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Legal Affairs and Safety Committee
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Dear Committee Secretary

Inquiry into matters relating to donor conception information

Thank you for the opportunity to make a submission to this Inquiry. Below, I address each of its terms of reference. Before doing so, I would like to make some general comments.

I make my submission in the capacity of a recipient parent with a donor conceived child. When I conceived my child, my partner and I selected a donor who had agreed to be identified and to be contacted. I had done my research, and knew that about two-thirds of donor conceived people have a desire to know their genetic heritage. As identification and contact were voluntary at the time (in NSW), we restricted our choice of donor to those who had agreed to both identity and contact. We have this consent in writing. We spent the first five years of our child's life telling them that they could contact their donor when they wished to do so (under the voluntary scheme applicable at that time, the procedure required us to contact the clinic). When my child was five, they asked to contact the donor. We contacted the clinic, as required. The clinic advised us that our donor had 'changed his mind'. Their interpretation of the NHMRC guidelines was that they could not even write to him to let him know someone was trying to make contact. In response, I cited the guidelines on numerous occasions. The clinic obfuscated, and avoided me. All in all, I spent four years trying to get them to act in accordance with the guidelines, all for nothing. In the end, the CEO of the company that had taken over my clinic (the third company after the one I had actually used), told me that, after all, they're just guidelines. In the end, I discovered that the donor had changed his mind the year my child was born, but the clinic did not tell me, resulting in great heartache for my child when we had to tell them years later that what they had been told their whole life thus far was untrue.

I subsequently applied to the clinic for records of the year of birth and gender of siblings. I eventually received a letter with four donor siblings. Then, after NSW changed its law to require clinics to provide information to a central donor register, I applied again through the donor registry as a recipient parent for the same information. This is because I knew that asking the registry would require the clinic to pass the information on to the registry for safe keeping. I was surprised that a response took a long time. I eventually received a response from the register, which contained a completely different list of donor siblings, a total of ten from this donor (the maximum permissible).

The difference between the information I was given by the clinic, and the information I received when the clinic was required by law to provide accurate historical information to the government-controlled register was phenomenal and life-changing for my child. This is why a government-controlled donor conception register is essential. This is critical information, which should not be held by private clinics that are bought and sold regularly, and that have a poor history of record keeping.

Donor conception has been practised in Australia for decades. Statutory regulation of this sector is emerging in other jurisdictions. South Australia, Victoria, NSW and Western Australia have made particularly important changes in recent years. The ACT is currently having a government inquiry. But in Queensland, donor conception is currently governed only by NHMRC guidelines, which require clinics only to use donor gametes where the donor has consented to identification. These guidelines do not work in practice to protect the rights of donor conceived people to identifying information about their donor.

Donor conception is a couple of decades behind adoption practices. Historically, people believed that adoption should be entirely anonymous. Subsequently, research has shown that it is best for adoptees to be able to have identifying information about their biological parentage, and the law was changed to reflect that. It is the same with donor conception. Historically, many believed that donor conception should be entirely anonymous, and indeed many donor conceived people do not even know that they are donor conceived. Subsequently, research has shown that it is best for donor conceived people to be able to have identifying information about their biological heritage. It is time the law caught up with this fact.

A final, general comment. Australian family law always prioritises the best interests of the child over any 'legal' claims regarding parental rights. In the area of donor conception, I am asking the committee to make recommendations that ensure that the interests of the donor conceived are put first; this is consistent with other areas of the law in Australia which prioritise the wellbeing of children.

1. The rights of donor conceived persons to know their genetic origins.

Donor conceived persons (just like adoptees) have the right to know their genetic origins, which can only be achieved by them having access to identifying information about their donors. The best way to ensure that the rights of the donors are protected is to allow them to veto contact. Identity and contact are two different things.

Access to identifying information is essential for three reasons. The first is the wellbeing of the donor conceived person, who otherwise spends their entire life wondering where they came from. It is hard to express to you how difficult it is to see donor conceived people literally wondering if they are related to people they walk past on the street.

