COMMONWEALTH OF AUSTRALIA

Official Committee Hansard

SENATE

LEGAL AND CONSTITUTIONAL AFFAIRS REFERENCES COMMITTEE

Reference: Donor conception in Australia

WEDNESDAY, 3 NOVEMBER 2010

MELBOURNE

BY AUTHORITY OF THE SENATE

SENATE LEGAL AND CONSTITUTIONAL AFFAIRS

REFERENCES COMMITTEE

Wednesday, 3 November 2010

Members: Senator Barnett (Chair), Senator Crossin (Deputy Chair) and Senators Furner, Ludlam, Parry and Trood

Substitute members: (As per most recent Senate Notice Paper)

Participating members: Senators Abetz, Adams, Back, Bernardi, Bilyk, Birmingham, Bishop, Boswell, Boyce, Brandis, Bob Brown, Carol Brown, Bushby, Cameron, Cash, Colbeck, Coonan, Cormann, Eggleston, Faulkner, Ferguson, Fielding, Fierravanti-Wells, Fifield, Fisher, Forshaw, Hanson-Young, Heffernan, Humphries, Hurley, Hutchins, Johnston, Joyce, Kroger, Macdonald, Marshall, Mason, McEwen, McGauran, Milne, Minchin, Moore, Nash, O'Brien, Payne, Polley, Pratt, Ronaldson, Ryan, Scullion, Siewert, Stephens,

Sterle, Troeth, Williams, Wortley and Xenophon

Senators in attendance: Senators Barnett, Crossin and Pratt

Terms of reference for the inquiry:

To inquire into and report on:

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:

  (i) payments for donors,

  (ii) management of data relating to donor conception, and

  (iii) provision of appropriate counselling and support services;

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

(d) the rights of donor conceived individuals.

WITNESSES

Committee met at 11.38 am

CHAIR (Senator Barnett)—This is the third hearing of the Senate Legal and Constitutional Affairs References Committee inquiry into past and present practices of donor conception in Australia. This inquiry was referred to the committee by the Senate on 23 June 2010. In conducting the inquiry the committee is required to have particular reference to the terms of reference:

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

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

  (i) payments for donors,

  (ii) management of data relating to donor conception, and

  (iii) provision of appropriate counselling and support services;

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

(d) the rights of donor conceived individuals.

On 30 September 2010 the Senate decided to re-adopt the inquiry with a new reporting date of 24 November. The committee has received 156 submissions to the inquiry. Some submissions have been authorised for publication and have been made available on the committee’s website; others have been accepted as confidential submissions to the inquiry.

I remind all witnesses that in giving evidence to the committee they are protected by parliamentary privilege. It is unlawful for anyone to threaten or disadvantage a witness on account of evidence given to a committee and such action may be treated by the Senate as a contempt. It is also a contempt to give false or misleading evidence to a committee.

The committee prefers all evidence to be given in public but, under the Senate’s resolutions, witnesses have a right to request to be heard in private session. It is important that witnesses give the committee notice if they intend to ask to give evidence in camera. If a witness objects to answering a question, the witness should state the ground upon which the objection is taken and the committee will determine whether it will insist on an answer, having regard to the ground which is claimed. If the committee determines to insist on an answer, a witness may request that the answer be given in camera. Such a request may of course also be made at any other time.

[11.40 am]

ADAMS, Mr Damian, Private capacity

BURNS, Ms Lauren, Private capacity

CUMMERFORD, Mrs Myfanwy, Private capacity

SPRINGFIELD, Ms Kimberley, Private capacity

WILLIAMS, Mr Michael, Private capacity

CHAIR—Welcome. Is there anything any of you would like to add about the capacity in which you are here today?

Mrs Cummerford—I am appearing to talk about my individual submission. I am also a member of TangledWebs.

Ms Burns—I am 26 years old. I am donor conceived. I am talking on my personal submission and I am also a member of TangledWebs.

Mr Adams—I am here to provide evidence on my submission, No. 38, as well as the TangledWebs and Donor Conception Support Group of Australia submissions.

Mr Williams—I am appearing as a member of the Donor Conception Support Group of Australia and I am 28.

Ms Springfield—I am here to give evidence on my personal submission as a donor conceived individual. I am also a member of TangledWebs and the Donor Conception Support Group of Australia.

CHAIR—Thanks very much, all of you, for being here and for being willing to be part of this Senate inquiry. So we have the TangledWebs submission, No. 61, and the Donor Conception Support Group of Australia submission, No. 122. We have received your individual submissions as well. Do you wish to make any amendments or alterations to those submissions at this time?

Ms Burns—I just want to add something to my submission. Part of my submission was in response to the Fertility Society of Australia’s submission, and I said there was also the possibility that doctors who were involved with donor insemination may have made some unethical decisions, since they were confident the cloak of extreme secrecy and anonymity would protect these decisions from ever becoming public. I felt that I wanted to corroborate that statement with a short statement from Kate Dobby, who was the registers officer at the Victorian Infertility Treatment Authority, 2005 to 2009. It was her job to maintain the donor registers. I have that statement here; do you want me to just hand that to the committee?

CHAIR—Yes, if you are willing to table that then the committee will accept that as a tabled document and it will be distributed accordingly. Thank you. We will go now to opening statements. I will leave it up to you as to the order in which you wish to speak. Then we will go to questions from the committee members.

Mrs Cummerford—I am not going to go too much into reiterating the points from my submission, since you already have them. I just thought I would give you a bit of my personal story to give more of a real face to this inquiry. I found out I was donor conceived at the age of 20, three days after my birthday. It was not in the most ideal circumstances—I was told by my mother after my parents had separated. I also have a brother, who is my full sibling. At the time that I was told by my mother, she decided not to tell my brother. So I knew that I was donor conceived but my brother did not find out that he was donor conceived, so I had to keep it a secret.

I immediately decided that, in order to resolve the emotional trauma that I was feeling, I needed to do something about discovering who I was. So I went to the Royal Women's Hospital in Carlton, where I was conceived, and sought information as to what ability I had to seek information about my biological father. I was basically told I had no rights whatsoever to any information. I was one of the first people to come back to the Royal Women's Hospital and seek out identifying information about my father, so they actually had no real protocol in place as to what to do when a person came back to seek information. I received counselling from the fertility counsellors there. I was able, after some counselling, to receive some non-identifying information about my father, which was very limited—just hair colour, eye colour, age, time of donation, any offspring that he had and that he was married and a student.

I then decided that I was not happy with that and put in a submission to the ethics committee of the hospital to see if I could have my biological father's identifying information released to a third party in order to do a search on my behalf. My request was refused by the ethics committee. I was then told that there was basically nothing more that the hospital could do for me and that I was on my own. At that point I was heading to Sydney to attend a meeting of donor conceived adults—there were about 20 of us who met around the time of the federal election in 2001—and as part of that meeting for the DCSG I did some media and my story appeared in the *Australian* newspaper on election day November 2001. My biological father saw my picture in the paper—it was on the front page of the *Australian*—and as a result he realised that I was his daughter. He contacted the DCSG and that was how I came to meet my biological father and also three half-sisters, his daughters from his marriage.

I also know that I have three other half-sisters who were conceived to three separate families as a result of donor conception. So I know that I am one of eight children, including my brother, who is my biological father's only son. Coincidentally, my biological father's name is Michael and my brother's name is Michael. I am left-handed; my biological father is left-handed. My brother and I have blond hair and my biological father has blond hair. His three daughters have brown hair because my biological father's first wife was Greek Cypriot. My brother and I are my biological father's only known children that share his physical appearance.

That was 10 years ago now. We have a really close relationship. I am having lunch tomorrow with my eldest half-sister. She had a little boy nine months after I had my little boy, so our two sons are sharing a cousinly relationship. That is something that would never have been possible if I had not been able to discover the identity of my biological father completely miraculously. I still have no legal right to know who he is. If it had not been for the picture that appeared on the front page of the *Australian* newspaper nearly 10 years ago I would still be in the same position as many of my friends are who are donor conceived.

CHAIR—That is quite a story. Thank you for sharing it.

Ms Burns—Thank you very much for giving me this opportunity to appear before the committee. I am sure that in the course of this hearing you will be speaking to many professionals involved in assisted reproductive treatment; however, I would like to think that we—the donor conceived people—are the real experts on these issues because they affect our lives every day. Past policies dealing with donor conception were based on secrecy and lies which cultivated a culture of fear. Donor conception under these terms is a disempowering experience for everybody involved, including parents and donors. However, the children are the most vulnerable and disenfranchised of all the players. In most cases we are still not permitted the grounding knowledge of our genetic identity that enables us to fully know ourselves.

I know how this feels because I have lived with this burden for five years. My mother told me and my sister when I was 21 that we were donor conceived. When the shock began to wear off I started searching for information that I felt rightly belonged to me and my story of identity. This was difficult because the clinic had closed down and nobody assumed responsibility for the records. To briefly sum up this search, it was like bashing my head against a brick wall with all the associated pain that that image conjures. The experience taught me to feel empathy with people whose relatives had gone missing. They do not know if their kin are alive or dead, happy or miserable, or when if ever they might see each other again. That was the situation I found myself in and I do not believe that anybody should be deliberately subjected to this cruel limbo.

Eventually I found a way out, but it took the intervention of Victoria’s Governor to make it happen. Professor David de Kretser was my mother’s former treating doctor and after sending him a letter and meeting him in person he agreed to look up the records and write to my donor to ask his consent to an exchange of information and/or contact. My donor replied within days and I no longer had to use that impersonal word ‘donor’. My biological father’s name is Ben. I was very fortunate to have the expert help of counsellors from the Infertility Treatment Authority to act as intermediaries during the fragile early days of forging this connection. The availability of expert counselling for all involved is crucial and should be given utmost priority by the committee.

A few months later Ben and I met for the first time and found we had a lot of surprising similarities and connections. I met his three children—my half-siblings—and these new relationships have had a very positive impact on my life. Above all else I feel a sense of relief that I finally have answers to the questions about where I get my looks, personality and interests. I no longer face an uncertain future of missing knowledge concerning my biological heritage and identity.

It is my belief that we should learn from our history: the mistakes made in past adoption practices, with the forgotten Australians and with the members of the stolen generation, each policy linked by a determination to cling to secrecy and lies when it comes to acknowledging biological and cultural connections. This approach disempowers people. Similarly, donor conception law and policy should be reformed and replaced with guiding principles based on openness, honesty and disclosure. I can offer my own experiences that a new approach to information management coupled with expert counselling can transform the experience of being donor conceived from disenfranchisement to empowerment.

I would like to end with the reflection that we sit down together today as strangers, yet for some of us in this room you are our best or only hope of ever meeting or knowing our biological parents and siblings and perhaps gaining respite from the unanswered questions that can haunt our sense of identity. Even though I have met Ben, I know that somewhere out in the community I have three half siblings, two boys and a girl, all born to separate families. They could live only a few dozen kilometres away from me, yet I might never know anything about them, and the loss of having them in my life makes me sad. I hope some day we can meet, because I am waiting for them. As members of this inquiry you have awesome responsibility and power over the fate of our lives to make such reunions possible. I hope it is not something you treat lightly but something that you reflect on often. I know you have been exposed to a vast, confusing array of facts and figures, so I hope I can distil a simple message: donor conceived people care about who we are related to from both a social and a biological perspective. All we want is the right to own this information and be empowered to make our own decisions. I hope you remember our real, lived experience when it comes time to make your recommendations.

Mr Adams—Being conceived in the early seventies, I was one of the early people conceived in this manner in Australia. By default, it sort of makes me the elder statesman of this group. It is a title that I certainly do not wear with pride. However, I used to be proud and happy with my conception because that is how society wanted me to feel. However, after having children of my own and holding them in my arms, I came to realise what my conception had truly deprived me of. I had lost kinship, my heritage, my identity and my health history. This realisation was crushing, depressing and immensely painful.

As a scientist who conducts experiments every day, I felt like I was an experiment in social and medical science. The choices made on my behalf by others that would systematically deprive me of the things that are intrinsically a component of everyone else’s lives were dehumanising, hypocritical and unethical. The legislation and regulations which determine what I am entitled to continue to dehumanise me, and relegate me to the status of second-class citizen.

Looking back to a period when I was happy with my lot in life: the consequences of my conception had profound implications and affected me deeply without my even knowing it, and it is something that will negatively impact on me for the rest of my life. Every day I have to get up and look at a face in the mirror that I do not know. As a teenager, I struggled constantly with my sense of self and identity. Even if I had been able to find out at the age of 18 who my genetic father was, it would have been too late to fill in the void of those formative years; therefore access to this information must occur before the identity construct window opens.

I despise the document that contains my birth details. While my parents never hid the truth from me and I have always known of my conception, to me it represents state sanctioned fraud and deception. I have since investigated through the courts about having my dad’s name removed from this and left as blank, but as they have never dealt with a case like this they were unable to provide any advice. As it will also cost considerable money to do, it will have to wait, but it is still something that I will do. I feel ashamed that I have passed on an untruthful surname to my children. Looking back, I should have given them my wife’s maiden name, because at least that has concrete familial heritage. Birth certificates must be the accurate and truthful records of paternity that they are always meant to be.

I am reaching a period in my life where genetically inherited health effects are becoming an increasing concern on a yearly basis, whether they be heart, diabetes, cancer—the list goes on and on. Without knowledge of a familial health history, the lifestyle choices I make now could adversely affect my life expectancy. This lack of knowledge is a constant problem for me and my doctor.

To me, the man who provided his sperm is not a sperm donor; he is a sperm vendor, as he willingly abandoned me in exchange for money. Knowing that you were sold in such a manner, as if you have no human value but are more akin to pets or toys, is crushing on a psychological level. I think if you just look at my compatriots’ faces here now you will probably see that in their faces. For this reason alone, there can never be any payment for donations, even to cover so-called expenses. But this man is not just a sperm vendor. He was, is, and always will be my father. Just as I am a father to my own children, he is a father to me. He will never be my dad but he is my flesh and blood, my heritage, my mirror, my family. I constantly search faces in the crowd for someone who could be my father or for someone who may be my brother or sister. It haunts me on a daily basis.

The pain of my parents’ infertility has been passed on to me but has taken on other forms. While it is extremely traumatic, the pain does not stop with me. It has also been passed on to the next generation. My children will also suffer from the same dissociation effects as me, and this just increases my pain. I have had to learn to deal with my own situation, but to see that it will also affect my own children is too much to bear.

What I am seeking and asking for is something that every other member of our society is automatically entitled to. Even those who were also similarly disenfranchised through comparable contractual agreements, such as adoptees, and through policy and legislation, such as the stolen generation, have had their rights and the damage caused to them acknowledged and appropriate steps undertaken to alleviate some of the trauma that they suffered. I am asking for equality and an end to the discrimination that we are subjected to based on our conception status, our age and which state of Australia we were conceived in. By providing anything short of full retrospective access to this information, we will continue to provide a source of anguish and suffering to offspring. It will be discriminatory and will go against precedents. To subject any group of Australians to such discrimination and dehumanisation is essentially un-Australian.

Mr Williams—Firstly, I too want to thank the committee for allowing me to tell my story. I echo what a considerable number of submissions have called for, which is national legislation to recognise the rights of donor conceived individuals, including having access to information on donors and a mechanism, should both parties agree, for donors and offspring to meet. Without national legislative reform, I will have almost no chance of gaining access to information about my donor or any other individuals that I may be related to. This is because I was conceived in Tasmania and grew up there. Tasmania is a state that has shown no serious intention to legislate to create a register or allow offspring to access information.

As you have already seen, senators, my story is not unique amongst offspring. I discovered when my mother informed me at 21 that I was conceived through donor conception. I too have struggled since that time with my identity, but less so in the last few years because I have resigned myself to not ever gaining access to any information—which was not for want of trying. I contacted the doctor who practised at the clinic at which was conceived, which was the clinic of a highly regarded obstetrician, Dr Lach Hardy Wilson, in Launceston. I contacted his junior doctor, Timothy Sutton, and he told me that all records of my donor had been destroyed. He was very nice to me. He apologised that attitudes in the early 1980s were different and that a policy of secrecy between offspring and parents and between the medical profession and the state and offspring persisted. I then joined the Donor Conception Support Group, who provided me with a lot of assistance and encouragement, and I proceeded to use the local media and the national media to try and gain access about my donor and also in the hope that he would notice me and perhaps come forward, but this has been to no avail.

Should my donor never want to meet me and never want identifying information about him to be known to me, I completely respect and support this. I think that that obviously would be his right. However, I believe that I do have a basic right to a whole range of other information that I am currently denied, such as my donor’s family history, medical information and hereditary or other genetic conditions and whether I have siblings. I grew up as an only child but, because my donor may have attended the clinic at which I was conceived multiple times or subsequently had his own children, I almost certainly have half-siblings. I no longer live in Tasmania—I have been here for a number of years—but it is not a remote possibility, especially in a small community in Tasmania, that half-siblings who do not know each other will meet and form relationships. In and around the Launceston area, I would not say that that is out of the realms of possibility at all. I would also like to have information and meet half-siblings if I have them. I would also like any legislation to provide a mechanism for connecting people who do want to communicate and meet, as has been done in Victoria—to at least have the means to set that up should people want it to happen.

To finish off, rightly or wrongly our society places enormous importance on genetic heritage as being central to one’s identity, and this explains the policy of secrecy concerning donor conception and, indeed, until recently adoption, because it was believed that it would undermine a family if children were aware that one parent was in fact not genetically related to them. The importance placed on genetic link also explains the desire of us, the donor offspring, to know our history. Being a lawyer, I know that one role of the law in our society is to balance the competing interests of various groups. I think that in this area, though, the interests of the medical profession, who are worried about a drop in donations if identity of donors is known and made available, and the interests of families, who have preferred to maintain a secret they regarded as shameful, have been predominant for far too long. Unfortunately, the law as it currently stands does not even begin to consider or address in any way the rights of donor offspring to information that they are entitled to.

