anonymity. It would be a grievous violation of their privacy, with potentially devastating consequences for their own families, to now compulsorily change these arrangements in retrospect.

As a consequence, the establishment of satisfactory voluntary donor registers has proved to be a very difficult undertaking indeed. The sad fact of the situation is that, desirable as it would be to promote contact and identification between donors and the individuals conceived from their donation, most donors who donated under the old anonymous system are either unable to be traced or unwilling to release their identity, once contacted. There are no simple regulatory solutions to resolving these sensitive difficulties.

Our members would like to work with donor-conceived individuals to provide them with support in trying, as far as possible, to contact their donors on a voluntary consensual basis to identify their genetic origins. Many clinics are now establishing clinic-based registers and providing support for donor-conceived individuals in this area. As described below, we have, through ANZICA, developed comprehensive guidelines for this and these are attached.

provision of appropriate counselling and support services

Informed decision making

There is agreement around the world that the social, emotional, medical, legal and ethical complexities of donor conception require thorough exploration by those donating and receiving gametes and embryos. The RTAC Code of Practice and the NHMRC Ethical Guidelines stipulate that individuals considering donor procedures must receive counselling before they proceed.

The following matters are covered in donor counselling:

- Circumstances that lead to considering being a donor
- Medical and practical aspects of the procedure for the donor
- Psychological and social aspects of being a donor
- Legal aspects of being a donor including the possibility that a child who is born as a result of the donation may contact the donor in the future
- Possible impact of the donation on the donor's relationship with his or her intimate partner
- Possible impact of the donation on the donor's own children
- Possible impact of the donation on the donor's relationship with the recipient if they are known to each other.

Counsellors also gauge prospective donors for their suitability to be a donor in terms of their medical and genetic history, personality characteristics and motivations for being a donor. People considering donating embryos are encouraged to contemplate their feelings about donating a potential full genetic sibling to their own child or children.
Counselling for recipients aims to ensure that they consider the implications of donor conception for themselves, a future child, their family and social networks, and, if the donor is known to them, the impact of the donation on their relationship with the donor.
The following matters are covered in recipient counselling

- How a donor was found
- The lack of a genetic tie to one or both parents of a child born after a donor procedure
- Medical and practical aspects of the procedure for the recipient
- Psychological and social aspects of using a donor to conceive
- Legal aspects of using a donor to conceive
- Possible impact of using a donor to conceive on the intimate partner relationship
- Possible impact of the donation on the recipient's relationship with the donor if they are known to each other
- The importance of disclosing the use of a donor to a child born as a result of gamete or embryo donation
- When, how and to whom to disclose the use of donor gametes or embryos
- Possible future interaction between the child and the donor.

In summary, at the point of treatment, provision of implications counselling by an ANZICA counsellor is a requisite of accreditation of ART clinics to facilitate informed decision-making.

However qualified counselling to support the ongoing needs of donor conceived families and individuals remain generally inadequate in their provision. The process of donor conceived persons accessing identifying information about their genetic origins is new and unchartered territory and people need support and education to guide them through what is usually a very emotionally challenging process.

As discussed above, many ART units are now developing voluntary registers enabling donor linking when all parties are consenting. In these situations the counsellor acts as a neutral mediator to facilitate information exchange, in a manner that is comfortable to each party. (See attachment ANZICA Donor Linking Guidelines)

(c) The number of offspring born from each donor with reference to the risk of consanguine relationships

This has always been a difficult area. The guiding principles have, for many years, come from a review by Professor David Danks (first Director of the Murdoch Institute, Royal Children's Hospital, Melbourne) in 1980 (Genetic Considerations. Danks DM AID Handbook, Wood CM, Melbourne 1980). In this study, Professor Danks calculated the risks of accidental consanguinity. He concluded that the number of permissible offspring depended on three figures:

1. The maximum acceptable risk of unwitting half sibling matings
2. Number of total offspring per donor - natural and donated
3. The size of the breeding pool

These calculations were the basis for much of the practice in Australia and New Zealand in the 1980s and early 1990s.

However it is now clear that consideration of limiting the number of families created from each donor involves more than the risk of consanguine relationships. It also involves the responsibility for the donor in linking with offspring, and the identity and kinship issues for donor conceived persons in linking with their donor and with half genetic siblings.

As a consequence, in more recent times, a much more conservative approach has been taken and clinics have complied with the NHMRC recommendations that no more than ten families be created from a single donor. Some of the state-based legislations now limit this to five families.

The Fertility Society clearly supports limiting the number of offspring from a single donor. However, we would strongly recommend that the limits are expressed in terms of the number of families created rather than the number of children. Using the number of children as the standard, leads to the possibility that some women may be artificially prevented from completing their family with one donor. Our observations are that each family created using donor sperm involves an average of approximately 1.25-1.8 children per family, although there may be considerable individual variation from that number.

(d) The rights of donor conceived individuals

The Fertility Society of Australia strongly supports the rights of donor-conceived individuals to have access to identifying information about their genetic origins

The role of national legislation

The Fertility Society has given careful thought to the role of national legislation in all of this. The FSA is a multi-disciplinary organisation and there are differing views within the Society about the value of national legislation.

Many members can see advantages in having national legislation, in view of perceived deficiencies in legislation in some States and the concerns that some donor-conceived individuals have about the limited progress being made with voluntary donor registers.

However, the view of the Society is that any perceived benefits will be outweighed by the serious difficulties inherent in national legislation in this area.

In particular, the Society can see serious problems in trying to resolve inconsistencies in current State legislation and possible Commonwealth legislation. National legislation that included the discrimination inherent in the South Australian legislation or the punitive requirement for criminal record checks in the Victorian legislation would be abhorrent.

On the other hand, national legislation that did not seek to resolve the inconsistencies with the different State legislations would result in a regulatory mess. At best, the result would be participants and donors having to consider two different sets of regulations and paperwork and the differing personal and ethical implications of these for their individual circumstances. At worst, the result could be a mass of red tape that would, in some cases, be impossible to satisfy and therefore seriously limit the capacity of doctors to treat patients.

The Fertility Society is sympathetic to the concerns that donor-conceived individuals have had with the slow progress with voluntary registers.

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However, in the view of the Fertility Society, progress in this area will be best made by further development and refinement of the existing local State based systems and that there is no evidence that a national approach will provide significant advantages in this very difficult area.