



**The National Support Group
for Solo Mums by Choice in Australia**

**Submission to the Senate Legal and Constitutional
Affairs References Committee**

Inquiry into Donor Conception in Australia

July 2010

Unprotected

Document Control

Preparation

	Name	Title		Date
Prepared:	R Bailey, F Hearne, N Gadsby, K Wilson, K Brandenburg, S Garniss	Committee Members	SMC Australia	20/07/2010
Reviewed	All interested members	Members	SMC Australia	29/07/2010

Revision History

Version	Date	Author	Details	Ref. No.
0.1	27/07/2010	All	Initial draft	All
0.2	29/07/2010	K Brandenburg	Review all	All
1.0	30/07/2010	R Bailey	Post member reviews and comments	All

Approval to Release

Version	Name	Title	Date
1.0	D Rohr	President	30/07/2010

Printed copies of this document are uncontrolled.

Contents

1. Introduction.....	1
2. Donor conception regulation and legislation across federal and state jurisdictions	3
3. The conduct of clinics and medical services.....	4
3.1. Payments for donors	4
3.2. Management of data relating to donor conception.....	4
3.3. Provision of appropriate counselling and support services	8
4. The number of offspring born from each donor with reference to the risk of consanguine relationships.....	10
5. The rights of donor conceived individuals	11
6. Recommendations.....	12

1. Introduction

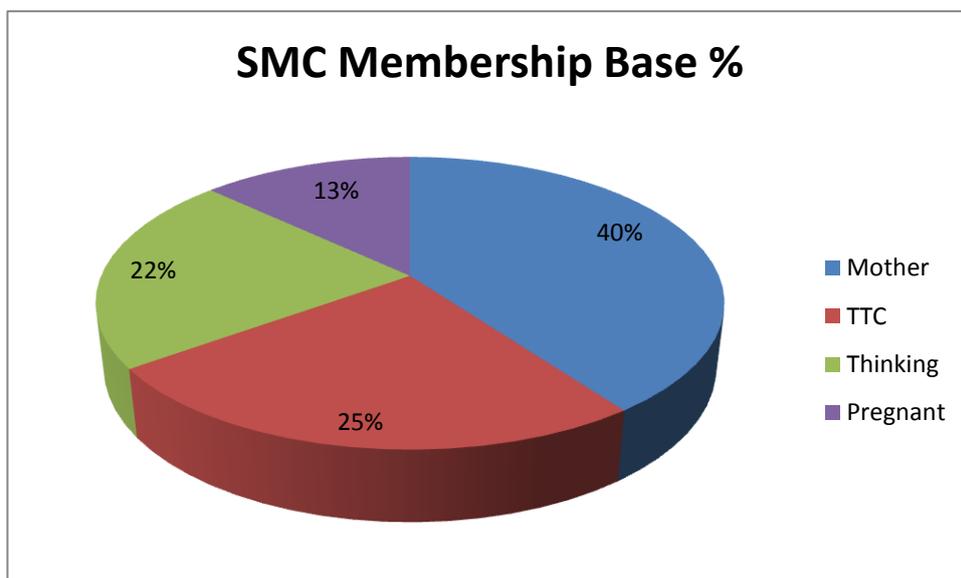
Solo Mums by Choice (SMC) Australia is the national support and advocacy group for women who are (thinking about, or have become) sole parents, and their children.

The group was initially founded in 2002, by two women from Queensland, one a solo mum by choice to one donor conceived child, and the other considering becoming a solo mum. In 2004, SMC Australia began communicating online, initially with a membership of around 30 members. In 2010, the group consists of well over 400 members from all states and territories within Australia, with support meetings being held in most capital and large cities. Our members are just a small subset of the total number of Solo Mums by Choice nationwide – there is estimated to be many thousands in the population at large.

SMC Australia is a self funded and managed organisation administered wholly by volunteers. We receive no government or corporate funding of any kind.