Ms Springfield—I would also like to thank the committee for this opportunity to speak. I learnt five years ago at age 21 that my biological father had given away his genetic material anonymously. This is how my parents, with the assistance of Monash IVF, created me and my older sister. I also have a brother; we discovered upon finding out five years ago that we were donor conceived that his biological father is different from mine and my sister’s. The news came as quite a shock, although growing up I had always felt somewhat out of place. The most devastating part of it all was discovering that I was not allowed to know where I had come from. I could not reclaim my identity and figure out where I fit into this world. It has been a long five years since then, from my initial silent grieving to dealing with the IVF clinic, which offered little support and showed no empathy. I am here today because I want to know and be proud of who I am; because I cannot stand to have the very essence of myself kept secret from me; because I owe it to my children to discover our history; and, finally, because I am mentally and emotionally exhausted from searching the faces of people every day wondering if they are my kin.

I lived in New Zealand for three years shortly after finding out that I was donor conceived and a Maori elder there told me that our ancestors are like the roots of a tree—without them it cannot stand. In order for us to stand in our place of belonging we must know where we come from, who our ancestors are and our roots. This suffering from being denied part of us does not ease over time but compounds more and more each day. Without access to our kin and our history, we remain lost within ourselves, and without it we will continue to search. That is all I really wanted to say.

CHAIR—Thank you very much to each and every one of you for your submissions and sharing. It is clearly personal and challenging and we appreciate it. Thank you on behalf of the committee for sharing the way you have. Now we would like to ask some questions. I know you have got individual submissions but we have also got Tangled Webs and the Donor Conception Support Group. I will go firstly to the Tangled Webs submission. My understanding from reading the submission is that you do not support donor conception because it is fraught with moral, social and other legal responsibilities. Could we get clarity around that if it is the position and, if not, what is?

Mrs Cummerford—That is the group position. Individually members of Tangled Webs have varying views on that.

CHAIR—On behalf of the group, could you outline your reasons in perhaps a little more detail?

Mrs Cummerford—I will just speak personally. It is my view that, because this is a practice that is funded by the state and legislated, we have to take regard to various provisions in legislation. One of the primary cornerstones of family law is that the best interests of the child are paramount. If you think about the timing in which the decision-making of donor conception occurs, the decision to proceed with the donor conception happens before a child is born and the child does not exist at that point. My personal position is that it is contrary to the best interests of the child to deny them indefinitely a relationship with their biological family, biological parents, and biological siblings. So my position is that with the decision-making process as it stands with donor conception it is unethical because we are indefinitely depriving the child of a relationship with their biological parent/s. Because you cannot know at what point that child is ever going to come into contact with their biological family, we are definitely depriving a child of relationships with their biological family. It is my position that it is in the best interests of the child to be able to choose whether or not they want to have relationships with their biological family and that choice is not possible with donor conception as it is currently practised.

CHAIR—So you cannot conceive of any arrangement that could be put in place, legal or policy arrangement—

Mrs Cummerford—Yes, I can. I would be, satisfied is not the right word, but if we had a system whereby the relationship with biological family was preserved, similar to an open adoption, whereby the child always knows that they are donor conceived and is able to choose to have a relationship with their biological family if that is what they wish.

CHAIR—You do draw the contrast with adoption procedures in Australia, which are very strict and regulated very heavily.

Mrs Cummerford—They are strict for a reason.

CHAIR—They are strict compared to donor conception, which appears to be not the opposite but—

Mrs Cummerford—Adoption is very child centric; donor conception is very parent centric. The adoption guidelines and regulations are strict because there is an emphasis that removing a child from their biological family is always a last resort, so the child is parented by people who are not their biological parents for a reason, because for whatever reason their parents were not able to parents them. In donor conception it is reversed: the practice exists because someone wants a child and so that child is not able to be parented by their biological family because the parents who are commissioning that child wanted to have a child.

CHAIR—So you are really saying that until there is an agreed legislative position where the child that comes into the world has the right to access and a relationship with their biological father then you do not support donor conception.

Mrs Cummerford—Yes.

CHAIR—I appreciate getting clarity around that. To both groups, can I ask a question on the rights of the child. I think there is an understanding across both groups but please confirm that the best interests of the child prevail in every instance—that is the key principle?

Ms Springfield—Yes.

CHAIR—Do you agree that a child has a right and a fair and reasonable expectation that, all things being equal and subject to tragedies and other circumstances, when they come into the world they are entitled to both a mother and a father?

Mr Adams—Yes.

Mrs Cummerford—They have a mother and a father. It is a biological fact.

CHAIR—It is a biological fact, but we had witnesses yesterday called SMC, Single Mothers by Choice, and they had a different view to you.

Mrs Cummerford—Are you talking about legal parentage or natural parentage?

Senator PRATT—I think, Senator, you have misconstrued their submission. They were maintaining that in most instances they are very supportive of maintaining a connection between the child and their biological male parent and that they would acknowledge the significance of that.

CHAIR—That is on the *Hansard*, so please review their submission. They made a lot of pertinent points, I thought, which were very valid. I just wanted to get clarity from you about your position as to the rights of the child and what is reasonable for them when they come into the world, and that is an entitlement to come into the world with an expectation of a mother and a father. You have responded to that.

Mr Williams—Can I just say that I was raised by a single mother. My father was largely absent—he was there but certainly took no active role. What are the markers of success? I have gone on to study law at Melbourne university. I am a high achiever. I have done all the things that society has expected me to do.

Senator PRATT—So you would not advocate that access to such technology be limited by marital status, for example?

Mr Williams—That would certainly never be my personal position, but I cannot speak—

Senator PRATT—I appreciate you might have different views.

Mr Williams—Yes, we probably have different views on that.

Mrs Cummerford—I think it is discriminatory, but I am not sure what relevance marital status has to this inquiry.

CHAIR—What do you mean when you say it is discriminatory?

Mrs Cummerford—To discriminate on marital status. It has already been decided in Victoria it is discriminatory.

Ms Springfield—What we are trying to say is that a child has the right to a relationship with their biological parents, regardless of the marital status of the couple raising them.

CHAIR—That is what I am coming at. I think there is a firm yes to that. And we certainly admire single parents for their roles and what they do. In terms of designing this regime for right-to-know information, when does that kick in? I understand that you can receive that information at 21 years of age, but you are indicating to us than you would like it much earlier. How early? As soon as possible? Can you respond on this issue of the right to know and how that would be rolled out if we did have some sort of national regime that applied that principle?

Mr Adams—I am a little bit different to the rest of them in that I am probably the only one here who has always known. When you are a kid growing up, quite often you are not worried about these sorts of things until later on. From the research I have done including on donor conception—I am a scientist and that is what I do—identity formation occurs throughout a child's lifetime, but one of the main important areas is in adolescence. Currently in certain states it is possible for donor conceived offspring to access information on their donor once they reach the age of 18. If we look at the way identity is formed in individuals, a lot of that, as I mentioned in my submission, will be missing during the time they are growing up and trying to form their identity and their sense of self.

So, if we mandate that it is going to be at the age of maturity, then you miss this critical period of the person’s identity formation. As we have also seen with a lot of people who do form relationships with their biological kin in adulthood, because you have missed all this shared life experience as you were growing up, the relationship is always tentative. It is not the same as if you were immediate family as it should normally be. So there are always some problematic ways there.

CHAIR—We are legislators. I am asking the question: how would You also then want to design and implement this principle of a right to know, which seems to be so important?

Mr Adams—For me, I would like, ideally, that the child should always know, right from the word go they should have access to it. It definitely needs to happen before adolescence.

Mr Williams—I would support that. I suppose I take a somewhat different view to the TangledWebs group. I respect their view, but I cannot say that, had I always known and had I always had two loving parents, whether one was related to me genetically or not, I would have necessarily grown up having poor life outcomes. I think if you have two parents who love you or one parent that loves you, I tend to think that that is more determinative. I would definitely support what everyone else is saying in terms of the access to the information, the information always being there and being open from the time of conception and everyone having that expectation that it is open and can be accessed.

Ms Cummerford—When I registered my son, his birth certificate stated that he had a right to have his father’s name listed on his birth certificate; conversely, his father had a right to have his name listed on my son’s birth certificate. Why should we be any different? That birth certificate is available to my son from birth; why should we only be able to access that information at a certain age?

Ms Burns—I think there is also the issue of owning the information. At the moment we are quite beholden to other people to inform us; whereas I think the paradigm should shift to recognise that it belongs to us. In that sense, I think there are a number of mechanisms to do with, for example, birth certificates. With adoption a biological birth certificate is issued, and then a social or legal parentage birth certificate is then reissued, but you can always go back and find that information. There are various means of doing so, parenting orders and so forth, in which you can maintain both the social and the biological information available to the child. I think you avoid a lot of the trauma of finding out later in life.

Mr Adams—The research definitely shows that if you find out later in life there is a greater chance of causing damage, because it allows the commissioning parents to actively see the child during their formative years. To find out later on is incredibly crushing.

CHAIR—Thank you very much. Did you want to contribute, Ms Springfield?

Ms Springfield—Yes, I just wanted to talk in support of what has been said. This information about genetic links does actually belong to the child. It is part of them, so I believe they should always have access to that.

CHAIR—Thank you. Senator Crossin now has some questions.

Senator CROSSIN—Thank you for coming here today. It is good to see some familiar faces again. We finally got on the path of uncovering some of the problems in this area. That is at least one welcome change. Can I put this to you: if a person wants to donate in this area, is it your view that, unless they are prepared to be identified and have their details released, then they should not be allowed to donate?

Mr Adams—Yes.

Ms Burns—Yes, that is covered by the NHMRC guidelines. That is a very widely held viewpoint.

Senator CROSSIN—It is covered by the guidelines, which are not enforceable.

Ms Burns—Exactly. You have hit the nail on the head.

Ms Cummerford—That is Victoria’s position. It is state law here.

Senator CROSSIN—Yes, that is right. And there are no laws in some states and in the Northern Territory.

Ms Cummerford—We know that.

CHAIR—Tasmania is one such state.

Senator CROSSIN—So you are saying that the position that the Victorian government holds should be a national position.

Mr Adams—Yes.

Ms Cummerford—Yes.

Senator CROSSIN—You do not donate, unless you are prepared to have your identity revealed?

Ms Burns—It is ridiculous what we have at the moment, where, depending on where you were born or conceived, you have completely different outcomes. It is the height of inequality.

Senator CROSSIN—Should the issue of contact, though, be up to the person—the child? The issue of whether or not you then want to make contact with that donor should be up to you, as the donor conceived person?

Mr Adams—Yes.

Senator CROSSIN—Which some people may choose to access and some may not.

Mrs Cummerford—Yes.

Senator CROSSIN—But the option should be there and it should be your choice. Therefore, we need a national register so that this inconsistency can stop?

Mrs Cummerford—Yes.

Senator CROSSIN—Therefore, we need national legislation that regulates the guidelines. Should we therefore then have an independent government body that ensures those guidelines are being regulated and that there is consistency across social, ethical and medical practices?

Ms Burns—Yes. Perhaps we could look at having an ombudsman for assisted reproductive treatments similar to, say, the banking or insurance industries so it gives people a way that they can investigate complaints.

Senator CROSSIN—Have I missed anything out of the chain or the link?

Mr Adams—No, I think that was a very good point, because to a lot of us who observe the current problem with RTAC and things like that there does seem to be a vested interest in there. It is hard to see that there is decent transparency.

Senator CROSSIN—Just explain that to me, Mr Adams, because, as I understand it, RTAC accredits and regulates fertility clinics, but the membership of RTAC is made up of those fertility clinics. Is that correct?

Mr Adams—That is my understanding.

Senator CROSSIN—So they are self-regulating, in a sense?

Mr Adams—Yes.

Senator CROSSIN—Or purport to be self regulating.

Mr Adams—Yes. That is my understanding.

Senator CROSSIN—The one issue that I want to ask you about, which goes directly to your situation, Mr Adams, is that at certain points around this country and in certain states and territories people can or cannot get access to information, depending on a certain date in time. Do you think that should be retrospective or—

Mr Adams—Definitely. We have had the precedents with the adoption legislation, so why should we be any different.

Senator CROSSIN—How do we get over the situation, though, if it is made retrospective? I am assuming donors back then donated on the understanding that they could remain anonymous.

Mrs Cummerford—Not necessarily.

Mr Adams—The anonymity is not absolute. It is commonly overridden in the courts.

Mr Williams—In a lot of cases it may not have even been discussed. For instance, in Tasmania there was a widely held, shared understanding that no-one would ever discuss it, even within the family. Probably it often would not even have come up as conversation.

Mrs Cummerford—In my personal example, my biological father did not even realise that any children had resulted from his donations. He thought that his sperm was being used for medical research. In terms of privacy, if you have read the Victorian report of the inquiry that is going on at the moment, his donor contract appears at the start of that report; there is no actual agreement between me and my biological father that we should not be able to contact each other. That agreement exists between my parents—

Senator CROSSIN—What inquiry were you referring to then?

Mrs Cummerford—The Victorian inquiry into retrospective access to information.

Senator CROSSIN—For donor conceived people.

Mrs Cummerford—Yes.

Senator CROSSIN—Is that current?

Mrs Cummerford—Yes.

Ms Burns—It is running concurrently with this inquiry. That particular donor statement and consent form says that the donor will not make any claims on the child and that the parents will not make any claims, but it does not cover the relationship between the donor and the child; therefore, that would not necessarily contravene the terms of that contract.

Mr Adams—The contradictory part is that in South Australia, which is the only state to have legislated anonymity, that was made retrospective when it was brought in.

Ms Burns—Changes to the Family Law Act were made retrospective. They cherry-picked when it was desirable to make legislation retrospective.

Mrs Cummerford—There are numerous examples, a number of cases, within the Family Law courts where privacy will be overridden to determine paternity.

Mr Williams—I think another point is that, even if retrospectivity exists, you cannot force people to form a relationship. So, even if that information is available, what harm could it really do? If the donor does not want to have a relationship with the offspring, it will not happen.

Ms Cummerford—The vast majority of us are adults now. I so often hear the argument about legal liability, claims on state and that sort of thing. I have not met a single donor conceived person who is interested in the monetary side of things.

Mr Williams—That is a complete red herring and a complete furphy—that whole argument about child support or claims on state. There is no basis for that at all.

Senator CROSSIN—The central point which is so consistent across submissions, though, is that this has to move from a parent focus to a child focus.

Ms Burns—From parent-centric to child-centric. I think that would bring it into line with—

Ms Cummerford—Adoption.

Ms Burns—Yes. For example, in Victoria's legislation the No. 1 guiding principle is that the rights of the child are paramount, and that is the legislation which contains the provisions whereby Kim is denied access to her biological father. So in a sense there is lip-service in that they say these things but within the legislation they actually have the exact opposite.

Mr Adams—It would also allow us to get in line with the UN Convention on the Rights of the Child. When I quizzed Attorney-General Philip Ruddock many years ago as to who was ensuring that we met that in regard to donor conception, he had no idea.

Senator CROSSIN—Have I missed anything in my loop of issues?

Ms Burns—I would just like to reiterate that, if you decide that this information is important and that the child has the right to this information, you simply cannot have it any way except retrospective, because once you decide that the child needs this information it does not make sense to apply it only to one group. It basically creates a two-tiered system which is in direct contradiction to procedural fairness and natural justice.

CHAIR—You mentioned adoption. What is your position with respect to this and adoption? Are you linking the two and the principles underneath them?

Ms Cummerford—Yes. With the example of the Victoria legislation, we already have a precedent where information was made available to adoptees even where their parents were guaranteed anonymity, and that was retrospective.

CHAIR—Ms Burns, you mentioned adoption. Do you support that?

Ms Burns—Yes. I think that they share a lot of issues in terms of fractured kinship links, and in a sense what we are looking for is restorative justice similar to what was pushed forward 20 or 30 years ago in adoption.

CHAIR—Thank you.

Senator PRATT—Drawing to begin with on the adoption parallel, in a state like Western Australia anonymity was removed and the option of contact vetos was put in place. There is a process of counselling and, if you like, a request for introduction that is exchanged by the government intermediaries; they can license community agencies to do that. Would you support something similar?

Ms Cummerford—Yes, with the qualification that there have been a lot of issues surrounding contact vetos. I would like to see a mechanism where, if a contact veto is revoked by a party, the other party is notified that that veto has been revoked, so the party that was originally subject to a contact veto is then notified that they are able to contact that person.

Senator PRATT—What about introduction to siblings? How would you envisage that? Clearly people can do this quite successfully themselves in many instances, but in others—

Ms Cummerford—I think counselling is vital.

Ms Burns—Yes. In Victoria the legislation works both ways in that donors have the right to seek contact with their offspring. There were a number of cases that the Infertility Treatment Authority dealt with where the donor requested contact and the child had not been informed that they were donor conceived. The way that they dealt with that was obviously quite sensitive in that they informed the parents first and gave them the opportunity to have that conversation with their child first. I think that is the best way: they should hear it from their parents.

Senator PRATT—These are adults?

Ms Burns—Probably over 18. The legislation did not say that they had to do that but that was the call they made. So there is some precedent or some policy you could adopt which has already been used successfully in Victoria. Obviously one of the issues is that a lot of donor conceived people are not aware of their status yet, although it is my belief that with time more and more people will find out through such things as medical treatment, looking at genetic sequencing and targeting certain illnesses. If one person knows, generally the secret comes out.

Mrs Cummerford—I know it is true for Lauren as well, but the reason my mum did not want to inform my brother that he was donor conceived was because she did not have any information to offer him. If this inquiry is successful and we are able to get access to information, more people will probably discover they are donor conceived.