The second is the risk of consanguinity; entering into a relationship with someone who a donor conceived person is genetically related to, without knowing it. There are documented cases of this.

The third is for medical reasons. While it is true that general medical information can be provided by a donor, this is general in nature. In some cases further, more detailed

information is necessary in order to provide adequate medical care for a donor conceived person.

The need to have access to identifying information has been recognised in other jurisdictions in Australia. In NSW, donor conceived people born after 2010 have access to identifying information about their donor. In Victoria, following a change to the law in 2016, all donor conceived people have access to identifying information about their donor, regardless of when they were born. Prior to this, those born before 1998 did not have access, and those born after 1998 (when previous law reform was undertaken) did have access when they turned 18. This created an arbitrary, and unfair, date dividing those who had rights and those who did not.

Recommendation 1: That the Committee adopt the principle that all donor conceived people should have access to identifying information about their donor, regardless of when they were born.

2. Extent to which identifying information about donors should be given to donor-conceived persons, taking into consideration the right to privacy of donors.

Some of the clinics will argue in their submissions to this inquiry that the current NHMRC guidelines are sufficient to protect the interests of the donor conceived. To support my argument that this is not the case, I attach an Appendix to this submission. This Appendix contains stories of donor conceived people and recipient parents. These are harrowing accounts of the failure of a reliance on guidelines to protect the rights and interests of the donor conceived.

Donor conceived people should have the right to be provided with identifying information about their donor. They should also have the right to access the year of birth and gender of any donor siblings. The primary consideration in determining who has access to information should be the rights and interests of the donor conceived people themselves.

Contact between a donor conceived person and their donor should be subject to the mutual consent of the donor and the donor conceived person. I fully believe that a donor has the right to veto contact, or to express contact preferences (as is the case in Victoria currently). That is how their rights and autonomy can be protected.

Donor conceived people should be able to request the identity of, and contact with, donor siblings. Both identity and contact between siblings should be subject to mutual consent, because the rights and interests of donor conceived people should be paramount. The register should include the ability to exchange information in this regard, as recommended in reviews conducted in South Australia in 2016 and Western Australia in 2018.

Recommendation 2: All donor conceived persons should have the right to access to identifying information about their donor when they turn 18, regardless of when they were born.

Recommendation 3: Contact between donor conceived people and their donor should be by mutual consent.

Recommendation 4: Provision of identifying information and contact between donor conceived people and their donor siblings should be facilitated by the register by mutual consent.

Unfortunately, due to the historical encouragement of secrecy, not all donor conceived people know that they are donor conceived. Many discover it accidentally when they are an adult, which can be very harmful to their wellbeing and identity.

In order to avoid this, all donor conceived people should have an annotation on their birth certificate stating that they are donor conceived. This empowers them as an adult to choose whether or not to pursue identification of their donor, or contact with a donor or siblings. Knowledge of the fact of donor conception is also essential to protect against consanguinity.

Recommendation 5: All donor conceived people should have an annotation on their birth certificate stating that they are donor conceived.

3. Access to historical clinical records and implications of retrospectivity.

It is absolutely vital that clinics be required to organise their historical records, check them for accuracy, and hand that information over to a government-controlled register. My personal experience, as outlined above, and the stories outlined in the Appendix, should be more than enough to convince you of that.

Clinics tend to be bought and sold regularly. Their historical records are vulnerable. These records are vital, life-affirming, identifying records and they need to be protected and secure.

All the relevant information currently held by private clinics must be provided to a government-controlled register as a matter of urgency.

Recommendation 6: That all fertility clinics in Queensland that practice, or have practiced, donor conception be required to provide accurate historical records to a government-controlled donor conception register as a matter of urgency.

I have no doubt that you will receive submissions that oppose retrospectivity. You will be told that donors were guaranteed anonymity for life, and that that was the basis on which they consented to become a donor. It is true that retrospectivity is usually to be avoided in public policy. However, in this case it is essential for several reasons.

First, without retrospectivity there is an arbitrary date beyond which some donor conceived people have access to vital, life-affirming information, yet others do not (as is the case currently in NSW). This is simply unfair.