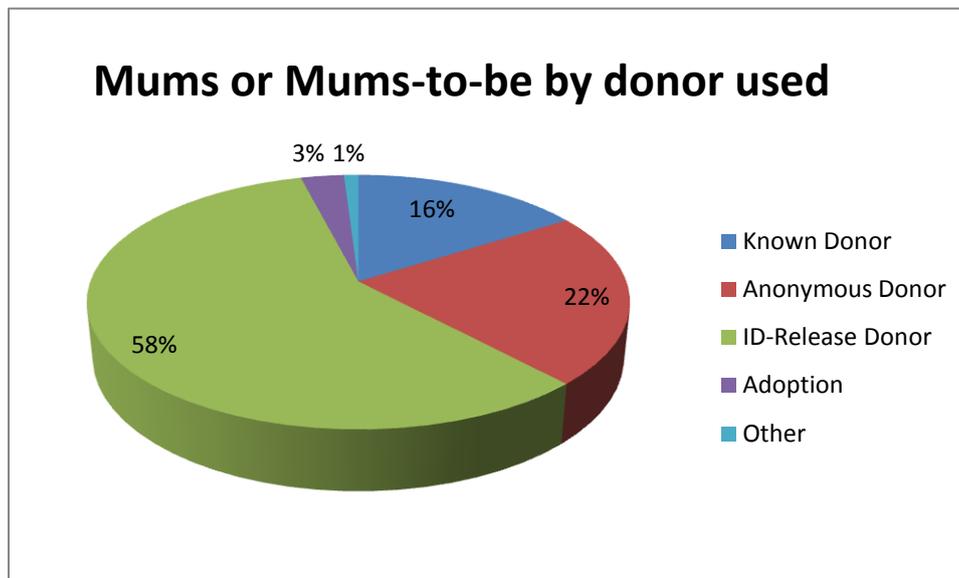
The Committee will receive submissions from other key action groups with a so-called “interest” in donor conception practices. It is critical to note that many of these “interest” groups have a theoretical interest only. This SMC Australia submission reflects the practical thoughts and issues of donor recipients and their children.

The following is representative of our currently active membership base.



TTC= Trying to Conceive

Out of our members who have conceived children by a donor, the following represents the type of donor used.



Please note that those women who used a truly anonymous (that is, non id-release) donor, did so earlier than 2005. Many of these women have at least 2 donor conceived children, whilst some have 3 or 4. The percentage of children who, under current legislation, will probably never know their donor's identity, would therefore be greater than indicated in the diagram above.

SMC Australia would welcome an invitation from the Senate Legal and Constitutional Affairs References Committee to act in a consultative role on this very important inquiry into Donor Conception in Australia.

2. Donor conception regulation and legislation across federal and state jurisdictions

Being a national support group, our members often report extremely different circumstances depending on the state in which the treatment took place. In some States where relevant legislation is absent, clinics make ad hoc policy changes on a regular basis. Clinicians and clinic administrators do not seem to understand or appreciate the significant ramifications these decisions hold for the life of a child and his/her friends and family. Without federal legislation, or agreed minimum standards if State-based, there is very high likelihood that children in some states or territories will be discriminated against on the basis of the circumstances of their conception.

We believe that all clinics should be audited by a truly independent body, and be accountable to a government authority. This would be very different to the current situation in which States that are legislated have a level of government accountability, whilst States that aren't, have no government accountability.

It is worth noting that the Victorian Law Reform Commission has also recently passed a motion for an Inquiry into Access by Donor-Conceived People to Information About Donors. <http://www.parliament.vic.gov.au/lawreform/inquiry/241>

Our members located in Victoria report that the clinics there seem to be well regulated, with very few negative experiences from those undergoing treatment or with children. The Victorian Government, through the Department of Human Services, fund a state-based support group for adoptees and donor conceived people - The Victorian Adoption Network for Information and Self Help (VANISH). It is believed that there are no other government funded support groups.

States that currently have no legislation around donor conception practices are to seek accreditation under the Reproductive Technology Accreditation Committee (RTAC) Code of Practice. Note that members of the committee consist largely of Fertility Specialists or Scientists from some of Australia and New Zealand's largest fertility clinics.

"Access" is a national support group for those undergoing infertility and the consumer representative on the RTAC. Access is largely funded by Queensland Fertility Group (QFG) and IVF Australia. This shows very little independent review or accountability toward clinic practices.

3. The conduct of clinics and medical services

3.1. Payments for donors

SMC Australia members strongly believe that donors should only be paid for their medical and travel expenses. Donors should give for altruistic purposes, not financial. We believe that this provides a better emotional base under which to discuss their conception with the children. However, non-payment to donors in Australia is a contributing factor to the low supply of donor gametes. This low supply is then driving the majority of our members to seek sperm overseas, where donors are paid for their donation.

A comprehensive list should exist so that there is no misunderstanding as to what is covered. For example, with medical expenses some donors might request payment for acupuncture or massages.