Ms Springfield—Can I support that as well. I actually was not told by my own parents and I was donor conceived. My mum did not tell us because she did not have the information to support that. She did not want to just leave us in limbo, and my grandmother knew, who told a relative, who ended up telling us for other reasons.

Senator PRATT—We heard evidence from fertility clinic practitioners that there is no problem with record keeping.

Mrs Cummerford—Rubbish.

Senator PRATT—I would think there needs to be some immediate action to protect what records are out there. What would you suggest we should do on that front?

Mrs Cummerford—In the interim, even before a report is tabled, there should be something done to preserve records. We know that there are records held in people's garages.

Senator PRATT—How do you know that?

Mrs Cummerford—Anecdotally from stories we have been told. People have gone back to doctors. My own records were not even held at the hospital, they were held in storage somewhere.

Ms Burns—Mine were in the public records office in a permanently closed file just randomly. Even though they will not supposed to be there, that is where they ended up.

Ms Springfield—The non-identifying information that I finally got out of the clinic has actually got the name and address filled in by hand and has got it scrubbed out, so there is nothing to stop people from removing information on that sort of thing.

Mr Williams—My records were in Launceston and Dr Hardy Wilson has since passed away and the clinic has been shut down. I think there should be some mechanism for gaining information that is not in written form. Probably my records have been destroyed but certainly Dr Sutton would know where donors were recruited from. He would probably have a fairly good idea where they targeted. I know anecdotally from other places that clinicians targeted medical schools for donors.

Senator PRATT—Should government be levying the reproductive technology industry to put some resources together to correct some of these historical injustices?

Mr Adams—Certainly. Considering the amount of cost that people pay to receive treatment, how much you would actually have to levy them would be minute. So there is no reason why that should not be passed on.

Senator PRATT—That could, for example, include resourcing a national DNA register to enable siblings to make contact with each other.

Ms Burns—I think that the records should be kept quite separate from the clinics even if they are funded by the clinics. On the issue of poor record-keeping, I will read out a short paragraph from the woman whose job it was to maintain Victoria's donor registers. She says: 'Some clinics, hospitals and doctors may oppose the granting of equal rights to access information from the donor conceived not only because it exposes the weaknesses and inadequacies of past records but because of what is revealed about past practices. Egg-swapping, sperm mixing, donors' identities not being verified or donors being encouraged to donate under pseudonyms, offering free vasectomies and sperm storage, STD testing and course credits in exchange for donating, knowingly creating up to 30 separate families or in excess of 40 children from one donor, using anonymous donors imported from interstate without paperwork, recoding donors, the practice of on-donation, utilising patients as donors whilst they are still in treatment and using donors for whom valid consent could not be verified are just some of the practices that I know to have occurred in Victoria even after the introduction of legislation. These can be viewed very negatively from a current perspective. For this reason it might be worthwhile to consider the idea that clinics, hospitals, doctors and allied health professionals might see the repercussions of these practices coming to light.’

Senator PRATT—I think that is a point you have made very well.

CHAIR—Are you finished, Senator Pratt?

Senator PRATT—I certainly have more questions but it is probably your turn, Chair.

CHAIR—I will just finish off with two areas. In terms of families to whom the donor conceptions occur, we have had witnesses who indicated it should be a maximum of five families, witnesses who talked about a maximum of one family and witnesses who talked about ten families or more. Do you have a view about that?

Ms Cummerford—My position is one family—only because of personal experience. I know how difficult it has been for even just me and my three half-sisters who all were raised together. I imagine it would be somewhat easier to form relationships, maintain relationships. We have found it really difficult. It has been a long, hard road, and it is still difficult. If my three other sisters from three other families come forward, I am not sure of my own capacity to have relationships with them. I cannot imagine how someone could even contemplate forty different offspring. How is one man supposed to—

Ms Burns—It is like being factory farmed.

Mr Williams—I hope that did not occur in Tasmania, because it is a very small place.

CHAIR—I am aware of that.

Senator PRATT—Clearly some of you have good relationships with your donors. If we say people with infertility should be able to continue to access treatment—and they need access to gametes that are not their own in order to do that—how should we encourage the right kinds of people to step forward? If we are suddenly going to limit access to those gametes in that kind of dramatic way, what story would you tell about the kind of person that you would or would not like to encourage to come forward to help someone create a family that way?

Ms Cummerford—The Victorian experience since banning anonymity is that a different type of man comes forward. He is usually a family man, someone who already has children of his own, someone who understands—I am a mother myself, so I can understand the need, the desire, to have a child—it is a person with more of an understanding of what it is they are doing, someone with an understanding that a child is going to be produced; as opposed to historically, where they were young men, students—

Senator PRATT—So, historically, we might have had fewer men and they were creating lots of families. If there is a sense of openness about what fertility is in Australian society today, there might be a wider sense of visibility around people creating families in that way?

Mr Adams—It needs appropriate counselling. The problem that currently occurs is that the counsellors are all provided by the clinics. So they all have a vested interest: if they start turning too many people away, they will be out of a job. So we need to have independent counselling so we can make sure that these people are informed of all the consequences and what may occur to their own family, the offspring and the donors.

Senator PRATT—Things like, for example, families using known donors—and that being a more visible thing—might just change the discourse in Australia about how these relationships are managed in a general sense?

Ms Cummerford—I think so. I think that, once that changes, the face of donor conception is going to change too. There will be a lot more interaction between biological parents and their children, and it will become so much less secretive.

Ms Burns—I was speaking before about this culture of fear. It is being fostered by the current policy which is based on secrecy, lies and lack of disclosure. I have seen a graph of the average age of donors from the early seventies to the current day and it has just climbed from men who were 19 to 20 years old, people who are enticed by the money—even only $100 can be quite a lot of money to young people—towards more men in their early to mid-30s who might have completed their own family.

Ms Cummerford—The experience of my brother and I of having a relationship with our biological father has been difficult but it has been nothing but positive. I hope that every donor conceived person can experience the same, because I think it is a case of ‘open hearts, open minds’. What damage can there be in enabling people to have relationships with one another?

Ms Burns—There are a lot of myths, and one of the myths is that the donors uniformly do not want contact. I do not think that is true at all. The majority of people who have been dealt with through the counsellors of the Infertility Treatment Authority understand why people are seeking information and they want to help them answer those questions. In my personal experience, I have found that it is a two-way thing. It is not just that I am hassling this man or whatever—I do not know—but he is also interested in me. He has mentioned that, at the beginning, when we first got in contact, he felt quite sad just at the loss of not really being in my life and not being able to see me day to day. It can be a two-way thing, that interest.

CHAIR—That is all very useful. I have just one final question. We had evidence on Friday regarding the importation of donor sperm. There was advice to the committee that the majority was coming from overseas and specifically the USA. I am wondering if you have a view on whether it is appropriate or otherwise to—

Mrs Cummerford—Inappropriate.

CHAIR—Coming from overseas.

Mrs Cummerford—Inappropriate. It is difficult enough for us to seek out our biological fathers who are Australian. It is only multiplied.

CHAIR—Is that a view across the board?

Ms Springfield—I definitely agree.

Senator PRATT—I wonder if there might be exceptional circumstances in which someone had created a family overseas and wanted to use the same donor, so you would not want to—sorry; I did not mean to interrupt.

CHAIR—Subject to families being overseas, just as a general—

Ms Springfield—Obviously, with regulations and things at the moment, things are not properly regulated as it is with clinics in Australia. How are we going to regulate that properly?

Ms Burns—I do not think it fits into that child-centric paradigm.

CHAIR—Mr Adams, did you want to express a view on that as well?

Mr Adams—No, that is fine. I agree that it should be ceased.

CHAIR—You agree? All right. Can I say thank you very much for sharing your story and sharing your evidence with us. It is very much appreciated. We have learnt a great deal in the course of this inquiry, and it has been most useful. Thank you again.

Proceedings suspended from 12.42 pm to 1.31 pm

ALLAN, Dr Sonia Marie, Private capacity

CHAIR—I welcome Dr Sonia Allan to today's hearing. Do you have any comments on the capacity in which you appear?

Dr Allan—I am a senior lecturer at the Adelaide Law School, University of Adelaide.

CHAIR—Thank you. We have your submission, No. 30. Do you wish to make any amendments or alterations to the submission?

Dr Allan—No, thanks.

CHAIR—I invite you to make an opening statement and then we will have some questions.

Dr Allan—Okay. As an opening statement I should let you know the position that I hold, which I think my submission reasonably reflects, and that is that I believe, not just from a social perspective but also from a legal perspective, that, once we recognise the right of donor conceived individuals to have access to information about their genetic heritage, that recognition can not be applied only to a small subset of donor conceived individuals or people who will be conceived via assisted reproductive technologies in the future. Once we make that recognition, we need to apply that recognition to all donor conceived individuals, which means that I am an advocate for retrospective release of information. What I have been doing, even in the lead-up to this, is trying to look at the legal arguments for such release and then weighing them against the arguments of people who are against that release. I would submit to this committee that the arguments for the release of information are far stronger than the arguments weighing in on the other side, and I think there are substantial legal arguments to back up both the release of information about genetic heritage and the release of such information retrospectively.

CHAIR—Any further opening remarks?

Dr Allan—No. I am happy to take questions.

CHAIR—All right. Thank you very much for that. I might kick off. In your submission you refer to international comparisons.

Dr Allan—Yes.

CHAIR—You also referred to the differences between the states and territories around the country and expressed your view about the lack of a consistent approach and the need for a national register and national legislation. But before we go to that I just want to go to the international comparisons. Based on your studies and your research, can you point us to some good examples overseas and describe them for us.

Dr Allan—I think you get the best examples of recognition of the need for information release in the more Nordic European states: Sweden, Austria, Switzerland, the Netherlands, Norway and Finland later. If you take Sweden as an example, as donor conception or the use of assisted reproductive technology became available in Sweden, they were one of the first nations to also recognise that this was going to result in an individual, a living, breathing human being, who would be concerned about where they came from. They have quite an emphasis on knowing your genetic heritage and so they introduced laws very early on, I believe, around 1984-1985, which incorporated the requirement to disclose the identity of or information about the donor. This has been followed by other countries—Austria in 1992 and then later Switzerland, in 1998, I think, but I would have to double-check that information. So all of these countries actually recognise the need for information about genetic heritage and place quite an emphasis on that.

I think some of them require—it was mentioned before—that if you are to donate gametes then you must agree to the information being released and the possibility of being identified. That differs from other countries in the world, as we know. But there seems to be a consistent move in those nations that do legislate on assisted reproductive technologies towards legislating by looking at the resultant child as well and not just focusing on the people who wish to access those technologies. The other thing that is quite striking in some of the countries is their recognition of the need for early information release; they do not leave it until the child is 18 or 21.

CHAIR—Where I am interested in your view, which is very considered one, an academic one, is if you can share with us, either now or on notice, some of the good models overseas in terms of the right to know, setting up a national register, including what is on the register, and the important, key ingredients in any successfully operating national legislative regime? Could you point us to such models so that we can in due course study them and learn from them?

Dr Allan—Really, I think we can look more closely within our own borders, because I think Victoria has over the years developed an approach in terms of record keeping, maintaining databases and requiring information release. The difficulty surrounding the models that exist in Australia is that, at different points in time, there were different rules relating to what sort of information could be released, and therefore we ended up with this mishmash where, depending on when and where you were born, you can access only certain information or none at all. But, if you want a model for maintaining registries, releasing information and the counselling processes that surround that, a number of donor conceived individuals in Victoria whom I spoke to said that, once they were able to link in with that system, the counselling that they received was actually crucial to them. So I think there are already models within Australia that we can work with but we need to look at that on a broader and more consistent scale across the country.

I think the United Kingdom also provides an example—although again, in discussions with some donor conceived individuals, they said that the voluntary nature of such schemes has been problematic and, again, it is based on dates. So you move forward from a date and you have all the access and the system works quite well; but, if you were conceived before a particular date, it does not. So I think, in terms of looking at models, probably some of the systems that are in place within Australia are workable, but they need to be workable across the country.

CHAIR—All right. In your submission, you set out your preferred model for a federal register, which you say should include all ‘identifying and non-identifying’ information. Can you outline for us what they would be in the ordinary course of events.

Dr Allan—In terms of identifying and non-identifying information, medically there are things that could identify a person and that are kept confidential. But in these circumstances donor conceived individuals want to know a name and also want information—particularly medical history and familial medical history. I suppose anything related to the donor is significant—possibly education, for example. I am not really sure of the comprehensive list that you would have. It would be what is held on the medical records and what the donor conceived individuals are asking for in terms of having access to information about their medical and familial history.

If you look at the adoption example then the children want to know who their biological parents were. That does not necessarily equate to contact; that is quite a different thing. But they do want to know who they were, where they grew up, what their medical history is, possibly their educational history and what they do as a job. All of those things can be important when somebody is concerned with their own identity and their own interests. You hear people say, ‘I just wanted to know why I was left-handed because neither of my parents were’, or ‘I have blonde hair’, or ‘I am really interested in science’, or ‘Why was I so academic when my social father was a labourer?’ It is all part of forming an identity so I think there should be as much information as possible to enable the donor conceived individuals to create a good sense of self—that is really important.

CHAIR—But if you are legislating—and if you could sit in our shoes for a few moments—and designing a system, what information, as a minimum, should be required of fertility clinics on their registers when they have the donor come in? When the donor signs the form to register, do you have a strict set of criteria as to the information that should be made available to donor conceived individuals in due course?

Dr Allan—You are asking if I have a stance. I do not have a strict set of criteria personally, but—

CHAIR—I am happy for you to take that on notice—if you could give further consideration to the issue of what should be held as a minimum, as well as what is voluntarily offered.

Dr Allan—I would be happy to do that. I suppose I would just make a comment that you have to put it in context as well, given the nature and practice of what is happening. Many parents will go—although not in some states in Australia because it is not possible—to seek donor conception or assisted reproductive technology wanting to know the height, weight, hair colour, eye colour, skin colour and educational level. If you look abroad—and you mentioned importing sperm from the United States—you can go on to the websites of the IVF clinics and they have great lists. The issue of academic qualifications is very important—they do not take anybody with less than a college education—but also identified are general characteristics, not only hereditable ones. You can get whole lists of what people are interested in. I would not go so far as mandating that clinics need to find out what every donor’s hobbies are, but I think as much information about biological heritage is important for the donor conceived individual. So on notice I would be happy to think about that.

CHAIR—Thank you for offering to do that. You mentioned the importation issue and we were advised that a majority of donor sperm has been imported into Australia. I do not know whether you have a view on that or if you are aware of that and can confirm it. Secondly, what is your view with respect to the merits or appropriateness of that, because our previous witnesses were all pretty much against it owing to the difficulty for the donor conceived person in accessing the identity of their parent?

Dr Allan—I suppose there may be a distinction between requiring information and requiring a relationship, and sometimes it depends—not that one is mutually exclusive of the other, but if you look at it from a donor conceived individual's point of view, if they want to go on to develop relationships then that can be quite problematic if the person with whom they want a relationship is abroad; it makes it more difficult. But if you are looking purely in terms of access to information about genetic heritage then I do not see an issue with having sperm donated from overseas provided that it meets the criteria that it needs to meet here for information release.

I think that can be problematic because, particularly in the United States, they are quite staunch about not releasing information. I might advocate against importing gametes not just sperm from any country that does not require the same stringent criteria in terms of information release. To control that there should be record keeping of who is the provider and that they are not using a pseudonym. In that sense it needs to be controlled.

CHAIR—Do you know how many donor conceived individuals there are in Australia and how many per year?

Dr Allan—I did my sums; a little bit of quick maths based on the neonatal statistics that they bring out each. I estimated that since the seventies, based on their reports, there would be about 20,000 donor conceived individuals in Australia. They are the ones that have been counted. I am aware that the Donor Conception Support Group estimated at somewhere more like 60,000. The other thing I would say is that what is not being counted—this was only drawn to my attention recently—is the way the donor conception is working in Australia now. Some people are not doing it through clinics, and you can do an easy search on Google and find men who are offering themselves up to donate sperm to multiple families. To be able to easily estimate the number is quite difficult but if we sit it anywhere between 20,000 and 60,000, and that is the donor conceived individuals, we are talking about an issue that significantly impacts on many Australians, because it is not just the donor conceived individuals, it is their siblings, their parents, their aunts, their uncles and their extended families.

CHAIR—Do you have a view on how many donor families?

Dr Allan—I would have no idea of how many donor conceived there are.

CHAIR—I am asking how many should there be.

Dr Allan—There should certainly be a limit. One of the concerns is about the risk of forming consanguineous relationships so you have to limit the number of families to which a donor can donate. I would say there should be no more than three and preferably less. Can I qualify that because I think that that should also be dependent upon the number of children within a family. If a donor is used to conceive six children in one family then that is enough or even three children within one family is enough. It is not an easy question.

CHAIR—You mentioned families and donor conceived individuals within a family. I assume when you say that you mean with a mother and father in a family situation. I am really asking the question: do you have any statistics on whether donor conceived individuals go to a mum and dad situation or just to single mums or other relationships?

Dr Allan—I think you need to separate the issue of access to information to the access issue. Access in Australia now in all states except for South Australia is open to single parents and people in same-sex relationships. You have all sorts of family types that are accessing assisted reproduction. In terms of the number of families, particularly heterosexual families where there is a mother and father, it is difficult to estimate the extent to which this practice has happened because it has been shrouded in secrecy for the last 40 years. They do not talk about it. There are many examples of children who do not find out until they are 21, 28 or so. We are seeing the adults now. To estimate the number of families when the record keeping has been probably dubious at best or it has been shrouded in secrecy is very difficult. On the other side of that you see the progress of technology and the different family types that are accessing it. It is obvious that they might have needed some assistance in creating a family. I think the secrecy in terms of information is not as prevalent within single-parent or same-sex families as it has been in heterosexual families historically for different social reasons.