Second, norms and expectations around anonymity have changed due to the decades of experience we now have with donor conception. This was recognised in 2011 when the federal Senate inquiry into Donor Conception Practices in Australia (https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Legal_and_Constitutional_Affairs/Completed_inquiries/2010-13/donorconception/report/index) recommended the development of nationally consistent legislation that includes:

- a prohibition on donor anonymity, and

- that donor conceived individuals should be able to access identifying information about their donor.

Third, many donors have historically been told they had to be anonymous and there are many who would prefer their identity to be known, but who are prevented from doing so by current practices and the lack of state-based registers in some jurisdictions.

Fourth, the interests of the donor conceived are paramount, and just as views and the law have changed around adoption, so should they change around donor conception. At the time when anonymity was regarded as standard, donor conception was an emerging and very new industry. We now have decades of research that tells us very clearly that it is not in the best interests of donor conceived people to preserve anonymity at their expense, and that their interests need to be taken into account. Maintaining anonymity is a head-in-the-sand approach to this changing area.

Finally, anonymity is disappearing informally and any promises once made to donors to preserve their anonymity can no longer be upheld. DNA testing makes it more than likely that a donor conceived person can discover the identity of their donor. This means anonymity is no longer an option. It is far preferable for disclosure to occur through a government authority, alongside appropriate counselling and support services, and based on accurate records, than for it to happen informally. This is the reality of donor conception today.

Recommendation 7: That the Committee support the principle of retrospectivity when legislating to provide for the release of identifying information about donors to donor conceived people.

4. Access to support and counselling for donor-conceived persons and donors.

It is vital that appropriate support and counselling services be provided to support both donors and donor conceived people. This is especially the case given the request to support retrospectivity.

It is also vital that those services be provided independently. Experience shows us that where support services are provided to both those seeking assisted reproductive treatment, and to donor conceived people, this can generate a conflict of interest. In Victoria, support services are provided by the Victorian Assisted Reproductive Treatment Authority (VARTA), which works with the industry as well. There have been instances of this presenting a conflict of interests, when the interests of recipient parents or donors have differed from the interests of the donor conceived.

One option would be for support services to be provided by Births, Deaths and Marriages.

Another would be for support services to be provided by an appropriate external provider with experience in supporting people seeking information about their biological heritage (and who do not have any conflicts of interest). An appropriate agency is Jigsaw in Queensland, which already provides support services to the donor conceived.

Recommendation 8: That support and counselling services be funded by government, and provided by an appropriate entity that does not have a conflict of interest, and that specialises in these kinds of support services as their core business.

5. Whether a register should be established.

Queensland should work towards establishing a register within Births, Deaths and Marriages. Best practice would be for all record-keeping to be undertaken within, and by those responsible for, the register of Births, Deaths and Marriages. This is because staff in Births, Deaths and Marriages are specialists in the retention of important family information in perpetuity.

Other jurisdictions handle this in different ways; some through a register held by government and others through a register held by an independent statutory authority.

Because the information being considered is vital identifying information that requires safe keeping in perpetuity, it is most appropriate for that information to be held on a register that is maintained by Births, Deaths and Marriages. Having information on a register that is controlled by government is just as appropriate for the donor conceived as it is for all other births.

Recommendation 9: That a donor conception register be established within Births, Deaths and Marriages.

6. Benefits, risks and implications on donor conception practices arising from any recommendations.

Some clinics are likely to say that ensuring identification will reduce their potential pool of donors, which will make it harder for those requiring assistance to be assisted. There are two responses to this. First, it is not clear that with sufficient time to engender a change of culture, the donor list will substantially reduce. It may just be that different types of people become donors, but it is not the case that in jurisdictions where donor anonymity has been removed, it is impossible to find donors. Second, and relatedly, it is important to have the right policy regardless of this. It is not clear why clinics should be permitted to take full advantage of anonymous donor conception when it harms the donor conceived people who are born as a result. The interests of donor conceived people need to be placed higher than they currently are. This requires abolishing anonymity.