3.2. Management of data relating to donor conception

Our members report a wide variation in donor data management policy and practice both between and within States, between and within clinics and at different points in time. Policy decisions are frequently made on an ad hoc basis and the decision-making process lacks transparency and accountability. Members are provided with little or no information about avenues for appeal or oversight bodies. Members report a range of experiences both past and current which provide examples of how the current arrangements are failing. They include:

- A member was informed by the donor co-ordinator of their Queensland clinic that sperm imported from the US would only be imported for use by that clinic. Through their own networks, that member later found that sperm from the same donor had also been imported by a clinic in New South Wales and used by a number of families in that state. Neither clinic seemed to have knowledge that the situation had occurred.
- In 2008 a member was told by a Queensland clinic that the sperm donor she had chosen was an "ID release" donor – a requirement at that time under the RTAC Code of Practice. After her child was born in 2009, she was told by the clinic that they had made an error, and the donor had not agreed to be identified to any children once they reached age 18. The clinic agreed that this donor's sperm should not have been offered to the recipient; however the child has been born, and must live with the consequences of this clinic's error.
- The mother of a donor conceived child, who had been told by her Western Australian clinic that they would pass on communication from her if the donor agreed to receive it, was then told that the email address and telephone number they had for the donor were no longer valid, so they had "lost touch" and could not find him. This donor is an "ID release" donor and the mother wonders how her child will now be able to access the donor's contact information at 16 when it is apparently lost now.
- Sperm collected by a Queensland clinic was provided to other clinics in a number of different States/Territories. A member who received such sperm at a clinic in the ACT wanted to obtain more, and found it at two different clinics.

She was told that none of these clinics had any record of the sperm being used by other clinics and therefore did not know of births of children from this donor in clinics other than their own.

- In another case where sperm from a Queensland clinic was provided to a New South Wales clinic, the member was told (in 2002) that the donor had not agreed to be contacted when any resulting children turned 18. When the member recently contacted the Queensland clinic looking for more of this sperm she was initially told that the donor had remained non id-release. It was only after the member prompted for more information that the clinic advised that he had changed his consent and had now agreed to be contacted.
- A member, through coincidence, made contact with another recipient of the same donor sperm she had used. In comparing their information, they found that one donor profile listed the donor as having blue eyes and the other listed brown eyes. When she contacted the ACT clinic for clarification, she was sent a profile that appeared to have "brown" eyes covered with correction fluid and "blue" eyes written over the top.
- A member from Qld met another recipient of the same donor through our support and advocacy group. This NSW member had received the sperm from a clinic in NSW who had "swapped sperm" with the Qld clinic. This information had previously been withheld from the Qld member during discussions (between Qld member and Qld clinic) about the number of other recipients and children associated with this donor. Upon additional enquiry, Qld member was told by Qld clinic that the Qld clinic had not - and would not ever - request or accept information (on the number of recipients or children born from the donation) from the interstate clinic. Qld member then approached the NSW clinic for this information but was told that Qld member was not a client of theirs, and as such they were unable to release this information. Additionally, when both members compared information provided by the respective clinics, they found that Qld member was in possession of information about the donor which had never been provided to the NSW clinic or NSW member.
- A member contacted her ACT clinic to ask if she could be told information such as the number of children who had been born from the same donor as she had used. She was told this was confidential information that could not be given. She contacted the clinic at a later date and was readily provided with the information she asked for.
- Members report great inconsistency regarding information provided about sperm donors. This ranges from a brief physical description regarding height/hair/eye colour to several pages of information relating to the donor's physical characteristics as well as medical history, interests/personality and family history. In some cases even minimal information is not provided until after a pregnancy is confirmed. It is not clear what steps clinics take to ensure that information provided by donors is accurate or complete.
- A member was not informed by her Queensland clinic (in 2007) that her children would be able to contact their donor when they turned 18. It was only through meeting other parents of donor conceived children that she realised this would be the case.