CHAIR—I understand that. But, of course, that law changed a few years ago as you indicated. Victoria, for example, did have a law which said that IVF was available for married couples or for people in long-term heterosexual relationships. Then that law changed. I think it was a Federal Court case.

Dr Allan—McBain.

CHAIR—McBain, that is right. It was in about 2002 or thereabouts. That said that the Sex Discrimination Act nationally was discriminatory so the law changed after that time as a result of that Federal Court case. I am just thinking whether you are aware, since then, what proportion were going to a family with a heterosexual relationship, or to single mothers or to a homosexual relationship.

Dr Allan—In terms of numbers I am not sure that it has changed anything because, although Victoria had laws that were considered discriminatory once they were brought up against the Federal Court in terms of access and those provisions were void, there were many states in Australia that did not legislate at all. All you had was forum shopping. You could go to New South Wales and access assisted reproductive technology. The number of families or the types of families that are accessing ART is quite a different issue to the one where you look at the individual that has been conceived regardless of their family type who has a right to know about their biological heritage. It is not necessarily, if we are talking about sperm, that they have a need for a father, per se, but that they have a need for information about who they are and where they come from. Regardless of who is accessing the technology if we focus on the individuals that are coming into being because of the technology then it is their rights that I am really concerned with.

Senator PRATT—Dr Allan, are your Victorian or are you from South Australia?

Dr Allan—I am originally from Sydney, I lived in Victoria for eight years and I have now moved to Adelaide.

Senator PRATT—I was looking at the Western Australian Department of Health submission and they have raised some legal questions in relation to the interaction of state and federal law in this matter. I wondered if you might comment on the capacity of federal law to act in this area. They have the Human Reproductive Technology Act and they talk about some of the retrospectivity and the fact that in the past donations were made with the assumption that that act would protect donor anonymity. They have that privacy act and privacy provisions and they have put in place a voluntary register in order to retrospectively create arrangements that can facilitate access but do not contradict the privacy provisions of that earlier act. I wonder if you might comment on that.

Dr Allan—That raises a lot of issues but there are two in particular. There is one about the ability for the Commonwealth to legislate on things that really fall to the state. The first thing to address that question is that there a number of ways to deal with that. If you take the research on human embryos and cloning legislation that was passed nationally, they can only regulate on certain aspects of that and only based upon certain constitutional powers. What needed to happen then was that the states needed to pass mirror legislation to make sure that it covered everybody. There are certain powers within the Commonwealth to legislate on certain family matters. The Family Law Act is a Commonwealth act so you could look at powers there. All the states can actually assign their power to the Commonwealth for certain things. There are ways that the law operates that would enable a national system.

Senator PRATT—Okay.

Dr Allan—For privacy, as I said, you cannot just come in and say, ‘Donor conceived individuals have a legal right to access information,’ without recognising the issue of privacy for the donors from the seventies or the eighties because of the voluntary registries and the retrospectiveness of it all. Sometimes there is evidence of clear agreements where they were told that their anonymity would exist, so it is a privacy issue. The legal issue then becomes how you weigh those, and it is a clear legal principle in Australia that privacy is not absolute—the right to privacy is not absolute.

In fact, we do not clearly protect that; we do not have a tort for right to privacy, and there are many examples where privacy can be trumped by other considerations. If we look at family law; when we talk about people who were conceived through intercourse we can order DNA tests to establish that child’s biological history. I think you need to look at the privacy issue and ask, ‘Is it absolute?’

Senator PRATT—In a sense, that DNA is almost a precedent in that you can order a DNA test to prove that someone is the genetic parent of a child conceived through intercourse. So that is a precedent for anyone who is seeking to establish their genetic connections with someone else.

Dr Allan—I would also say that all of the adoption legislation acted retrospectively to allow people to seek access to information where people were guaranteed complete privacy and secrecy, and actually signed documents about that. There are more records which exist in that context than in the donor conception context.

When I went through the Office of the Privacy Commissioner's submission to the Senate I thought, 'If I look at every single thing that they have said they haven't actually set up an argument to say that this information cannot be released.' They have said that there are exceptions to release of information that pertain to health and identity; there are exceptions related to releasing information to genetically related individuals; and the thing that trumps it all is that if another law is passed that says this information can be released then whatever privacy protection does exist plays second fiddle, so to speak.

Senator PRATT—And in this instance it would only be the Commonwealth Privacy Act 1988 that is significant? I am not sure of the—

Dr Allan—There are also other state acts. There is a health information and privacy act in New South Wales that has similar provisions for when there is other competing legislation that enables the release of information and creates an exception to the criteria related to withholding information.

Just on that point, there are other arguments for information release that trump privacy concerns retrospectively as well. We do it in relation to any situation that may pose a risk to public health or interests. For example, we have mandatory reporting of people's HIV or communicable disease status. Or you can release private information to genetic relatives if they are at risk of certain conditions as well.

Senator PRATT—And a person conceived using this technology would not know if they were at genetic risk unless they have access to that information, so that is almost a precedent in and of itself.

Dr Allan—Exactly. If we look at the types of health risks we might be talking about, certainly there are health and lifestyle risks and heart disease. As we get more and more information about our genes we know how important that information is. Psychologically as well, we know that anybody with a history of mental disorders in their family are anywhere between three and seven times more likely to suffer psychological disorders. That is passed on to children. We have a whole body of people who could potentially fall into that category.

Senator PRATT—So in a sense there may be many donors out there who as they age are finding out this information about themselves but when their child contacts the clinic there is no way of connecting that information adequately currently.

Dr Allan—That is right.

Senator PRATT—There are some voluntary registers but there is no systemic way of people making those connections. The WA Department of Health says:

> … it could be said that health professionals are under a legal and ethical duty not to disclose confidential information concerning a patient which has been identified in the course of their professional attendance upon that patient. That legal duty may arise in contract or in equity. A third party who comes into possession of confidential information which he or she knows to be confidential falls under an obligation not to pass that information on to anyone else.

To what extent does being a donor qualify you as being a patient? Also, I suppose when you have a medical consultation there is an assumption that there is privacy attached to that, but from what we have been hearing in evidence the statement about whether it was actually a private contract is not in any sense clear.

Dr Allan—They seem to take that there is only one legal argument and that is that this information is completely private and we can back that up with contracts and equity law. There is a principle in equity law under breach of confidence where there may not exist a contract; there may exist a promise. If you look at breach of confidence there are again precedents where they say that the right to withhold information, even about somebody's identity, is not absolute. The case A v Hayden talks about the iniquity principle and talks about the situations in which private information can be released. In a different context there was a government contract with employees that they would not release their information. They were being trained for ASIO. They engaged in some activity that looked doubtful and the court said that in certain contexts again that that private information could be released.

In medical contexts in tort law there are examples. In the case of BT v Oei it was considered a duty of the doctor to go beyond the private information between the doctor and patient and inform the patient's spouse of that person's medical condition. So there are clear precedents that say that that argument is not absolute.

Senator PRATT—I want to go back to the question of state versus federal law. Births, deaths and marriages are clearly state law. To get the states to attach information to birth certificates about someone's genetic origins could only be done by uniform legislation I suspect. That would be the only way of doing that I would imagine.

Dr Allan—Yes. I think I said this is my submission. It is not just a question then of information release; it is also about trying to get as much openness as possible, so the birth certificate issue becomes quite important. You would have to have something, because that falls to the state, that uniformly makes all of the states do the same things.

Senator PRATT—But in the context of the remaining records that are not well regulated out there, would the Commonwealth have the power to mandate protection of those records in some way?

Dr Allan—I would have to look that up to find the actual legal principle and constitutional power that they would have. In terms of maintaining information, I think that is a crucial point now in the interim no matter what is decided to make sure no other records are destroyed and have some kind of decision that says that any information that is now held needs to be preserved. I am not sure under which power that they would operate.

Senator PRATT—If you have any advice that you would be able to provide to that end that would assist the committee in exploring that question, that would be terrific.

Senator CROSSIN—Thank you very much for the information in your submission about legislation in other countries—eight of them, by the look of things. Do all of those have things like a national register and outline what sort of access to information you can have and what is required on that register?

Dr Allan—The difficulty with looking abroad with these sorts of models is that they do not have the same federal system that we have with the states beneath them. They do, as far as I know, have national systems. They certainly stipulate what sort of information needs to be held, how it should be accessed, where it is held and the age of release. That is a very important issue as well. Some of them are as early as the age of 14. I think one of those countries does not stipulate an age at all provided there are proper support systems in place. So they do provide in conjunction quite good models for saying: ‘We have considered these issues. We have had these things in place for a long time and they are really important. This is how we do it.’

Senator CROSSIN—So there are international precedents to regulate what is happening in this area?

Dr Allan—Most definitely.

CHAIR—Dr Allan, thank you very much for your submission today. It is very thoughtful and appreciated.

[2.07 pm]

JACOBSEN, Dr Nyaree, Acting Manager, Reproductive Technology Unit, Department of Health, Western Australia

MIDFORD, Mrs Suzanne Maree, Chair, Reproductive Technology Council Counselling Committee, Department of Health, Western Australia

O'CALLAGHAN, Ms Jenny, Acting Manager, Office of the Chief Medical Officer, Department of Health, Western Australia

Evidence was taken via teleconference—

CHAIR—Before we begin our next session, I remind senators that the Senate has resolved that an officer of a department of the Commonwealth or of a state shall not be asked to give opinions on matters of policy and shall be given reasonable opportunity to refer questions asked of the officer to superior officers or to the minister. This resolution prohibits only questions asking for opinions on matters of policy and does not preclude questions asking for explanations of policies or factual questions about when and how policies were adopted. Officers of the department are also reminded that any claim that it may be contrary to the public interest to answer a question must be made by the minister and should be accompanied by a statement setting out the basis for the claim. At this juncture I welcome representatives of the Western Australian Department of Health. Do you have any comments to make on the capacity in which you appear?

Dr Jacobsen—I am a senior policy officer in the Department of Health for the Reproductive Technology Unit and under the Human Reproductive Technology Act I also have a role as acting executive officer of the Reproductive Technology Council.

CHAIR—Thank you. We have received your submission as No. 126. Do you wish to make any amendments or alterations to your submission? If there are no alterations or amendments to your submission, I invite you to make an opening statement at the conclusion of which we will invite members of the committee to ask questions.

Ms O'Callaghan—May we submit some written changes to our submission? We have identified some minor matters and I will be able to email that to the secretariat if you agree to accept the changes to our written submission.

CHAIR—Yes, we would be happy with that. Thank you.

Ms O'Callaghan—In terms of the submission on donor conception issues in Australia, I guess WA's position is that we have a reproductive technology register and we have legislation that means that children from the age of 16 years can access identifying information about their donor and non-identifying information prior to that time. We also have a voluntary register. That was set up in 2002 in recognition of the need for donor conceived persons to have access to identifying information about their biological origins. The two are separate and I understand that this committee is particularly interested in those on the reproductive register and the reproductive technology register's parameters.

Western Australia's Human Reproductive Technology Act 1991 regulates all ART practices and a significant amount of information is held on the reproductive technology registers. It is administered by the Department of Health and it would be the registers from which offspring would be able to access identifying information regarding their donor once they reach the age of 16. The registers were established in 1993 along with the act. The changes were made on 1 December 2004 when donor- conceived children were able to access the information about their origins. Our submission covers quite a lot of detail and we would be very happy to answer particular questions in relation to the submission.

CHAIR—Thank you. Mrs Midford and Dr Jacobsen, do you wish to make an opening statement or are you happy to start with questions?

Dr Jacobsen—We are happy to start with questions.

CHAIR—Would you give us a bit more detail about your register in Western Australia—for example, the information recorded, the information that can be released, the identifying information, who maintains it and any other details about it?

Dr Jacobsen—In terms of the reproductive technology register and information that may be released, the 2004 amendments allow a child, on reaching the age of 16, to access identifying information about their donor only for those donations made after 2004. It is a prospective rather than a retrospective release of information. However, if the donor consents, there is the capacity to provide that identifying information to a child before they are 16 if both the parents of the child and the donor consent to the release of the information. Jenny O'Callaghan will discuss what information is held on our registers with regard to the donors.

Ms O'Callaghan—Obviously the sex of the donor is recorded and we record name and date of birth. Other descriptive information recorded includes colour of hair; colour of eyes; complexion; build; height; marital status; occupation; religion; country of birth; ancestry, which is the ethnicity of grandparents; highest education level attained; personal and/or professional interests; the number of existing children; details of the person's health history; details of family history; the donor's blood group; reasons for participating in the donor program; and, then, there is an optional personal statement of about 100 words which can be attached. That is the donor information recorded and that is covered in the directions under the Human Reproductive Technology Act and can be found in its form V4 for donor information.

CHAIR—What about confidentiality? Do you want to add anything further to what you have said about maintaining confidentiality? We have the principles of the individual donor's right to know and then the donor himself or herself and their right to confidentiality. We have had a range of witnesses express the view that it should be retrospective and we are obviously aware of your position in Western Australia. I was not sure of the year you mentioned just then. What is your position on that?

Ms O'Callaghan—We had a select committee report done in 1999 which made some recommendations that led to some changes to our legislation in 2004. It was clear from the select committee evidence that people's opinion was that it could not be retrospective and that it could only be prospective requests for information that the legislative changes would accommodate. That, I guess, is the position in our legislation. An undertaking was given that information would not be made available retrospectively, and that was when the Western Australian government Department of Health decided to establish the voluntary register, which was done in 2002. That means that people who want to share their information—that is, donors and other participants—can join that register. When there is a match made of the donor number with the participant number, counselling is provided and that may then proceed to the sharing of information. That is for the voluntary register. In terms of our actual registers and our HRT Act, section 49 of the act has quite strict conditions around confidentiality and they would need to be adhered to, from the perspective of Western Australia, at this time.

CHAIR—We have been trying to get estimates of how many donor conceived individuals there are in Australia. Firstly, do you know how many there are per year? Secondly, how many in Western Australia are there and how many per year?

Ms O'Callaghan—That is information that I would need to provide to you, perhaps in written form later, if you were able to pose those questions in writing. Our register would capture that information so we could let you know.

CHAIR—That would be very much appreciated. We are happy for you to take that on notice.

Ms O'Callaghan—That information has been recorded in WA since 1991 with the establishment of the RT register. Before that we would not be able to say how many donor conceived children there were in this state.

CHAIR—Okay. We had a change in the law in 2002 with the Federal Court case of McBain where that Federal Court struck down the federal law and said that it was discriminatory if these services were offered to people in a single-women or homosexual relationship other than being in a heterosexual relationship whether it was inconsistent with state law or not. I am interested to know if you have any numbers on how many—again, I am happy for you to take it on notice—of the donor conceived individuals going to a heterosexual relationship or any other type of relationship and if you can break it down, again on notice, into single mothers or same-sex relationships or heterosexual relationships and marriage relationships. Are you are able to break that down for us?

Ms O'Callaghan—On notice we may be able to tell you information about married couples or couples in a de facto relationship. We would also be able to tell you single women who are treated under the HRT Act.

CHAIR—Thank you very much.

Ms O'Callaghan—However that is not going to identify necessarily those women in a same-sex relationship.

CHAIR—To the extent that you can provide that information, that would be appreciated.

Senator CROSSIN—In relation to page 3 of your submission, access to information held under the RT registers is not permitted unless one falls within one of the exceptions set out in sections 46 or 49. In section 46, essentially, you have to meet that criteria in order to access the register. Is that right?

Ms O'Callaghan—Yes. To access any information under the HRT Act and information collected in the reproductive technology register the criteria would need to be met.

Senator CROSSIN—In Western Australia can you only donate if you agree for your identity to be released?

Ms O'Callaghan—Essentially, yes, you are given information. Information about counselling is provided to donors of semen, eggs and/or embryos or eggs undergoing fertilisation. Information must be given by the licensee encouraging the donor to seek assistance with decision making and counselling in preparation for donation and also provide information about the possible impacts of becoming a donor.

Senator CROSSIN—Is the possible impact of becoming mean that you must, not optional but must, be prepared to release your identify if the donor conceived person request it?

Ms O'Callaghan—Actually you would not be releasing it. The information is collected on the reproductive technology register and the registrar of the registers would release that information. Yes, in consenting to donate, you are given the information about the implications of your donation and that is that your identifying information will be shared once the child reaches the age of 16 years. I am talking about donations after 2004.

Senator CROSSIN—Yes. I would like to address the way in which fertility clinics operate in Western Australia. There are the NHMRC guidelines, and I think it is RTAC who actually registers those clinics, but is there any particular requirement under the WA act in relation to how those clinics operate and the relationship between RTAC and the guidelines?

Ms O'Callaghan—You cannot be licensed unless you meet the RTAC accreditation requirements. You must also comply with NHMRC guidelines. To obtain a licence you must meet the requirements under the HRT Act, which are more onerous than the other two but which sit alongside or over the top of those other regulations.

Senator CROSSIN—Who polices or monitors that? What quality control is there and what penalties are there if you breach any of that?

Ms O'Callaghan—You have asked a fairly complex question. The licensing process is essentially administered by the reproductive technology unit in the Department of Health. The licences are issued by the CEO—who is in fact the Director General—of the Department of Health on recommendation from the reproductive technology unit and the council. So there is a fairly thorough assessment of a whole range of information. They must also have RTAC accreditation. But they must meet the requirements under the HRT Act as well. So that includes information being given to the reproductive technology register and council's fairly close scrutiny of things like information brochures, consent forms and the policies and procedures of the clinics. That is done prior to licensing. There is a three-year cycle for licensing. There is a penalty in terms of if they are not meeting the requirements or if there are omissions in the information that we are requesting then the clinics are notified and given an opportunity—obviously, as with their RTAC accreditation—to rectify the situation. That can then proceed to licensing.