A second risk is that donor conception laws need to apply both to gametes donated within Queensland and to gametes used in Queensland but imported from elsewhere. There is a current problem in Victoria; a loophole which allows Victorian residents to access donor gametes from international donors. Where this occurs, the resultant donor conceived people do not have the same protections in terms of access to identifying information as those conceived with gametes donated within Victoria. This loophole should not exist. Queensland should ensure the provisions ensuring donor conceived people have access to identifying information apply to all donated gametes used to achieve conception in reproductive treatment in Queensland, not only those gametes donated in Queensland.

A third risk is that the development of this register will require an allocation of appropriate government funding, as will providing appropriate support and counselling. My response to that is as above; we have to get this policy right.

People's lives, their core identities, are at stake. The federal Senate inquiry recommended over a decade ago, in 2011, that Queensland, one of the jurisdictions that at that time did not yet have a statutory regime in place, act 'as a matter of priority' to protect the rights of the donor conceived. All the other jurisdictions that did not yet have a scheme in place in 2011 have subsequently enacted policy change. Queensland has not yet done so.

We now have the advantage of being the last jurisdiction in Australia to legislate. This means we can learn from the others, and get the policy right. We have the opportunity to have best-practice, world-leading policy in this area.

I implore this Committee to adopt these recommendations and move with urgency to implement a government-controlled register, so that all donor conceived people born in Queensland have access to identifying information about their donors.

Thank you.

Katharine Gelber

APPENDIX

Protecting the rights of the donor conceived: stories around donor conception practices in Australia under the NHMRC guidelines

These stories humanise the problems with relying on the NHMRC Guidelines instead of statutory provisions, and allowing privately held clinics to control incredibly important information about people's biological heritage. The stories have been anonymised to protect people's privacy.

Clinics giving incorrect and misleading information

Case Study 1:

A parent located in another state used a well-known and highly reputable Queensland fertility clinic to access donor sperm, and gave birth to a child. When the child was approximately 10 years old, the parent had contact with the clinic, and the clinic advised that the donor conceived child would be able to access information about the donor when the child turned 18, because the donor had given consent. The parent was also told that the limit of 10 families had been reached for this donor.

This parent subsequently made contact through informal channels with another recipient family with donor conceived twins from the same donor. This parent was told that the donor had consented to the release of information, but the other parents were told the same donor had not. Yet they had used the same donor. It was only through the first parent providing the information they had been given that the other family was able to continue to press the clinic for information.

Case Study 2:

A recipient parent became pregnant with donor sperm, with a donor who had agreed to identification and contact. This occurred in Victoria prior to the establishment of VARTA, when clinics held all the relevant information. At that time, Victoria operated on the NHMRC guidelines, as Queensland currently does.

When the recipient parent was pregnant she wrote a letter to the donor and asked the clinic if they could forward it to him. The clinic told her they had attempted to pass on her letter but that the donor was unable to attend the clinic for additional counselling which they required before they would forward the letter to him. The recipient parent has since found out from the donor that he was never invited to attend additional counselling and was never told there was a letter from a recipient waiting for him. He has the same phone number and email address as he had at the time he donated. He was upset that the clinic had tried to paint him in a negative light by suggesting that he had made the decision not to have contact, when in fact he was never given that decision to make.

After this recipient parent's child was born, two other parents who had used the same donor located her through social media. The information each had been given by the clinic regarding gender and age of siblings didn't match with each other, or with what the recipient parent had been told.

Years later, through VARTA and following legislative reform, the recipient parent has now been able to confirm actual sibling gender and month and year of birth. This information does not match with the information any of the three recipient parents received from the clinic, but does confirm that they all used the same donor.

In 2020 the recipient parent and her child used VARTA to find the donor. VARTA were able to find the donor quickly and he readily agreed to contact. He advised the recipient parent that the clinic had never told him anything about VARTA and he knew nothing about the voluntary register which he could have joined. He was surprised but happy to hear from them.