- A member made contact with a potential sperm donor through a website and he told her he had donated to a number of women through that website as well as through a clinic. It is not known whether clinics ask donors to declare other “private” donations.
- A member who used an anonymous donor (in 2003) contacted her Queensland clinic to ask if the donor had recently been asked if he still did not wish to receive any contact from children born from his donation. She was told again that he was an anonymous donor but it was unclear whether the clinic had made any attempt to check on whether the donor might now wish to receive communication from offspring or be identified to them when they turn 18.
- A member in Victoria, where donor and offspring registers exist, was not given clear information by her clinic regarding the use of these registers.
- Members have received very conflicting information from clinics regarding whether or not they will pass on correspondence to donors, whether they ever contact donors.
- A member was given donor profiles by her Tasmanian clinic which indicated whether or not the donor would consent to contact with recipients prior to the child turning 18 years. The member used this information to inform her choice of donor. When her child was born and she initiated contact through the clinic she was told that there were no precedents or procedures in place to facilitate contact and there would have to be discussions to see if the donor would be told she was seeking contact. These discussions are ongoing.
- A member’s older child was conceived prior to clinics recording any information.
- Many members seeking to ‘fill the gap’ in finding information about their donor and / or donor siblings for their children have accessed private databases such as the Donor Sibling Registry (www.donorsiblingregistry.com). However there is no evidence that donors or recipients are routinely provided with information about the Donor Sibling Registry during their clinic counselling process.

Why are these experiences a problem?

It is well established that donor conceived individuals who are informed about the circumstances of their conception in early childhood typically go on to have a more positive attitude towards their conception than those donor conceived persons who find out about their conception in late adolescence or adulthood (see, for example, Shieb, Riordan & Rubin 2003; Shieb, Riordan & Rubin 2005). Most single women choose early disclosure of their child’s conception ‘story’ as part of a strategy of normalising their child’s conception story and ensuring their child’s positive adjustment to their conception (Klock, Jacob & Maier 1996). More broadly, there is strong evidence that for donor conceived individuals, access to information about their donor helps inform their social and genetic identity and is a key human rights issue (Blyth 2002).

For these reasons the United Nations Convention on the Rights of the Child (1989), to which Australia is a signatory, sets out in Article 8 the right of the child “to preserve

his or her identity, including nationality, name and family relations as recognized by law without unlawful interference” and “Where a child is illegally deprived of some or all of the elements of his or her identity, States Parties shall provide appropriate assistance and protection, with a view to re-establishing speedily his or her identity.”

To facilitate implementation of the Convention, UNICEF set out guidelines (2003) which ask the following questions:

Do children have the right to know from the earliest date 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?

It is clear therefore that our members, seeking to provide their children with full disclosure about their conception and genetic origins, do so with the overwhelming weight of scholarly research and international policy guidance behind them.

However, as described in the examples provided above, they are frequently stymied in their attempts to do so through the poor practices of some clinics with regard to management of data. Current policy settings and industry practices are letting down our children and we ask that Senators view our recommendations with the wellbeing of our children in the forefront of their considerations.

What do we want to see?

- A national body and register that keeps track of donor’s current contact details, including imported donors from overseas, and if donors contact details change, the clinic should use all methods at their disposal to find them. This is imperative if legislated family limit numbers are to be adhered to in any way.
- If no national body or register is to exist, then clinics should have mandatory guidelines regarding how they record and maintain donor data and how they should facilitate contact between donors and recipients and donors and donor conceived children.
- A national register that keeps track of children born from sperm donors.
- A system such as the one in Victoria where contact between donors and sperm recipients and donor conceived children is facilitated where there is a mutual desire to do so before donor conceived children turn 18 or 16 depending on State.
- A central, voluntary Australian register of DNA.

There are cases where our members report that they are satisfied with how their clinics have managed data. Particularly in New South Wales, South Australia and Western Australia, some clinics have kept track of donors and facilitated early contact with donors and donor siblings where all parties have been agreeable. These cases highlight that it is possible for good outcomes with regard to clinics managing data related to donor conception.

We ask that Senators do not support the continuation of the current system in which jurisdictional differences and industry intransigence related to donor data management have combined to produce outcomes which are demonstrably inequitable, inefficient, unfair and unreasonable.

3.3. Provision of appropriate counselling and support services

Our members report a wide variety of counselling services in their journey to become a parent. There does not appear to be a consistent approach or consistent costing across Fertility Clinics or even across clinics within the same group. This feedback is consistent across all States of Australia.

Counselling appointments have ranged from 15 minute chats to multiple appointments prior to being able to progress with treatment. Most felt it was a "tick in the box" exercise. Whilst some members got some value out of the counselling many members have stated that the counselling session did not add any value to the process and did not provide them with any tools about talking with their child about their conception or origins nor did they provide any useful information about contacting donors - in fact this was often never mentioned. Some members stated that they felt more like they were being "vetted" than that they were to receive information. Some were given brochures about Voluntary Registers (in some states) at that initial counselling session, but as it may take months or even years to actually conceive, that brochure and the counselling session is well and truly forgotten about by then. There is currently no follow up at all by the clinic.