Senator CROSSIN—So there is a three-year cycle of licensing but in the meantime is somebody in the Department of Health charged with ensuring there is compliance with the act and seeing that there is consistency across the clinics?

Ms O'Callaghan—Yes, there is. Both the Reproductive Technology Council and the reproductive technology unit require information about quite a number of procedures—things like embryo storage, permission to go ahead with pre-implantation, genetic diagnosis, export of donor material from WA and import of donor material to WA. All of these things are covered under the HRT Act and there is a process for monitoring this. The licensees well understand that they must meet the requirements under the HRT Act in order to continue with their licence.

Senator CROSSIN—Currently under your act a donor conceived person has the right to access non-identifying information. Do they have the automatic right, though, to access identifying information, or can they only access that information if the donor agrees?

Ms O'Callaghan—They can access that information once they turn 16, but that is only for children born from material that was collected or used after 2004.

Senator CROSSIN—You have got in your submission 'provided that each donor and recipient consents'. But what if the donor does not consent?

Ms O'Callaghan—The donation is not collected and the donor material will not be used.

Senator CROSSIN—That is what I am trying to get at. If, even after 2004, the donor does not consent to the identifying information being shared then why do they become a donor in the first place?

Ms O'Callaghan—They do not.

Senator CROSSIN—I am just clarifying your submission then.

Ms O'Callaghan—The clinic would not accept the donation of someone who does not consent to the sharing of the information. This is after 2004. There may well be donors who donated prior to 2004 where the families are seeking to create siblings for existing children, and the donor has not consented for his or her identifying information to be released.

Senator CROSSIN—I understand that. It is just that your second last paragraph on your last page is not clear that if you do not consent to identifying information being released after 2004 you are not accepted as a donor. Could you clarify that for the *Hansard*.

Ms O'Callaghan—This is on the last page, on page 7?

Senator CROSSIN—Yes, it is the second last paragraph.

Dr Jacobsen—I will just reiterate our position. After 2004, when a donor has provided donor material, whether that is sperm or eggs, they are provided with information that sets out that their identifying information must be released when a child reaches 16 years of age. If they do not accept that condition then the donation does not proceed. In terms of non-identifying information, they can access non-identifying information prior to 16 years of age, or with donor consent they can access identifying information before they reach 16 years of age. The consent to the release of identifying information is implied because that information must be given to the donor before the donation is accepted in WA. That is after 2004.

Prior to 2004, donations were not made with that requirement. If they wish to remain anonymous, our legislation does not retrospectively seek their identifying information for release unless they consent to it. The voluntary register was set up to allow that consent process to be made.

Senator CROSSIN—Under your legislation would you say the main focus is on the rights of donor conceived individuals or the rights of donors?

Dr Jacobsen—We are very much focused on the rights of donor conceived individuals. Our legislation is very concerned that donor conceived individuals be able to access identifying information about their genetic origins.

Senator CROSSIN—Okay. Thanks.

Senator PRATT—I note you have a voluntary register for donor conceived individuals before 2004. Some donor conceived individuals who are concerned about their origins and want more information are asking for access to schemes that are more like, for example, what is currently put into place for previous adoption practices in Western Australia, where that information is to be released but it is to be maintained with a contact veto in place if someone wishes to uphold their privacy. Has such an approach been considered at all?

Ms O’Callaghan—No. As Sue Midford confirmed, no-one has actually requested that.

Senator PRATT—That was my next question. Clearly, you have put some reforms in place that were effective as of 2004. What was the history of the kinds of concerns that people were bringing, and do you have a consultation process in place to stay up to date with what the wishes of donor conceived individuals might be today?

Ms O’Callaghan—I am not sure that we heard all of your question.

Senator PRATT—What consultation processes do you have in place for staying up to speed with what donor conceived individuals might wish today, as far as their legal entitlements go? I also appreciate that you just said that you had not had any requests, or that there had not yet been any lobbying, for a change to those pre-2004 practices in Western Australia.

Ms O’Callaghan—There is consumer representation on the council. The council is very happy to hear from consumers. The council and the reproductive technology unit seek the views of consumers. In relation to this particular issue, my history is only really in the last three years. Our focus in terms of legislative change has been on our surrogacy legislation and certainly we sought the views of consumers around that particular issue. The issue of donation for donor conception is something that the council has on its agenda, as does the reproductive technology unit, to continue to seek the views of consumers, to promote the voluntary register and information that will be available for children after 16 years of age from the reproductive technology register.

Senator PRATT—How would you distinguish consumers? I assume the consumers are those requesting access to a service as opposed to donor conceived individuals who, I assume, you do not consider to be consumers but who might have representation on the council?

Ms O’Callaghan—We do not have a donor conceived person on the council. Certainly, if such a person indicated an interest we would consider hearing their views. We just have not had an approach from someone with that background. I will let Sue Midford explain about the council.

Mrs Midford—I have been on the council for a long time, and I was around when we did a number of seminars and sought the opinion of different people. We have actively sought over the years to have consumers of all three kinds—donors, recipients and offspring—participate. It has been really hard to get offspring to participate, and we worked really hard to get them. We have managed to find some for our seminars and public meetings—in one case we brought someone in from another state to talk. So we have actively sought that representation but we have no-one. The council would not in any way object to the input. As I have said, we have actively sought input from donor conceived adults. As far as I know, there is no-one around.

Senator PRATT—Currently the only access to identifying information, as I understand it, would be through the voluntary register. Behind that, what actions were taken to protect records held by clinics or other parties to underpin information that might appear on that voluntary register?

Ms O’Callaghan—Until the Human Reproductive Technology Act 1991, there was no legislation that meant that clinics needed to hold that information. Subsequent to this legislation being passed and enacted, clinics are obliged to hold records regarding anyone who is a participant in a donor procedure.

Senator PRATT—But in terms of what records did exist, was there retrospective legislation to capture what remaining records there were?

Ms O’Callaghan—No, that is not my understanding.

Senator PRATT—What is the status of those records prior to 2004 for genetic material and its origins.

Ms O’Callaghan—I guess they were under the NHMRC guidelines.

Dr Jacobsen—Just to clarify that, the register captures information from 1993 and that information is still held, so all donor participant and recipient information has been held on the register since 1993. The information prior to the Human Reproductive Technology Act 1991 is kept in clinics, but there was no legislation that requires those records to be captured by the RT register before that date. So there is no retrospective collection of data that goes back beyond 1993, which is when the RT registers were established. In 2004 the register information is still the same; however, the release of that information to donor offspring can be facilitated by the current legislation—after 2004.

Ms O’Callaghan—In 1999 the Select Committee on Human Reproductive Technology did actually look at the issue of retrospective access to information and sought the views of members of the public, licensees and other bodies regarding this and formed the view that we would proceed with the legislation as we have it now—amended. So, after 16, it is not retrospective. It is only from 2004 that donor information could be released to donor offspring.

Senator PRATT—If someone who was conceived in the late 1980s or earlier using donated gametes and they were looking for information, I am a little unclear as to what process they would go through to try to access any remaining information, if it exists.

Ms O’Callaghan—They would need to contact the clinic where the procedure was undertaken directly, or the doctor.

Senator PRATT—So Western Australia did not do anything to capture what was left of that information prior to 1993 but did so for anything post 1993. Is that the right date mark?

Ms O’Callaghan—That is true. I would say, though, that the voluntary register may in fact capture people conceived before the HRT act came into being and the registers came into being, in 2003.

Senator PRATT—What information is used to underpin that voluntary register? Is that information voluntarily put forward by the clinics or did you mandate, in some way, retention of that information to support—

Ms O’Callaghan—We have not mandated retention of information prior to the establishment of the registers. We did not do that.

Senator PRATT—I want to ask about the statements about privacy in the submission. We have had some debate about this on the committee and in evidence, as to the extent to which people making donations perceive that that is indeed something that is private information. Was there any legal status to the privacy provisions of those donations prior to 1993?

Ms O’Callaghan—I am sorry; I am not entirely clear what you are asking. Could you repeat the question?

Senator PRATT—We have had some scenarios put to us—and these are not necessarily Western Australian; I am interested to see the extent to which they would apply in Western Australia—where donor conceived individuals have through other means made contact with their biological parent and that parent has said, ‘I was never concerned about my privacy; I would have been free for you to make contact with me,’ but when those donor conceived individuals have sought to access that same information through the clinic they have been told, ‘We can’t do that because of privacy concerns.’ As I understand it, the actions you have taken in putting a voluntary register together would overcome many of those things, but I am interested in the extent to which that would still be the case in Western Australia.

Ms O'Callaghan—It is under section 46 of the HRT Act, 'Access to information'.

Senator PRATT—This is the act as it was prior to 1993?

Ms O'Callaghan—It is only after 2004.

Senator PRATT—I beg your pardon, 2004.

Ms O'Callaghan—Prior to 2004 and from the establishment of the voluntary register in 2002, there is nothing that WA has in place that will allow information to be shared from the reproductive technology register. In fact, the legislation precludes us sharing that information.

Senator PRATT—Who mandates that information being private? Is it the clinic itself? Is it the law? The contract with the donor, in a sense, is irrelevant. It is simply that the law states it is private information.

Ms O'Callaghan—This is prior to 2004?

Senator PRATT—Yes.

Ms O'Callaghan—I think from 2001—but I would need to take some advice on this—essentially requirements around confidentiality are pretty much the same. What happened in 2004 was that greater sharing of information, allowing donor conceived children to have access to information about their origins, was enshrined in the legislation, and donors understood, in donating, that that information would be shared once the child reached 16. But the confidentiality limitations probably applied in much the same way as they have in the act post 2004, and that is, as it says in section 49(1), 'Confidentiality':

> A person shall not divulge, or communicate to any other person, any information disclosed or obtained by reason of this Act respecting the identity of—(a) a donor of human gametes, a human egg undergoing fertilisation or a human embryo;
>
> (b) a participant in any procedure involving reproductive technology; or
>
> (c) a child born as a result of any artificial fertilisation procedure,
>
> unless subsection (2) applies.

Senator PRATT—What seems to have happened across the country—and I would be interested to know whether this is happening in WA or the extent to which people have not asked the question—is that because that is the status of the law, when people request information from clinics they are simply given the answer: 'This information is private and confidential by law and therefore we cannot give it to you without a request of the donor as to whether they are willing to make that contact ever actually being made.' So I suppose the law stands on its own in opposition to what the actual issues of the donor and the donor conceived person may be. I understand that the registry you have would help overcome some of those issues, but it is certainly not the case in many other states. Would that be a true observation?

Ms O'Callaghan—I think that is a true observation. Our voluntary register is an attempt to capture those people who are interested in sharing information. Our clinics are informed and encouraged to direct people to the voluntary register if they are making inquiries.

Senator PRATT—In terms of the voluntary register, does it enable siblings to find each other, irrespective of whether the genetic parent does not want to be identified?

Ms O'Callaghan—Yes, it does. It allows participants who are registered on the voluntary register to share information about themselves.

Senator PRATT—Finally, I think we have covered this already, but you have not found any pressure to possibly take the next step to release information but put a contact veto in place? You have not had to respond to demands like that because you found that people in Western Australia have not asked for that information?

Ms O'Callaghan—We have not found that.

Senator PRATT—What happens when someone is seeking information on the voluntary register and their donor declines? What is happening to those people who reach a blank when they access the voluntary register?

Ms O'Callaghan—I guess that reaching a blank can be interpreted as no other parties are registered, in which case they are informed: 'At this stage, no other parties are registered. We will continue to hold your information and, should any other parties join the voluntary register, we will contact you again and seek your opinion about information that you may want shared.'

Senator PRATT—With respect to the parties that most commonly come forward to put their information on the register, what is the balance between donors and donor offspring?

Ms O'Callaghan—We have relatively few donors and relatively few offspring, remembering that the offspring are fairly young. We could perhaps give you those numbers, but the predominant number of people who are registering on the voluntary register are parents of donor conceived offspring who are seeking contact with other parents of donor conceived offspring.

Senator PRATT—In terms of, say, parallels of adoption where if someone seeks to make contact then the state has an obligation to try to find that party, the voluntary register is purely voluntary. So if someone puts themselves on the register then the register itself does not seek to find the other party. It is only if that party comes forward that people find themselves on the register. Is that what you are saying?

Ms O'Callaghan—That is true. What we attempt to do is, at least annually, advertise the voluntary register. We encourage people to refer to the voluntary register should they have any inquiries.

CHAIR—Thank you to the witnesses in Western Australia. It is very much appreciated.

Ms O’Callaghan—We would be very happy to have any questions in writing if you wish to seek further clarification.

CHAIR—I think you have taken some questions on notice, so you can liaise with our committee secretariat regarding that if you think you need to. Otherwise, we look forward to hearing from you. Thank you.

Ms O’Callaghan—Thank you.

[2.54 pm]

BOWMAN, Dr Mark, Vice President, Fertility Society of Australia

ILLINGWORTH, Associate Professor Peter, President, Fertility Society of Australia

CHAIR—Welcome, and thank you for being here. We have your submission, which we have labelled No. 106. Do you have any changes or amendments to it?

Prof. Illingworth—No.

Dr Bowman—No.

CHAIR—I now invite you to make an opening statement after which we will have questions.

Prof. Illingworth—We thank the inquiry for the opportunity to represent the Fertility Society, which is the society for professionals in assisted reproduction and the patented body for RTAC, the Reproductive Technology Accreditation Committee. Thirty years ago when this all began, everybody involved at that time from all over the world—the doctors and scientists delivering the care, all the couples who sought this treatment to have their family, the politicians and the legislative bodies—supported the principle of anonymous sperm donation. All of this changed when the first children began to approach adulthood and discovered the profound sense of loss, which they have expressed, of not knowing their genetic or biologic antecedents. We have all listened to these people—then children, now adults—and have recognised the wrongs that have been done and resolved not to repeat the mistakes of the past.

We would like to make a few specific points—firstly, that 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 clinical accreditation to the RTAC code of practice by independent assessors. We are particularly supportive of the current state legislations, which we believe do a good job of regulating fertility care in a balanced and public manner, although we do have concerns about aspects of some state laws where access to fertility treatment is limited in a discriminatory manner.

We support the establishment of public donor registries, both prospective compulsory registries and voluntary retrospective registries, including in those states which do not currently have it. At present 70 per cent of treatment cycles in Australia involving donated gametes take place in states with legislation and statutory donor registries. We are, however, strongly opposed to compulsory retrospective registries as, in our view, this would be a violation of the privacy of sperm donors who have, in good faith, agreed to make altruistic donations to help other families have children. We believe that the way forward for dealing with this very serious issue is by families, clinics and regulatory bodies working together and using some of the mechanisms that have already been discussed today to develop and support better voluntary registers.

We do have some concerns about national legislation, as we see little evidence that state governments are going to relinquish legislation in this area and believe that duplicate legislation 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. Nowadays 1,000 babies are born every year in Australia as a result of the truly generous gift of donated gametes and embryos. Nowadays, these children are conceived only after careful counselling of all participants about the long-term implications of the decisions being made and are born into a modern environment of openness and disclosure of identifying information. These children add immeasurably to the happiness of the Australian families into which they are born and will, in the vast majority of cases, look forward to happy and fulfilled future lives within stable families.

Finally, over the past few days you have heard many distressing and painful stories about the difficulties that have arisen from the practices of the past. Clearly, we all—professionals, legislators and families—need to work together to repair the damage.

CHAIR—Thank you very much. Dr Bowman, would you like to add anything to that?

Dr Bowman—I think that summarises things pretty well, except to add personally that we sit here as a society of health practitioners—doctors in our case—doctors, nurses and counsellors, whose primary motive has always been, both in the past and today, to alleviate suffering and to help people. I found it a privilege to listen to the stories from the donor conceived individuals this morning. I mean that sincerely. Nobody wants ever to hear those stories apply to anybody in the future again. As a society and as a craft group, if you like, we have worked very hard, and continue to work very hard, to ensure that the current environment is quite different to the previous one.

CHAIR—Thank you for that.

Senator CROSSIN—Thank you for your submission and to you both for coming. Who are the members of RTAC?

Prof. Illingworth—RTAC is a committee which involves scientists, doctors, counsellors and consumers who oversee the process of the accreditation system. But the actual assessments themselves are done by professional independent assessors under an assessment system accredited to JAS-ANZ, the Joint Accreditation System of Australia and New Zealand.

In the past, we did have a system whereby counsellors and consumers would go into each other’s clinics and review their practices. About three years ago it became clear that this was not tenable in the long run and we moved to a much more independent assessment process where professional assessors assess clinics against the defined code of practice. We have a technical committee to establish the scheme rules for that, and to which we have invited representation from all of the state governments, the Commonwealth’s NHMRC, the HIC and the Department of Health and Ageing.

Senator CROSSIN—Who do you define as ‘consumers’?

Prof. Illingworth—We have representation from AccessA, which is the Australian consumers’ association for patients experiencing fertility problems.

Senator CROSSIN—So you do not have any donor conceived people involved in RTAC?

Prof. Illingworth—No, we do not.

CHAIR—Can you on notice, if you cannot do it now, tell us exactly who is on RTAC? I would like to know exactly who is on RTAC and also exactly who is on your technology committee and any other committees you have. Could you advise us exactly who they are?

Prof. Illingworth—Of course. We have quite a lot of committees doing functions which are not directly related to this. We can certainly supply you with the details of full RTAC membership and the technical committee membership.

Senator CROSSIN—Can individual fertility clinics be represented on RTAC, or their clinical supervisors or CEOs? Are they directly on RTAC?

Prof. Illingworth—No. The people who are appointed to RTAC are elected by their peer groups. There is a counsellor who is elected by the counsellors around Australia and there is an embryologist who is elected by the embryologists' group around Australia; people cannot just nominate themselves to be on RTAC.