If it had not been for the Victorian central register with VARTA, this family would never have been able to find out about their child's cultural heritage. The information from the clinic only showed the donor and his parents were Australian, but the information provided by VARTA showed that in his grandparents there were 2 other nationalities. Through email contact with the donor that family has now found out there are 3 other nationalities in the great grandparents.

The recipient parent and her child are both very grateful that they live in a state where there is a state-run donor registry. The recipient parent hopes Queensland can get a similar, effective, state-run registry and organisation because time and again it has been shown that fertility clinics cannot be relied on to provide information and support to donor conceived people and their families.

Case study 3:

A couple living in Canberra pursued artificial insemination using donor sperm provided by an accredited, well-known fertility clinic located in Queensland. The couple gave birth to twins in 2001. At the time, the couple reached out to the fertility clinic to advise them of the births for their records. But they were advised that the clinic was only aware of births if people contacted them, and that they had no formal arrangements in place between centres to capture this information.

When the twins reached the age of 18, when (according to the existing NHMRC guidelines) they had a right to identifying information about their donor, the parents reached out to the clinic. They were advised by the clinic that it was impossible to provide this information. They parents persisted, and were advised to fill out a number of forms and a statutory declaration. The parents did so, but were again advised by the clinic that it was impossible to provide the information. When they parents pressed as to why, the clinic advised that their donor had donated before 2004, and therefore he would not have provided consent. When the clinic was again pressed by the parents on the accuracy of this information, the clinic said they had been unable to contact the donor. It turned out he had, in fact, given consent, but because his location had changed in the 20 years since donating, the clinic said they were unable to follow up and find him. The clinic refused to provide any details about their efforts to contact the donor. The clinic did advise the parents that there was a total of 20 offspring from the donor, and provided gender and dates of conception based on their information.

The clinic consistently refused to provide information to the parents. Contacting them was described by the couple as 'pulling teeth'. Numerous emails had to be sent to obtain an answer.

Case Study 4:

A couple living in Sydney pursued artificial insemination using donor sperm provide by an accredited, well-known fertility clinic located in Sydney. The couple gave birth to a child in 2006. At the time of receipt, the clinic advised that some donors voluntarily agreed to being identified and being contacted. The parents deliberately chose a donor who had agreed, in writing, to being identified and to being contacted.

The parents spent the first five years of the child's life telling him he could contact his donor if he wished. After the child started school, he expressed a desire to contact his donor. The parents contacted the clinic, as they had been advised to do, to request contact and identifying information. There ensued at least two years of obstruction, lying and disinformation from the clinic. The clinic claimed at various times to have sent letters to the parents, which never arrived. The parents were told that the donor had at some point contacted them and told them he had remarried, and that he no longer wished to be contacted or identified. When the parents requested that the clinic re-contact the donor, they refused to do so. When the parents cited the NHMRC Guidelines, the clinic said they were 'after all, only guidelines'. The parents eventually received a small amount of information on the gender and year of birth of sibling offspring. The clinic consistently refused to answer requests for information, to pass messages on from telephone calls, and to answer letters. Contacting them was very, very difficult.

In 2010 the NSW government amended the legislation to provide for a voluntary register. The parents registered on the voluntary register, and received new information on siblings (by gender and year of birth) that contradicted the information they had previously received from the clinic. The parents subsequently re-contacted the clinic to try to clarify the number and gender of offspring, but without any success. The clinic refused to cooperate.

Case study 5:

A couple living in Queensland pursued artificial insemination using donor sperm provided by an accredited and well known fertility clinic in Queensland. A daughter was born in 1991. In 2017, at the age of 27, the donor conceived person (DCP) reached out to the clinic seeking a donor number and non-identifying information about her mother's donor. The clinic advised that in order for this to occur, the mother would need to provide her permission for this information to be provided as this information was considered the private medical records of the mother. This is despite the information relating directly to the DCP's conception. Luckily, the DCP's mother was alive and supportive, providing the required permission for this information to be accessed.