In many cases it is members of this SMC Australia group that have provided information to counsellors at the clinics about support services available for people using assisted reproductive technology. One clinic on the east coast advised that they were going to set up a Support Group for donor recipients - that was 10 years ago and still there is no such support group run by the clinic.

A number of members have thought that their children were conceived with anonymous donors, only to find out that as their child/ren were conceived post 2005 that they had used an id release donor. This is both a clinic issue and a counselling issue as the counsellors should know the individual issues pertaining to each of their clients and be able to counsel them accordingly – i.e. – you have chosen an anonymous donor and this is what that means. Or you have chosen an ID release donor and this is what that means

We've lost count of the number of people who have come to the SMC Australia site after their initial round of clinic appointments only to be educated via the information on the site as to what exactly they are being offered and what avenues are available to search for the donor(s) and what their rights are during the process of trying to conceive.

Members of SMC Australia have indicated that there is a great discrepancy in the cost of counselling – some paying nothing and others paying \$200 per session for 3 compulsory sessions and others paying \$1500 for one session.

The Victorian Assisted Reproductive Technology does promote workshops about "Telling and Talking" modelled on the very successful workshops run by the UK Donor Conception Network (telling children about being donor conceived) and VART does appear to be proactive in supporting donor recipients. While Victoria is held up as a State that gets it right – we have seen that things don't always run smoothly, as can be seen by the example below.

One of our members rang her clinic a couple of months after her child had been born to ask if there was any way that she could get in contact with their donor. It was not clearly explained to her that she could apply to the Register of Births, Deaths and Marriages and that there were two types of Registers in Victoria; the

Voluntary Register and the Central Register. She was told to leave her card with the Donor Sperm Co-ordinator and if her donor contacted the clinic her details would be passed on. Without understanding the situation, she applied to the Voluntary Register which meant that she would have to wait for the donor to make contact with the register.

What she did not know and had not been explained to her was that if she had applied to the Central Register they would have written to her donor.

This story does have a good outcome as the donor eventually got the card left with the clinic, but it was many months later and only by accident and he then had to try and find them, which took a further few months.

This example highlights the flaws in the counselling services provided, as the process for contacting donors should be one that counsellors are familiar with and they should be providing this information to their clients.

What do we want to see?

Counsellors should make further information available to recipients of donor products – i.e. information about on-line support groups/registers.

We would like consistent counselling services offered at the initial stages to be followed through as the patient progresses and follow up should be offered in the ensuing years if required. This could be an annual appointment for 5 years for both recipients and donors.

Fertility Clinic's websites should contain links to support groups available. These support groups should receive government funding.

All Assisted Reproductive Technology Bodies in all states to conduct regular "Talking and Telling" workshops. Mail outs to be done to all recipients and donors as well as public advertising to promote the workshops.

4. The number of offspring born from each donor with reference to the risk of consanguine relationships

SMC Australia members believe that the number of children who are donor conceived per donor should never be limited. However, the number of families (single parent or two parent families) should be limited. At present each State and Territory sets the limit for the number of families who can conceive children from each donor. The exception is NSW who has an archaic rule that limits it per female discriminating against families who have two Mums. The limit varies between each State and Territory, with some smaller States such as Western Australian, limiting donor sperm to 5 families, whereas those unlegislated States and Territories currently limiting to 10 families.

It is important to note though, that this limit setting is unlegislated and not currently mandated. Victoria, Western Australia and NSW do mandate the limit, however, it can be argued that even this isn't done well.

Section 27(1) of the NSW Assisted Reproductive Technology Act states that

“An ART provider must not provide ART treatment using a donated gamete if the treatment is likely to result in offspring of the donor being born, whether or not as a result of ART treatment, to more than 5 women (or such lesser number as may be specified in the donor’s consent), including the donor and any current or former spouse of the donor”.

There has been much discussion and confusion around clinics' interpretation of this Act, with members who are clients of one NSW clinic stating that they were advised that the limit applies only to women in NSW, whilst members who are clients of another NSW clinic being advised that the limit was worldwide.

Clinics often ship sperm between the States and Territories, often without tracking and potentially resulting in more than the limited number of families using the same donor throughout Australia. A similar situation could occur with donor sperm that is imported to Australia where the sperm could have also been sent to other countries as well as the originating country.

Members have reported that they have found their children's sperm donor being used in other states such as Queensland, NSW and the ACT. There are several members whose children at the last count have 30 donor siblings, however these conceptions were usually prior to the RTAC's Code of Practice.