Senator CROSSIN—The CEO of a fertility clinic in, let us say, Wollongong in New South Wales would not be there by virtue of their connection with the clinic, they would be there because they were elected by their peers. Is that right?

Prof. Illingworth—There are no CEOs on RTAC.

Senator CROSSIN—So when RTAC actually goes to accredit and license an individual clinic, who undertakes that assessment?

Prof. Illingworth—Independent assessors, who are accountable to JAS-ANZ, the joint—

Senator CROSSIN—Who are they? What is an independent—

Prof. Illingworth—There are firms of independent assessors, who are accredited by JAS-ANZ to carry out these assessments.

Senator CROSSIN—Can you give me the names of some of these firms?

Prof. Illingworth—SAI Global is one firm and Benchmark is another firm.

Senator CROSSIN—Do they have interests in the fertility clinics?

Prof. Illingworth—No.

CHAIR—They are private businesses, are they?

Prof. Illingworth—They are private businesses.

CHAIR—What is their expertise?

Prof. Illingworth—Their expertise is in accreditation. They will hire a technical expert who has no financial interest in the clinic being assessed.

CHAIR—But they are paid for their work?

Prof. Illingworth—Yes, they are.

CHAIR—By whom?

Dr Bowman—They assess against the standards. There is a code of practice and a series of standards backed up by technical documents that they then check.

CHAIR—Who pays their bills?

Prof. Illingworth—The clinic does. In exactly the same way as ISO quality systems operate all around the world—it is a quality system.

Senator CROSSIN—Yes, I understand that. There are also the NHMRC guidelines, but there is no overarching national legislation, or even regulations that guide the accreditation and assessment of these clinics other than the NHMRC guidelines. Is that correct?

Prof. Illingworth—The NHMRC guidelines are a criterion by which the clinics are assessed. They are required to demonstrate compliance with the NHMRC guidelines.

Senator CROSSIN—They are not enforceable guidelines.

Prof. Illingworth—If the clinic is noncompliant with the NHMRC guidelines, they will not be compliant with their RTAC accreditation and if they are not complied with their RTAC accreditation they are not allowed to practise under Commonwealth legislation.

Senator CROSSIN—Who ensures the consistency of guidelines being implemented from one clinic to another, from New South Wales to WA? Who ensures that there is consistency?

Prof. Illingworth—Each clinic is assessed individually for their compliance with the NHMRC guidelines.

Senator CROSSIN—Clearly, though, if you read the many hundreds of submissions we have got and if you listen to the evidence we have had over the last three days, people believe and have evidence that there are significant gaps in what you have just outlined to us. People actually do not believe that and have evidence of being treated differently by different clinics, information on registers being different and the access to information being treated differently, compliance with access to information fob-offs by other clinics. So clearly the model you are outlining, and I am not laying any blame here on the Fertility Society of Australia, but clearly the professional ethical model your are outlining to us is not working or else we would not hear such strong negative critique of the system. Where do you believe there are gaps in what is happening?

Prof. Illingworth—Let me make two points. The first is that 70 per cent of treatment nowadays is done under statutory legislation and it is likely and we would strongly support a process whereby 100 per cent of treatment is carried out under statutory legislation—

Senator CROSSIN—Let me interrupt you there. What you are saying therefore is that most treatments are being provided in the states that have legislation as opposed to the states that do not have legislation.

Prof. Illingworth—That is correct.

Senator CROSSIN—But that is not a reason for me to suggest that things are okay.

Prof. Illingworth—I understand that point. There are also large aspects of how clinics interact with the individuals who come to them either to seek assistance or information that fall outside the terms of legislation or of ethical guidelines. For example, how helpful are you to someone who comes looking for information about old case records? There are different ways of handling that. There are ways that are good, where you are open and open the books as far as you possibly can, and there are ways that are bad. There are bound to be examples in such a large-scale activity as this of individual examples where things simply do not work well, but that bears little relationship to a regulation or an ethical guideline.

Senator CROSSIN—People would strongly differ, I think, with that sentiment. If in fact you looked at the rights of donor conceived people who say that they want absolute access to those records, there is no national legislation that underpins what must be asked by a donor when they go to donate, what must be agreed to by that person and then what must be shown to a donor conceived individual. We have heard that it happens in WA but I put it to you that it does not happen, for example, in my home state of the Northern Territory. The fact that there are differences between clinics, yes, but there will not be any uniformity in the way in which clinics treat people unless it is underwritten by national consistency in legislation, I would have thought.

Prof. Illingworth—You are dealing with the Northern Territory, where there is no legislation. The same applies to Queensland, Canberra and Tasmania. We are supportive of there being legislation around. The issue in the states which have legislation, if you look at the core elements of the data that the states are required to store and provide, the core elements are broadly very similar. They relate to the full medical history of the donor, they relate to identifying physical information about the donor, they relate to the full details of identity of the donor, they relate to family history, the very critical step of recording the donors’ family histories.

Senator CROSSIN—But it does not in all places go to the donor consenting to their identity being provided if it is asked of by the donor conceived person.

Prof. Illingworth—RTAC are required to specifically assess that no donor treatment should take place in Australia nowadays without the donor giving their consent to the release of identifying information further down the track to the donor conceived individuals.

Senator CROSSIN—If it is requested?

Prof. Illingworth—That is correct.

Senator CROSSIN—How do you know that that is happening in every clinic?

Prof. Illingworth—That is specifically assessed at every RTAC assessment. There are provisions for that. Every time an RTAC assessing group goes in the RTAC assessing group seek from the national database a set of case-note numbers of donor cycles that have been recorded with the national database. It is up to the assessors to look at the consent forms in all those notes to ensure that consent to the release of identifying information has been given by the donor in every case. For a clinic not to be able to provide that information would be a serious breach of the RTAC code of practice and they would be required to take corrective action within 48 hours to remedy that.

Senator CROSSIN—What is your view about regulating donor sperm that is imported from overseas?

Prof. Illingworth—Let me give you to two separate answers to that question. The first is that the FSA is not opposed to regulation. The situation in the United States works very well where there is a combination of statutory regulation and statutory donor registries. The FSA is not opposed to statutory regulation. The issue around imported sperm is a complex one. There is a variety of views even within the Fertility Society about the pros and cons of this sort of approach. It is not true to suggest, as was raised earlier today, that the majority of donor gamete treatment in this country is through the use of imported sperm. Most clinics in Australia do not use sperm that has been imported from overseas. However, there are situations, particularly with ethnically diverse families, where the use of imported sperm may be the only option couples have to have a family. In deciding whether to use sperm that has been donated overseas, clinics have to weigh up the interests of the couples in front of them who trying to have a family against the long-term interests of the children who have been conceived from donor gametes.

The way that clinics have approached this and the way that RTAC approaches this is to ensure that every clinic which provides treatment with donated gametes, whether the treatment uses gametes imported from overseas or gametes donated locally, provides treatment that is compliant with respect to NHMRC guidelines, state legislation and Commonwealth legislation, which prohibits payment of donors. Clinics will be assessed as to whether the donor has given his consent for identifying the information to be later released. Clinics will be assessed as to whether they have a traceability process.

Senator CROSSIN—You are saying that no-one can import sperm from overseas to be used to conceive individuals unless that donor, no matter what country they are in, agrees for their identification to be released?

Prof. Illingworth—That is correct.

Senator CROSSIN—How do you ensure that that is happening? How do you know that that is happening?

Prof. Illingworth—I will go back one step to explain the situation more clearly. All RTAC accredited clinics are required to send a record of every treatment cycle using either IVF or donated sperm through artificial insemination to the national perinatal statistics unit with a number of data items in that set.

Senator CROSSIN—How often are they asked to do that?

Prof. Illingworth—They are asked to make a return every six months on that basis. Whenever RTAC goes to assess a clinic, they assess two aspects of that. Firstly, they assess that that is a complete record of all the treatment that has gone on in that clinic and, secondly, they are supplied with a set of clinic record numbers, selected at random from the donor treatment cycles carried out in that clinic.

Senator CROSSIN—Who holds that information?

Prof. Illingworth—That information is held by PRERU, which is the national clinical statistics unit of Australia. The database is at the University of New South Wales. It is an independent body. It is a confidential database that is held securely. It is the main source of records—

Senator CROSSIN—So a donor conceived individual trying to track who their biological father might be, for example, cannot access that database?

Prof. Illingworth—Correct.

Senator CROSSIN—Why not?

Prof. Illingworth—Because the processes are not in place to allow that. It is a confidential record.

Senator CROSSIN—But if I am supposed to be able to approach the clinic and find out who my biological father is, and you are telling me that the clinic should have all of that information, I would not need to go to university.

Prof. Illingworth—Precisely.

Dr Bowman—But the university does not have donors' names. It basically has a record that says: this was a pregnancy that occurred either by IVF or by donor insemination and either had donor eggs or sperm involved.

Senator CROSSIN—That is a different matter, isn't it? I am talking about when sperm enters this country how do we know that the person who has donated that sperm has agreed for that to happen? Do you only then check that if there is a successful pregnancy?

Prof. Illingworth—No, not at all. What happens is that the clinics are assessed for their compliance with the code of practice, and they are assessed for their compliance with the code of practice by assessors who receive the case numbers for a random set of case numbers of donor treatment cycles that have been carried out in that clinic. So when they go in to do the assessment they have a list of somewhere between 10 and 20 case numbers of cycles that have been reported using donor-donated gametes of one kind or another. They are then required to go through the case notes of those case note numbers and check that the relevant consent forms are in place and that in every case the donor has given his or her consent for the release of identifying information to the children conceived from that treatment.

Senator CROSSIN—And what is the penalty if they are not there?

Prof. Illingworth—If they are not there the clinic is in non-compliance with the code of practice.

Senator CROSSIN—But they can still practise—the very next day they can keep practising—or does the clinic immediately have its licence suspended?

Prof. Illingworth—There has to be a formal process. You cannot immediately stop a clinic practising.

Senator CROSSIN—Who is in charge of that?

Prof. Illingworth—There has to be a formal process. All of that is set out in the scheme rules, which are approved by the technical committee which includes representation of external stakeholders including legislative bodies, and the NHMRC and other bodies that are on that committee. Under that process the clinic has 48 hours to reply to non-compliance. The non-compliance is reviewed by the assessors under the auspices of JAS-ANZ, the Joint Accreditation Society of Australia and New Zealand, according to the scheme rules which are identical to those, for example, of an ISO accreditation. If the clinic is unable to achieve a compliance with that within 48 hour, then they risk having their RTAC accreditation revoked.

Senator CROSSIN—Who does RTAC report to?

Prof. Illingworth—RTAC itself is a subcommittee of the Fertility Society of Australia, but the accreditation—

Senator CROSSIN—They report to you?

Prof. Illingworth—It is a subcommittee of our society, that is correct.

Senator CROSSIN—So it is not governed by any legislation in the way it operates? It does not have to provide an annual report to you?

Prof. Illingworth—No. The point that you are making that it is not governed by any legislation is a valid concern. It was a valid concern that was raised a few years ago by many stakeholders in the fertility treatment process and it was as a consequence of that that the processes under which the assessments operate were put under the auspices of JAS-ANZ, the Joint Accreditation Society of Australia and New Zealand. So the processes by which the assessments take place by which the non-compliances are monitored are those of JAS-ANZ. As the president of the FSA, I have no say on any individual assessments; I have no say on the details of a clinic's performance or how a clinic—

Senator CROSSIN—If they are a subcommittee of your society, do they provide an annual report?

Prof. Illingworth—They do. They provide a report to our society.

Senator CROSSIN—Can you provide us with the latest copy of their annual report?

Prof. Illingworth—I think it is a verbal report. But I can provide you with the processes by which RTAC operates and with a list of all the clinics that are accredited by RTAC, and I can provide you with a list of the membership of RTAC.

Senator CROSSIN—We will have all of those, but what you are saying to me is that RTAC's work or annual reporting is not publicly available.

Prof. Illingworth—But there is no other annual reporting. The role of RTAC is to set a code of practice. That code of practice is publicly available. The scheme rules under which the assessments take place are publicly available.

Senator CROSSIN—All right but we are talking about a body here that has the power to regulate or not regulate fertility clinics, which then have the power to create or not create life in this country, and yet it does not provide a public annual report, it is not accountable to any Commonwealth agency or department and not subject to any federal legislation. We would not have the same situation with our pharmaceuticals in this country would we? We would not allow the Therapeutic Goods Administration to just report to a society and tell us that the drug they have tested is okay.

Prof. Illingworth—The process under which the clinics are accredited is accountable to JAS-ANZ. The process around which RTAC runs—

Senator CROSSIN—Who is JAS-ANZ accountable to?

Prof. Illingworth—JAS-ANZ is a federal body. It is the Joint Accreditation System of Australia and New Zealand. It is a recognised accreditation system to the federal government.

Senator CROSSIN—Underpinned by legislation.

Prof. Illingworth—It is underpinned by legislation. It was under the government recommendations from the Department of Health and Ageing that we moved to that system. It was under recommendations from the governments of both Australia and New Zealand that we moved to that system.

Senator CROSSIN—Does RTAC report to them in writing every six or 12 months?

Prof. Illingworth—RTAC is not doing the assessing. It is the assessing bodies that are doing the assessing and the assessments are under the auspices of JAS-ANZ. RTAC's role is to write the code of practice. The code of practice is a public document. RTAC has been around and doing this function for 25 years. We have done it in consultation with governments. We have regularly had inputs from governments on how it should operate. Governments have generally said to us that they are happy with the way that RTAC functions. You have already heard evidence from the NHMRC that they are happy with the mode by which RTAC functions. We do not operate in isolation.

Senator CROSSIN—No, but if you read the many hundreds of submissions that this inquiry has been given and if you look at the representation we have had from consumers in this area, particularly donor conceived people who ought to be and as they are saying to us should be at the very core and essence of what drives what you do because they are the outcomes, clearly what we have seen over the last three days—and my colleagues might have a different view—is that this is not a system that is well regulated, open, accountable and transparent. People are particularly unhappy and frustrated with what is happening.

Dr Bowman—But are we not referring to practices that were in the past not the current practices that have been in now for some years? There is a distinction between our current regulatory and accreditation processes, which we recognised as an industry body needed to be evolved and developed. So someone bringing a grievance and being unable to resolve a problem that emerged 20 years ago is quite different from our current legislative, accredited and other practices moving forward which we believe are robust in a prospective sense.

Senator CROSSIN—Go back and have a look at the transcript but we are hearing about people who are unhappy from one year ago, five years ago and 10 years ago. Clearly, what I am trying to get to the bottom of is whether you think there are still gaps in the system. I think I am hearing from you that you do not believe that there are any gaps in the system now.

Prof. Illingworth—No, we would argue because of the state based nature of legislation that there are state-by-state variances but, nonetheless, where states do have legislation that process we believe is now working well. We would support the concept of having those remaining states also move to similar processes.

Senator PRATT—You have said, Dr Bowman, that there are problems relating to past practices. I put it to you that you are in the business of creating lives and relationships that last people for their whole lives long. In that sense, the regulations we have today are not just for the lives that you create from this point forward; they are about how we go about repairing the mistakes of the past, if you like, and having regulations that adequately support individuals to resolve those things. Yet, as Senator Crossin has highlighted, we seem to be devoid, within our guidelines, of any real way of addressing those historical problems.

Dr Bowman—The Fertility Society of Australia would welcome active involvement in any processes that help to repair or help some of those challenges that occurred previously. Senator Crossin’s question was about current practices and current cycles being undertaken today, and we are saying that that is quite different.

Senator PRATT—It is not all that different in some aspects. We have had examples of things like families being given undertakings that the donor that they are using has only been used by a number of other families, only to be told at a later date that that is not in fact the number of families that have been created. So that is a very current example of the kinds of problems that we are dealing with.

In relation to historical issues, what is the extent to which clinics update a donor’s consent? The previous privacy provisions might be in place, but a donor offspring might approach a clinic to seek access to their information, to contact their donor. Is a clinic obliged to contact that donor for each offspring, each time that offspring makes a request, to see if that donor is willing for contact and for exchange of information?

Prof. Illingworth—Clinics will be expected to do that—that is correct. In fact, the ANZICA, which is the counsellors association for infertility to this side of Australia, has established a set of guidelines so that counsellors can assist—

Senator PRATT—That is a guideline. Is it mandated?

Dr Bowman—In some states there are various legislative requirements in terms of registry details and updating.

Senator PRATT—We just heard evidence from Western Australia which said, yes, they have a registry, but as I understand it they will advertise to donors to come forward, but that does not involve contacting the donor on behalf of the offspring in order to join them together and put them on the registry. It is simply if either party chooses voluntarily to come forward without any specific contact being made.

Dr Bowman—My understanding is, yes, with regard to retrospectivity.

Senator PRATT—I think in most instances we are talking about retrospectivity. As we outlined before, we are talking about the holistic practice when you are setting people’s relationships up for life and how we go about putting people in contact because of previous practices.

Prof. Illingworth—I think everything you say is true and that this is a very difficult area. Clinics should be seeking and striving to assist donor conceived individuals who attend them looking for assistance. Clinics should be doing everything that they can within the constraints of the consent of the original donor to approach the donor and seek the donor’s consent.

Senator PRATT—Within the constraints of the consent of the original donor as it is given at the time? What obligation should they have to update that consent and make new contact?

Prof. Illingworth—In practice, very often when a donor is contacted and the situation is explained, the donor will vary his or her consent at that point—very often.

Senator PRATT—It is good that that practice does exist sometimes, but what you have explained to me makes it very clear that that is not something that is mandated in any way that gives people who are seeking to access that information any kind of confidence that every effort is being made on their behalf to make those connections. So what role is there for government in assisting people to put the picture of their lives together?