In addition to non-identifying information, the DCP requested that the clinic attempt to make contact with the donor and queried whether any other children had been conceived. The clinic advised that they had attempted to make contact with all prior donors a few years earlier to update their records and that they would try to make contact with the donor. The clinic also advised that they would review their records as to further confirmed births. The result of this was that the clinic advised that they were unable to make contact with the donor and that the DCP was the only confirmed child born from his donations. The DCP questioned this given the high probability that no further births was unlikely and was informed that the clinic was only aware of births if recipient parents or medical professionals contacted them, and that they had no formal arrangements in place to capture this information.

The DCP persisted and one day the clinic advised that they had identified another family conceived with the use of the same donor. The clinic's records showed that the child was born the same year as the DCP, however, they did not show the gender of the child and the contact details for the family were not up to date.

The DCP decided to try an alternative strategy and completed a DNA test. The results showed a half-sibling match and the DCP reached out to the match. The DCP received a

response from the sibling's mother who consequently contacted the clinic to ascertain whether her child was the child recorded in the clinic's records. The clinic advised that her child was not the child listed in their records. The DCP requested that the clinic search their records for further siblings and attempt to contact the donor again. The DCP had to insist upon this occurring as the clinic believed that they had exhausted all options.

Through DNA testing, the DCP identified the donor but was then contacted by the clinic advising that they had made contact with the donor and that he was willing to have contact. The clinic then began the counselling process which they advised was compulsory before any information would be shared between the DCP and the donor. After this occurred, the clinic advised that the DCP could meet her biological father via Skype with the counsellor present. The DCP did not accept this and considered it a breach of privacy, instead requesting that her email be shared with the donor. The clinic begrudgingly accepted this after the DCP revealed that she had identified the donor and was simply following the clinic's process out of respect for the donor.

The donor reached out to the DCP via email and advised that he had been the one to make contact with the clinic a number of years prior and was required to complete a long process to provide permission for any children conceived via his donations to know who he was and to be able to contact him. At this time, he provided up to date contact details.

The clinic consistently provided incorrect information and when information was received, this occurred through a high level of persistence from the DCP through numerous emails and telephone calls. The process of making contact with the donor and gaining his consent to contact was a process that took many months, despite the donor having registered his contact details and consent with the clinic years prior. Additionally, the DCP found the counselling process to be invasive and conducted by a counsellor without tertiary qualifications. Lastly, the DCP had no ownership over the medical records relating to her conception and was reliant upon her mother being willing to provide access. This is troublesome given that that research suggests most parents do not even tell their children that they are donor conceived, let alone support them to access information about the donor.

Experiences such as this are not uncommon and demonstrate that clinics cannot be relied upon to provide accurate and timely information or support the process of connecting donor conceived people with donors. Additionally, it shows the need for a centralised register and associated organisation able to provide information and support to donor conceived individuals, donors, and recipient parents. Lastly, the right of donor conceived people to access the information relating to their conception should be legislated as a personal right and not be reliant upon parental consent.

Need for a national register

Case study 6:

One parent of a donor conceived son contacted the Queensland government first in 2012, and then again in 2020. Both times this parent raised the issue of the lack of a national, central register, as recommended by the 2011 Senate Inquiry, due to the fact that some donors have donated in more than one state, people have travelled interstate to access donated gametes, and that donors and recipients move interstate regularly. The lack of a national register

greatly increases the risk of co-sanguine intimate relations between donor conceived individuals.

Lack of cooperation by clinics

Case Study 7:

A recipient parent's first daughter (now almost 5 years old) was conceived on her first IUI using a Xytex donor through a clinic in Queensland. When her daughter was 9 months old, the parent started trying to conceive her sibling. She had IUI treatment with the same donor with no success. She and her fertility specialist decided the best option moving forward was IVF, but this was not affordable at that clinic. The parent switched to a different clinic that offered bulk billed IVF.

Neither clinic would even have a conversation about letting the parent continue to use the same donor. It was a flat 'no'. The parent already occupied a family spot, and the donor was an overseas donor that both clinics imported from. The parent didn't even need to move sperm from clinic to clinic, it could have simply been ordered directly from the sperm bank. It would have impacted literally nothing and noone, except her family.