Members have found sperm donors who have donated through a clinic and reached their family limit then donate privately. Examples include;

- A sperm donor who is currently in his late 20s donated to a Sydney clinic and has since successfully donated to another four women privately. The donor also has four children of his own and has openly said that he will continue to donate without setting any limits on the number of families.
- Another sperm donor who donates privately had around 27 offspring in 2008 and he is still donating to families.

In Australia there is no limit to how many times a donor can donate privately. A National Register would go some way to help prevent donor siblings meeting up by accident and consanguine relationships occurring.

5. The rights of donor conceived individuals

Obviously, a donor conceived child should have equal rights to any other child.

Every person has inherent dignity and value. Human rights help us to recognise and respect that fundamental worth in ourselves and in each other. Australia has agreed to uphold the human rights standards set out in a number of international treaties and declarations, including, but not limited to, the United Nations Convention on the Rights of the Child (1989).

This Convention states that children will not be discriminated against on the grounds of their birth. Article 8 sets out the right of the child “to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference” and “Where a child is illegally deprived of some or all of the elements of his or her identity, States Parties shall provide appropriate assistance and protection, with a view to re-establishing speedily his or her identity.”

Most single women choose early disclosure of their child’s conception ‘story’ as part of a strategy of normalising their child’s conception story and ensuring their child’s positive adjustment to their conception (Klock, Jacob & Maier 1996). More broadly, there is strong evidence that for donor conceived individuals, access to information about their donor helps inform their social and genetic identity and is a key human rights issue (Blyth 2002).

Kerry Petersen’s, ‘The Rights of Donor-Conceived Children to Know the Identity of Their Donor’ in Belinda Bennett and George F Tomossy (eds) *Globalization and Health: Challenges for Health Law and Bioethics* (2006) states:

“It is shown that courts and parliaments in a number of jurisdictions have re-visited the assumption that donor anonymity is in the best interests of ART offspring and are granting them varying degrees of access to information about their donors. This gradual and incremental change is reinforced by a human rights discourse which prioritises a child’s right to a personal history and a heritage over the privacy claims of the social parents and the donor.”

Under current legislation, many of our member’s children are discriminated against because they were conceived at a time when clinics were unregulated. Clinics do currently hold identifying information on most of these individuals donors, yet are not obliged to release the information due to donors privacy requests made many years previously. Our members, and their children, strongly believe that the child’s right to their identity outweighs a donor’s right to privacy, especially where it is unknown whether that privacy right is still current.

Furthermore, donor conceived children in some States and Territories are legally not included on the birth certificates of their younger siblings, apparently due to archaic legislation stating that if a child is donor conceived, the child has only one parent, hence the child is not a product of the relationship between the same mother and father. This is demoralising, impersonal and discriminatory.

SMC Australia strongly recommend that all donor conceived individual’s rights (regardless of birth time or place) are upheld and prioritised as matter of urgency by providing a governed, audited and retrospective legislation around Donor Conception practices.

6. Recommendations

- A Federal or State-based legislation that is consistent between all States and Territories and does not discriminate. It may be possible to achieve this through extension of the NHMRC guidelines to incorporate specific donor conception practices. These should be mandated and audited independently.
- A national body and register that keeps track of donor's current contact details, including imported donors from overseas. The clinic or body should use all available methods of obtaining contact details if they are changed and the donor doesn't advise the clinic or body.
- A national register that keeps track of children born from sperm donors.
- A Federal or State based legislation that ensures that all donor conceived children, regardless of the year or State/Territory of their conception, are able to access identifying information upon the child reaching 16.
- A system such as the one in Victoria where contact between donors and sperm recipients and donor conceived children is facilitated where there is a mutual desire to do so before donor conceived children turn 16.
- Consistent counselling services at the initial stages to be followed through as the patient progresses and follow up should be offered in the ensuing years if required. This could be an annual appointment for 5 years for both recipients and donors.
- Government and/or ART clinic funding and interest in support groups. This should extend to client and clinician awareness programs.
- The number of families used per sperm donor be limited to 10, perhaps with smaller States and/or Territories having lower limits of 5.
- A central, voluntary Australian register of DNA.
- All donor conceived individual's rights (regardless of birth time or place) are upheld and prioritised as matter of urgency by providing a governed, audited and retrospective legislation around Donor Conception practices.
- That a consultative committee be established immediately to include all practical stakeholders in donor conception issues. SMC Australia welcome the opportunity to participate on this committee.