Dr Bowman—What you have sometimes heard is that a donor has been contacted and it turns out, perhaps in retrospect, that he did not have a difficulty with being contacted. It is easy, looking back, to say that that process was successful. I can understand how individual practitioners and units have difficulty in not knowing the best way to approach a donor who may not have been in contact with that clinic for some time. That is purely an exercise of professional prudence. I am not necessarily sure that is managed well by a blunt legal instrument.

Senator PRATT—I can see that, but I would probably say that it may not be managed well by clinics either if they are in the business of creating life and their focus is the want-to-be parents in front of them. It is not within the general professional practice of these clinics to manage these lifelong relationships and connections.

Dr Bowman—I think that was right in the past. That may have been true in the past.

Prof. Illingworth—I think the clinics are very aware of this and need—

Senator PRATT—They are aware now but they might not be aware of how they need to go about repairing that historical picture, because of those past practices. For example, how do you deal with individuals who are trying to come to grips with that past legacy? Do they have a right to know that they are one individual who might be part of 30 separate families? The system in some way needs to mandate a way of assisting that person to put that picture of their life together.

Dr Bowman—I personally would have no hesitation. I would not disagree with that. The question is how best to do that.

Prof. Illingworth—That question is a challenge.

Dr Bowman—This is an issue we are dealing with regularly.

Senator PRATT—Would you object to a national DNA register so that where records do not exist anymore people are able to put some of that information together? The Fertility Society would not have any problem with that, even if it were to reveal, for example—I do not know; this is just a hypothetical—that you have perhaps got a doctor who has made donations to a number of families? That is the kind of thing that might come to light as a result of something like that.

Dr Bowman—I would hope not. The sticking point I think comes back to the original consent of the donor. Through DNA testing and imaginative approaches to linking donor conceived children and their genetic parents, a whole lot of work can be done. We are very supportive of all of that. The sticking point is the consent of the donor who refused to change his consent.

Senator PRATT—Regarding the kinds of accreditations that we have discussed today, it might be appropriate to include within those accreditations how clinics go about contacting previous donors, updating their consent and making sure that they do that on a systematic basis and that they do so in response to each contact from any offspring that has been made to the clinic, for example.

Dr Bowman—Much of the activity that you describe is normally undertaken by councillors rather than doctors—of necessity, because they are the people with the professional skills in those areas. The Counselling Association is working through a whole set of procedures and guidelines to give the councillors expertise in managing those problems. We submitted that is part of our submission. Our main concerns are not to have an unnecessary duplication, and I guess there is a secondary constitutional issue about where it resides. One of the previous submitters talked about the fact that there is Commonwealth legislation with mirrored state legislation. I think that having two sets of registries, seven for each of the states and one for the Commonwealth, would be unworkable in all respects.

Senator PRATT—I understand that. I want to ask about records. Clearly, there are now record-keeping systems in place. However, I am concerned that the records that exist should be protected in some way so that, depending on the decisions regulators and politicians make, the information can be accessed in some way to help people put these pictures of their lives together. Currently there is quite a bit of information out there which is being held by clinics, or even individuals under other circumstances. I am interested to know how the fertility Society believes that information should be protected.

Prof. Illingworth—If you look at the mistakes of the past, the biggest mistake has been the one of records. I think we all recognise that now and the need to maintain records of donor conceptions ad infinitum. The process that has evolved, whereby a legislative register holds a lot of the key information that is required to be held and the clinics are required to hold the medical records in perpetuity, will work well for the future. That is a mistake that we can get around.

Senator PRATT—I would like to ask you about how we protect what information remains in order to correct the mistakes of the past.

Dr Bowman—I am not able to quote legal chapter and verse, but there are already quite significant legislative issues around the storage of medical records generally. You may find that there are already established legalities that you do not need to recreate. How long you keep a medical record for, how that record is kept and the circumstances of storage are already legislative issues, to my understanding.

Senator PRATT—All right. So the next question is what right or obligation we have got in terms of using that information and actually starting to make connections for people based on what records remain.

Prof. Illingworth—Yes.

Senator CROSSIN—I want to go to page 8 of your submission. It has Reproductive Technology Accreditation Committee at the top of that page. Your second paragraph on that page says—and I take it this is prior to 2007—that RTAC actually performed the inspection visits.

Prof. Illingworth—That is correct.

Senator CROSSIN—But then from 2007, if I read your submission correctly, JAS-ANZ, the Joint Accreditation System of Australia and New Zealand, actually wrote the new RTAC scheme. Is that correct?

Prof. Illingworth—That is correct.

Senator CROSSIN—You then go on to say that the ART units—do you mean the fertility clinics?

Prof. Illingworth—The fertility clinics, that is correct.

Senator CROSSIN—Is that what ART units means?

Prof. Illingworth—Yes.

Senator CROSSIN—You say they engage a CAB—

Prof. Illingworth—Certified accrediting body.

Senator CROSSIN—to undertake the audits of their clinic. Is that correct?

Prof. Illingworth—Yes.

Senator CROSSIN—Where are each of those audits reported to?

Prof. Illingworth—JAS-ANZ.

Senator CROSSIN—JAS-ANZ, though, is the very body that actually wrote the scheme under which these audits are occurring.

Prof. Illingworth—There are two documents there. One is the code of practice and one is the scheme rules or the scheme. The code of practice is the criteria against which the clinic is to be accredited.

Senator CROSSIN—Who wrote those?

Prof. Illingworth—RTAC wrote those.

Senator CROSSIN—In conjunction with the NHMRC?

Prof. Illingworth—No, the NHMRC requirements are part of the RTAC code of practice. It is one of the essential criteria in the code of practice that clinics are compliant with the NHMRC guidelines.

Senator CROSSIN—So you have got a subcommittee of the Fertility Society of Australia writing its own code of practice.

Dr Bowman—But the scheme rules and the code of practice were written with the auspices of input and direction of government bodies, the NHMRC, law makers and other independent professional medical people like the College of Obstetricians and Gynaecologists. They have just had input on that for the latest edition, only within the last few months.

Prof. Illingworth—We invite all of the state governments to the technical committee. We invite the Commonwealth department of health to the technical committee.

CHAIR—Do they all participate?

Prof. Illingworth—We have had two meetings to set the scheme up in the first place. Most of them came to the first meeting. Fewer of them came to the second meeting. We took it from that and from our general comments with the departments that they were satisfied with the way the scheme was operating.

CHAIR—Is that what you mean when you talk about law makers?

Prof. Illingworth—That is right. May I clarify once again that we are not advocating that our tack be the only way of regulating fertility clinics. Our tack is a technical assessment that falls within the overall framework of a legislative approach.

CHAIR—You are probably getting an understanding that the evidence you are providing to the committee provides an impression, whether it is true or not, that everything at this stage currently is okay. But the evidence, as you will see from the *Hansard*, from many witnesses, particularly the donor conceived individuals, is that it is not okay. In fact they feel somewhat aggrieved, frustrated, annoyed and upset that they cannot access relevant information that is important to them.

Prof. Illingworth—I think we would like to break that into two separate aspects. The first is that, for people having treatment now and for future the donor conceived individuals, with the systems that are in place at the moment, we think that the experience of those donor conceived individuals will be different from the experience in the past. Like you we listened to the very moving stories and accounts and to the distress and the frustrations that the donor conceived individuals have in dealing with the problems that are left over from the past. We as a society do not think that it is all okay. We as a society do not think that we have solved those problems and we fully accept that there is a lot more work to be done in that area.

CHAIR—How do you relate to them? What mechanisms are in place for your society to interact with donor conceived individuals and the relevant bodies that represent them, or doesn’t it happen?

Dr Bowman—I think at present it does happen on a unit-by-unit basis, because it gets back to the original professional medical relationship that was involved.

CHAIR—Based on the feedback and witness statements we have had to our committee, we are not seeing much evidence of that. If I am a donor conceived individual and have a complaint or a concern with a particular unit, as you call it, or a fertility clinic, where do I go?

Prof. Illingworth—The complaint mechanisms are through the standard healthcare complaints systems established in each state.

CHAIR—Yes, but come on: there is no particular complaint system with respect to donor conceived individuals. If they get what is called the fob-off, they have nowhere to go. They have no rights at this stage to take the matter further. There is no ombudsman and there is no appeal process. They simply close the doors and say, ‘We don’t have the information and, if we did have it information, it may not be available anyway.’

Prof. Illingworth—For patients who have difficulties or who are discontented with medical treatment they have received, there are processes in every state for people to go to.

CHAIR—Yes. I am not talking about patients; I am talking about donor conceived individuals.

Prof. Illingworth—Individuals who are dissatisfied with the level of professional care and support they are getting from clinics such as IVF clinics, again, have recourse to complaints mechanisms.

CHAIR—I am asking about their right to know information. I am not talking about their particular health care. These are donor conceived individuals.

Dr Bowman—I can speak for my institution. At Royal Prince Alfred Hospital—which is presently in the South-Sydney West Area Health Service—the original model of anonymous donor insemination was undertaken for probably two decades before I was there. We have requests from donor conceived individuals. We usually manage that process to the best of our ability within the clinic in its association with the department of andrology that originally stored the sperm. There are times when those requests can be managed well because of contact with donors or because of consent of donors. Sometimes that may lead to challenges or a lack of satisfaction on behalf of the donor conceived individual. I know that process has resulted in an area, as a representative of the health department processes that have been taken up, where there is a patient representative who has handled those issues potentially and there are also policy and ethics reviews in helping us to move forward in that. What I am trying to suggest is that this is an evolving process.

CHAIR—Right; it depends on the clinic, on a case-by-case basis.

Dr Bowman—Yes, it would, but I am suggesting that those mechanisms are all representative of very well established mechanisms that exist within our health service.

CHAIR—Are you familiar with the Victorian Parliament Law Reform Committee report *Inquiry into access by donor-conceived people to information about donors*? This interim report came out in September 2010.

Dr Bowman—No, I am not.

Prof. Illingworth—We are both from New South Wales.

Senator CROSSIN—Shouldn’t the Fertility Society of Australia know about that interim report?

Prof. Illingworth—No, we are not familiar with it.

Senator CROSSIN—You are the Fertility Society of Australia. Why would you not know about an interim report done by the Victorian government?

Prof. Illingworth—Because each state’s legislation operates separately. I can tell you all the details for New South Wales. That is where I operate. I know all the documents there.

CHAIR—You are a national body and Victoria is a key part of the nation. There are a few Victorians here who would support that. That is a concern for me and, I think, for Senator Crossin. The Law Reform Committee reports’ first recommendation is:

> The Committee recommends that, pending a further inquiry and report,—

because the government is in caretaker mode, as you know—

> the Victorian Government considers as a matter of urgency whether measures should be taken to ensure that existing and unprotected donor records are preserved.

Can you provide a guarantee that all your members are preserving and will preserve donor recipient individual records?

Prof. Illingworth—It is a requirement of the ART Act code of practice that they are annually assessed for their compliance with that. They are annually assessed for their compliance with the records retention policies.

CHAIR—But you cannot guarantee it, can you?

Senator PRATT—And what about historical records?

Prof. Illingworth—It is an ART Act requirement that clinics retain all records, past and present, relating to donated gametes. In the past there was a problem with records being disposed of and I think all clinics now accept that that was a huge mistake. All clinics are required under the ART Act code of practice to retain all records relating to treatment with donated gametes.

Senator PRATT—Even if, previously, you could destroy those records, it is now no longer possible to destroy them?

Prof. Illingworth—That is correct. Once again, the society—

CHAIR—It is not correct. You cannot guarantee it. You are saying that they must fulfil the guidelines to be accredited, but the guidelines are not legally enforceable. The guidelines are exactly what you said they are: they are guidelines, but they are not legally enforceable. Is that correct?

Prof. Illingworth—Guidelines are guidelines. The society’s position is that we are strongly supportive of state based legislation to ensure the retention of records.

CHAIR—To make it legally enforceable?

Prof. Illingworth—That is correct.

CHAIR—So are you confirming that today they are not legally enforceable?

Prof. Illingworth—I am not confirming that, no. I am confirming that the society's position is that we are supportive of legislation making it legally enforceable. In 70 per cent of the cycles carried out in Australia, there is state based legislation which makes the retention of records legally enforceable. There is a medical requirement to retain records.

CHAIR—What about the other states and territories, and the other 30 per cent?

Prof. Illingworth—That is a matter for the legislatures in those states.

CHAIR—You cannot guarantee it for that 30 per cent, can you?

Prof. Illingworth—We are a voluntary society. Each clinic is accredited and each clinic has satisfied the accreditors that they retain the records.

Senator PRATT—Some of those records might not be held by a clinic, though, these days, if, say, the clinic was bought out or closed. So in a sense there is no protection of records that might help people piece together their genetic origins that is mandated across the country.

Prof. Illingworth—In the past many bad things have happened with records.

CHAIR—I want to go back a step to the numbers. Professor Illingworth, I think in your opening statement you said 1,000 babies per annum are donor conceived.

Prof. Illingworth—That is correct.

CHAIR—Is that across the country?

Prof. Illingworth—We dug out the statistics as I thought that was a likely question.

CHAIR—What is the total number for Australia today?

Prof. Illingworth—I do not know that yet. I will happily provide that on notice. Let me explain once again the basis of how the statistics are collected. ART Act accredited units are required to report every cycle and every birth involving donated gametes. The data collection system changed in 2002. Yesterday, within the last 24 hours, after I realised this would be a question, I was only able to get access to the most recent five years of data. But we will within two weeks—

CHAIR—What are the numbers for those five years?

Prof. Illingworth—Let me explain that to you. In the last five years there have been 5,000 babies born from the use of donated gametes in Australia and 1,500 of these have resulted from the use of donated oocytes; 150 have resulted from the use of donated embryos and the remaining 3,373 births have resulted from the use of donated sperm. That was during the years of 2004 to 2008, the last year for which published data are available.

Senator PRATT—Can I ask how many of those are known donors as opposed to donors sought through clinics—not anonymous but I suppose—

Dr Bowman—Do you mean clinic recruited versus client recruited?

Senator PRATT—Yes. I beg your pardon for interrupting you, chair.

Prof. Illingworth—We do not record that data. Nor do we record the informal private treatment with donor sperm that we know goes on. We can tell you with certainty that there are 1,000 babies born through treatment in fertility clinics. We have no idea—there are no data anywhere—on the number of donor conceived individuals who result from informal treatments, in which doctors are not involved.

CHAIR—That was one of my questions: how many of these are happening in the fertility clinics and how many outside? You do not even have a guesstimate?

Dr Bowman—Nobody knows.

CHAIR—But it is happening outside.

Prof. Illingworth—We hear that it is happening, and we see the evidence on the internet that it is happening but the extent of it—whether it is a tiny activity or a large one—we have no idea.

CHAIR—Just breaking down the figure a bit more. We were advised, I think, on Friday in Canberra that the majority was from overseas and the vast majority of that was from the USA. You are disagreeing with that. What is your evidence? Please outline the detail.

Prof. Illingworth—Of course. I have no idea of the proportion of births that result from imported sperm or sperm from donors based in Australia. That information is not collected. What I do know, from a survey of the practices of—

Senator CROSSIN—Aren't they held at the university?

Prof. Illingworth—No, that is not recorded.

Dr Bowman—It is not subdivided as to the origin of the sperm.

Senator CROSSIN—So there is a deficiency in the record keeping.

Prof. Illingworth—In setting up those databases we have consulted with government regularly. The data items were achieved through consultation with government.

Senator CROSSIN—That does not mean to say that it is good, accurate, transparent or relevant, just because—

Dr Bowman—The database's primary role is about success of medical treatment—the percentage success rate of IVF cycles and what the multiple pregnancy rate is. It is primarily around that, but there is secondarily important information around the origin of gametes, but it is only subdivided to origin of gametes.

Senator CROSSIN—I see.

Prof. Illingworth—What we do know, from a survey of practices, is that the majority of clinics in Australia state that it is their practice not to use imported gametes in treatment programs.

CHAIR—So that means that some of the major or bigger fertility clinics may be importing?

Prof. Illingworth—Of the six major clinics most do not use imported gametes.

CHAIR—Of the six, how many do?

Prof. Illingworth—I do not know for certain, but I would say it is less than two.

CHAIR—Less than two would be one!

Prof. Illingworth—Two or less.

CHAIR—But it does happen. Is it mostly from the USA, to your knowledge?

Prof. Illingworth—My clinic person is not involved in that. My understanding, from informal communications—which is probably no better than the evidence that you have had so far—is that for donors in the USA, the systems are in place to meet the RTAC requirements that we have already gone through: identification and traceability of donors or their willingness to give their identity.

CHAIR—Can you understand the views of the earlier witnesses who were aghast to think that they may or may not be required to try and find their father, the donor, somewhere in the USA—knowing their views and their value system with respect to the right to know information is entirely different to ours in Australia, today?

Prof. Illingworth—Traceability is clearly a major concern for gametes that are imported. Clinics that make those decisions are weighing up the long-term issues of potential traceability and are setting out mechanisms to ensure future traceability. They are weighing this up with the fact that for many of the couples who come to see them there is no other option for treatment.

CHAIR—Going to that breakdown on notice, can you provide details of the donor recipient if they are living in a heterosexual relationship, a married relationship or a homosexual relationship or are a single mother?

Prof. Illingworth—It is not recorded.

CHAIR—It is just not recorded?

Prof. Illingworth—Remember these are records of clinical treatment cycles; they are not social or demographic records. They are simply records of clinical treatment cycles.

CHAIR—Have you ever done a survey of your members?

Prof. Illingworth—A number of surveys have been done around Australia. This database was a technical database of medical treatments.

CHAIR—On notice could you advise the committee of the surveys that you are aware of and alert us to them?

Prof. Illingworth—Yes, I will.

CHAIR—What is the cost for a donor these days?

Prof. Illingworth—Women who access donor sperm will be charged to meet the travel expenses of the donor—donors are not recompensed for time off work.

CHAIR—Go on and give me some costs.