The parent did not care about her children being 'full' siblings. They're sisters, period. What she did, and still does, care about, is that they may have disparate experiences of what it means to be donor conceived. What should be a shared experience now has the potential for tension and fraught emotions. What if one grows up to have a great relationship with their donor, and the other donor is disinterested, or dead? What if one grows up with close donor sibling relationships and the other doesn't? What if one of the daughters has 100 siblings and the other has very few?

This is already playing out. The youngest child has twice as many donor siblings, some of whom ARE, despite the distances, interested in developing relationships. The few parents of her oldest's donor siblings they have managed to find, are not. Right after the change of clinics her oldest child's donor joined Xyconnects and they are now in (sporadic) email contact. At the very least, she will have identifying information when she's old enough to show an interest, and the potential to be able to reach out and ask whatever questions she has. At this stage, the youngest child does not have the same information/opportunities. And it is unlikely that she will - her donor donated 10+ years ago and has not yet sought contact.

Maybe if their family's information was clearly and easily accessible on a central register, the clinics' excessive and unnecessary caution could have been challenged. At the very least, a central register would help the recipient parent manage the now incredibly complicated task of tracking down and managing the combined 40+ donor sibling relationships her children don't share.

The clinics themselves are certainly no help. The first clinic concerned does actually have their own donor sibling register. They simply refuse to tell anyone about it. If you happen to call/email asking to be put in contact with donor siblings, they'll take your information and agree to match you if someone else also happens to call/email. They refuse to promote it. The second clinic has nothing at all. Yet both these clinics had the power to dictate the makeup of her family.

In addition, both these children have at least one sibling each in a different state, that were conceived at clinics that are not affiliated with either of the Qld clinics using this donor. There's no way to even find out if there are more.

'Loopholes' and gaps in the NHMRC system

Case Study 8:

A couple donated the leftover embryos produced from their third IVF cycle completed in Canberra. Using a now defunct online forum, they found a couple living in Sydney who had been trying, unsuccessfully, to have a child through IVF and sperm donation for a considerable time.

During the mandatory counselling, they were told that 'worst case scenario' they would be told of the gender, and year of birth of any child resulting from a successful birth from the donation. This is in accordance with the NHMRC's *Ethical guidelines on the use of assisted reproductive technology in clinical practice and research*, specifically paragraph 5.7.1. Furthermore, in New South Wales under the *Assisted Reproductive Technology Act 2007* (ART Act) there is a Central Register where details of any child born for donor conception are recorded and details of their donors and donor siblings can be accessed when they turn 18.

Approximately 12 months after the donation was completed, the donor received a follow up call from the clinic to say that the recipient had transferred two embryos which didn't work, and they didn't want to use the last remaining embryo. Therefore, it was up to the donors to decide what to do with remaining embryo. The donor found the recipient on social media, along with pictures of a child that would have been conceived at the time of the donation. The clinic claimed that after the embryo transfer, the recipient had reported bleeding and did not attend a follow-up blood test.

The donor applied to the Reproductive Technology Accreditation Committee board to address this issue in the *Code of Practice* that clinics are required to follow, along with the *Guidelines*. The board unanimously agreed to produce a Technical Bulletin, which in turn was included in the subsequent addition of the *Code of Practice*, however (then Vice-President) Dr Luk Rombauts warned that 'IVF units face limitations in enforcing patient compliance', which he indicated ultimately are the responsibility of state regulatory bodies.

The donor was able to close the loophole in the state of New South Wales with passing of the *Amendments to the Assisted Reproductive Technology Act 2007* (NSW). This Bill gave more powers to the Secretary of the NSW Ministry of Health, and the Ministry was able to investigate whether the child that the recipient gave birth to should in fact be on the Central Register. As a result of this investigation, the donors were told that it was the Ministry's finding that the child born to the recipient was a result of their donation and should be on the Register. However, this loophole is still not specifically addressed in the *Guidelines*, nor do IVF units have the power to enforce compliance.