Prof. Illingworth—I do not know of any costs in my one clinic.

Senator CROSSIN—Do we pay the taxi fare for people who donate blood?

Prof. Illingworth—Donors in Australia—and I do not know the details of every cost paid in every clinic; it is not my job to know that—

CHAIR—No, but you would know what the costs are because you are the President of the Fertility Society of Australia.

Prof. Illingworth—Donors are recompensed for travel expenses. Travel expenses may include getting a taxi or parking their car.

CHAIR—What is the standard cost?

Prof. Illingworth—There is no such thing as a standard cost.

CHAIR—Isn’t there?

Prof. Illingworth—No.

CHAIR—There must be a range.

Dr Bowman—Any more than I know what my colleagues charge from a medical consultation in Western Australia or Sydney, I do not know what another unit considers to be reasonable expenses in terms of recruiting or having a sperm donor contribute. What we do know is that there is Commonwealth legislation that quite clearly forbids that being an incentive to be a sperm donor. It quite clearly says that.

CHAIR—You are both involved in clinics. I do not want to get into confidential details, but please give us some figures.

Dr Bowman—My figure is zero because my clinic made a decision many years ago to not have any more clinic recruited sperm donations. So when I manage sperm donations the individual themselves has recruited themselves a sperm donor. Therefore, there is no payment or inducement. They are doing it because they want to help the other person. I cannot comment on another unit that has a different practice.

CHAIR—But you are the Fertility Society of Australia.

Dr Bowman—With respect, I do not ring up my colleague and ask him whether it is $50 or $60 to offset the expenses of a sperm donor.

CHAIR—What about $90?

Dr Bowman—I do not know the answer to that.

CHAIR—What about you, Professor Illingworth?

Prof. Illingworth—In our clinic a donor’s expenses will be summed up and in general they get an average of $50 for each trip that they take to come to the clinic. It is not financial recompense. We can remember the days 30 years ago when medical students would earn beer money from donating sperm. Nowadays it is not all like that. Nowadays the donors spend hours in counselling and spend a long time working through the long-term implications of both giving sperm and having their identity given to children who will approach them in the future. They get a small amount for the expenses to travel to the clinic.

CHAIR—We were given evidence on Friday from somewhere in Melbourne that it was $90 a visit.

Prof. Illingworth—Whether that is true or not I cannot comment.

CHAIR—That is in Friday’s evidence. It is on the *Hansard*. You can check it if you wish. I want to look at the constitutionality of what we are doing and your preference. Is your preference for state and territory regimes across the country which are consistent, for a national register set up by the Commonwealth or for nothing at all? What is your preference?

Prof. Illingworth—Our preference is for the state based legislation. It is locally based. It is sympathetic to local needs. The existing state based legislation provides a framework that works well to ensure that there is proper record keeping and proper disclosure of information going forward, prospectively. The toughest problem of all of this is the voluntary registers—sorting out the problems of the past. We just do not see legislation as the solution to that. We would like to work forward and look at some of the imaginative solutions that are there involving legislation, where it is helpful, to do whatever can be done to solve the problem.

CHAIR—Do you agree that it should be consistent in each state and territory so that we do not have different laws applying in WA compared to Tasmania?

Prof. Illingworth—In the laws that vary between the different states, the variations are very minor. There are not major variations. And each state is capable of looking at the deficiencies within its own. None of the states' laws are perfect. In New South Wales, for example, the access is only guaranteed at the age of 18, which is too old. In South Australia there are elements of discrimination, and in Victoria there is a requirement for a criminal record check, so none of the legislation is perfect.

CHAIR—If you would like to, on notice, design the perfect system and let us know, that would be welcome!

Prof. Illingworth—I would like to decline that request!

CHAIR—All right. You mentioned JAS-ANZ and this assessment. Who pays them? Is it the facility clinics?

Prof. Illingworth—The facility clinics pay for the assessors in exactly the same way as any ISO accreditation system is paid for by the body being accredited.

CHAIR—And they get accredited every three years, don't they?

Prof. Illingworth—Every year. There are two sets of criteria. There are critical criteria, including all the donor issues, and there are practice criteria, which are less critical. The practice criteria are accredited every three years. The critical criteria, including the donor issues, are accredited every year.

Senator PRATT—Can I ask by way of follow-up to that question, Chair—

CHAIR—Yes.

Senator PRATT—if you are, I suppose, paying the accreditation bodies to accredit you, is there any reason why you should not be levied to put something like a national DNA register together for people to find their siblings?

Prof. Illingworth—We are happy to contribute to whatever is going to make things work. This is a serious problem.

Senator PRATT—Okay, thank you.

CHAIR—Thanks for your evidence today.

Proceedings suspended from 4.02 pm to 4.17 pm

COLES, Mr Gary, Manager, Victorian Adoption Network for Information and Self Help Inc.

CHAIR—Welcome. We have your submission; it is No. 62. Do you have any changes or alterations to it?

Mr Coles—No.

CHAIR—We now welcome you to make an opening statement, after which we will have questions.

Mr Coles—The basis of our submission is that adoption is an existing framework that displays many similarities to donor conception. The following are the underlying reasons why we at VANISH maintain that the lessons learned from adoption can be applied to a donor conception setting. Adoptive and donor conceived families are created as a result of loss. The biological parents lose the opportunity to raise the child and to fulfil the traditional parenting role. Adopted persons and the donor conceived lose their biological parent, ties with extended family, genealogical continuity and everyday evidence of their heritage. Birth parents and the donor parent lose their genetic descendant, who is raised in another family.

There is an underlying assumption that the love provided by the social family will overcome the losses experienced. Within the social family, there are similarities in upbringing. At least one parent, and in the case of adoption two, is not genetically related to the child. Therefore, physical and other differences are usually obvious. This matter is compounded if there are racial distinctions between the social and biological parents which are evident in the child.

The underlying issues within social families may be similar, particularly where infertility has resulted in the decision to create a non-consanguineous family. Shame, guilt and self-concepts may be unresolved matters that intrude into personal relations. Some parents hope that the child they have adopted or donor conceived can compensate for the children they are unable to conceive themselves, which may place unrealistic expectations upon the child.

Secrecy may be an inhibitive factor within social families out of shame related to infertility, a desire to pretend that the family is no different from a family where all members are related by bloodline or perhaps a fear that the child will not approve of their origins. For these reasons, some social parents withhold information about the biological parentage of their adopted or donor conceived child. This suppression of the child’s heritage can, when discovered, especially in adulthood, have a negative effect on the wellbeing of the child.

The withholding of identifying information was a feature of adoption laws in Victoria prior to 1984. The legislation here in Victoria continues to be discriminatory against birth parents. The donor conceived also suffer from legally sanctioned information discrimination.

As a bit of background, VANISH have been providing services to the adoption community since 1989. We resulted from the passing of the Adoption Act in 1984. We operate under the self-help model, a feature of which is that the majority of the staff have adoption experiences of their own. Their insights inform the support we give to service users. At a personal level, I am a birth father and the author of two published books. That is my opening statement.

CHAIR—Very good. Thanks very much. I will kick off with questions. Can you just tell us a bit more about VANISH—who you are, where you are, why you are.

Mr Coles—Okay. We are a not-for-profit organisation, fully funded by the state government of Victoria. As I said, we were established as a result of the passing of the Adoption Act 1984. Initially, search requests were handled within the department, but the overload was such that they made the decision to set up a discrete organisation funded by the state government—hence the formation of VANISH. Our primary role is to provide search and support facilities for adopted persons under the Victorian legislation. We offer support to birth parents and other members of the adoption triangle, but we cannot conduct searches beyond those that we do for adopted persons.

CHAIR—So you do not support donor conceived individuals in their search?

Mr Coles—We are set up to provide searches for the donor conceived—

CHAIR—You do?

Mr Coles—No, we are set up to do it. To date we have not had any requests come through.

CHAIR—But, if they did request that, you would happily support that?

Mr Coles—Yes.

CHAIR—Because you believe it is consistent with your objectives—

Mr Coles—With our ethos, yes—with our founding principles, yes.

CHAIR—Okay. You indicated that you were set up after the 1984 legislation, but you have also said in the conclusions to your submission that the law in Victoria at the moment is discriminatory. Can you explain why that is, with respect to adopted and donor conceived individuals.

Mr Coles—What I was referring to there, when I was talking about adoption, was the fact that adopted persons have the right to identifying information; birth parents do not. So that is the discrimination within the Adoption Act. Within the donor conceived community, it is that three-tiered structure, depending on when the gametes were donated: 1988 and 1998 are the cut-offs that mark the three periods.

CHAIR—Right. Just to make it clear, VANISH's position is that they should be consistent with the rights of adopted persons?

Mr Coles—No, not necessarily at all. Our position would be—and indeed we put a submission in to the state government of Victoria to this effect—that birth parents and adopted persons should have equal rights in terms of access to identifying information, in line with the other states.

CHAIR—Yes, that is what I was trying to get at.

Mr Coles—And we would advocate that the donor conceived should have unfettered rights as well to access identifying information, in line with what the other states provide to the adoption community.

CHAIR—That is slightly problematic for us, because four of the states have laws, the two others do not and then there are the territories. That is why we are having an inquiry—to look at what possible options we have federally as well as at a state level. So what are your preferred criteria for access to information and the right to know for the donor conceived individual?

Mr Coles—That that should be unfettered—available to all.

CHAIR—Right. But when you say 'unfettered', at what age and stage?

Mr Coles—At 18, the way it applies in the adoption community—in other words, getting to adulthood.

CHAIR—What about earlier?

Mr Coles—No, I think not, in terms of access to identifying information—unless it were via the parents. Under the Adoption Act, the adoptive parents can make representations.

CHAIR—We have had quite a discussion during our inquiry on the issue of retrospectivity. What is your position on that?

Mr Coles—In terms of?

CHAIR—Access to information prior to 1984—or any other date that may be relevant.

Mr Coles—I am not quite sure where the question is coming from.

CHAIR—Do you believe the donor conceived individual should have access to their information, in terms of their parenting and the identity of the donor, going back till day dot?

Mr Coles—In principle, yes.

CHAIR—You support that?

Mr Coles—Yes.

CHAIR—That is consistent with a lot of other evidence we have received, but there is a body of opinion that has a different view. That is what I am trying to ascertain from you. So that is helpful.

Do you have views on cost? This has come up from a number of witnesses, as to the cost for the donors and whether donations should be made at no cost.

Mr Coles—No, I do not.

CHAIR—You do not have a view?

Mr Coles—No. I consider that that is outside my expertise.

CHAIR—That is fine. I will pass over to other senators for their questions.

Senator CROSSIN—Mr Coles, thanks very much. Do you have any view about whether access to information should be—not 'restricted'; that is not the right word. Do you have a view that a person should not be able to get access to that information unless they can also prove they have access to counselling at the same time? Do you think it should go hand in hand with support?

Mr Coles—I do, yes.

Senator CROSSIN—Should that be left up to the individual?

Mr Coles—It should be up to the individual, but certainly made available. In Victoria at present there is no state funded postadoption grief counselling available.

Senator CROSSIN—So where do you go?

Mr Coles—At VANISH we just on-refer people to counsellors and they have to pay for the service, at $100 an hour or whatever the rate is. Other states actually subsidise the provision of postadoption grief counselling. For our equivalent organisations in other states like New South Wales, Queensland and South Australia, that is part of the funding that they receive. So that is something else that we are trying to get changed at a government level in Victoria.

Senator CROSSIN—Do you have evidence that a lot of people do not access that counselling because they cannot afford it but would still need it?

Mr Coles—That is part of the reason why people do not access counselling. The other is that many have said they did not have faith in the counsellors to understand the fundamental adoption issues. We have had lots of people say to us: 'I went to that counsellor and they didn't understand what my issue was, because when I talked adoption they said to me, "Put it behind you. Get over it. Move on." But it's not as simple as that.' In South Australia, for example, our equivalent organisation runs training sessions for counsellors, and they accredit the counsellors, and then they on-refer to those people. They are basically information sessions for the counsellors about adoption issues.

Senator CROSSIN—Could you do a similar thing in Victoria?

Mr Coles—We are looking to do that in Victoria, but it does require some money and we operate on the smell of an oily rag.

Senator CROSSIN—That is all I had to ask.

Senator PRATT—I am not very clear on the arrangements in Victoria for managing past adoptions and facilitating contact. Could you take me through how that works here, so that I can compare it to what happens for donor conceived people.

Mr Coles—If you are initiating a search, you come through VANISH. We are the primary search organisation.

Senator PRATT—Are you an NGO?

Mr Coles—Yes. We are funded by the state government of Victoria. We are accountable to the Department of Human Services, but we are an independent organisation—we have our own constitution et cetera. There are agencies in Victoria that were responsible for arranging adoptions. They are the state government itself and three independent agencies. They can also conduct searches. But many people, if they want to initiate a search and their adoption was arranged through that agency, prefer to go to an independent agency, and so they come to us.

Senator PRATT—I am sorry to interrupt you, but is there a state register that you hang off in order to facilitate those contacts, or do you hold the register?

Mr Coles—We hold the information about the initiation. Once the search has begun, we retain those records.

Senator PRATT—Okay. Where is all the information about past adoptions that might relate to those contacts that have been made?

Mr Coles—That is held by the agencies and centrally, I believe, by the Adoption and Family Records Service.

Senator PRATT—I think that is quite similar to WA, where organisations like Jigsaw provide the counselling and manage the contacts that are made, whereas the adoption information is, as I understand it, held by the central department.

Mr Coles—Yes, identical.

Senator PRATT—What commonality do you think those processes have with the kinds of things that could be put in place for donor conceived people seeking to make contact with siblings or with any parents?

Mr Coles—Once people have acquired their records and they go to the Adoption and Family Records Service and then on to Births, Deaths and Marriages, the next step is to come to us armed with those records. We have names then—the adoption record and the name of the birth parents—and we can begin the searching process. I would imagine the same thing would apply in the donor conception setting with the donor’s name.

Senator PRATT—So you are managing, for example, a relinquishing parent—although that is probably not the correct terminology these days—

Mr Coles—No.

Senator PRATT—What is the correct terminology? Birth parent?

Mr Coles—Well, ‘natural parent’ or ‘birth parent’.

Senator PRATT—The birth parent, because I understand it was not necessarily voluntary relinquishment in many instances. You are the ones with the expertise to say, ‘Right, you have currently got a veto in place; you currently do not want contact; but we have received—

Mr Coles—There is no veto in Victoria. We are the only state in Australia that does not have a—

Senator PRATT—Without a contact veto?

Mr Coles—Yes. No information or contact veto applies in Victoria.

Senator PRATT—All right. But you might be the party that is exchanging information that says, ‘They do not want contact but this is how we would facilitate it.’ You would exchange those wishes irrespective of whether there is no—

Mr Coles—Our approach in acting on behalf of adopted persons is that once we are as near as possible to 100 per cent sure that we have identified the right person we will generally write them a letter—so that it is non-intrusive—saying that we have some important information and asking them to get in touch with us. It is at that point, when they make contact, that you would ascertain their readiness to be the recipients of a person-to-person outreach.

Senator PRATT—And that might take many months to facilitate?

Mr Coles—It might.

Senator PRATT—Or you might have numerous requests from an adoptee and some of those might be rejected over time, but finally there might be something that cuts through. Basically, what you are doing is the equivalent of what is faced by many fertility clinics with the same kind of requests, but without really any experience to facilitate and mandate what you are doing as an organisation. There is not actually an equivalent for donor conceived people other than, as far as I can tell, the goodwill—if it exists—of the clinic, if the clinic still exists.

Mr Coles—Yes.

Senator PRATT—Thank you.

Mr Coles—We believe that the readiness of the recipient of outreach is critically important so that there is no shock and disruption to that family.

Senator PRATT—I know that there are no contact vetoes in place any more and that information that was previously private is therefore no longer private because of that. There is clearly a different set of laws in relation to donor conception in place. If you were the organisation in charge of that, I would imagine you would have to make contact in a way that says, ‘This was your consent at the time; are you ready to vary that consent?’ Perhaps as each new request comes through, depending on how many offspring there are or whether such offspring want to make repeated contacts, that is the kind of thing you would be in a position to manage. I think that is how you start in relation to adoption in Western Australia. That is because they still have contact vetoes in place there. Is my understanding of that correct?

Mr Coles—Yes. We argue that restricted access to birth parents here in Victoria is a quasi veto. There is not a veto in name. For birth parents seeking the release of identifying information from adopted persons, you have to go to the adopted person and say, ‘Will you consent to that?’ So, in a sense, that is a form of veto. It is a barrier, if you like. It is not an automatic reciprocal right. That is what we are endeavouring to get changed.

Senator PRATT—That does sound a bit different to Western Australia, where that information is automatically released but parties can put a veto on contact. So you do have an automatic right—which is a slight variation on what you have suggested—

Mr Coles—Each state has subtle differences.

Senator PRATT—Has each state got a system that is fairly equivalent to what Victoria has for adoption?

Mr Coles—No. We are still the only state that does not have vetoes. Queensland recently amended their legislation. They abolished the word ‘veto’ but they call it something else. Those who do not wish to have contact can make it known.

Senator PRATT—I am wondering whether, if states do similar things for donor conception or if we have a national system for that, that will underscore the kinds of inequities that exist between people who are in similar circumstances by virtue of being adopted or by virtue of being donor conceived or the level of contact that they are allowed which might result because of that—and we do not know yet.

Mr Coles—No.

CHAIR—I notice that you have made a submission to the Victorian inquiry into access to donors. Were you happy with the interim report?

Mr Coles—Yes, as far as it went. It is an interim report and there is going to be a follow-up in the next parliament.

CHAIR—Are there institutions like VANISH in other states and territories?

Mr Coles—Yes, there are.

CHAIR—In Tasmania?

Mr Coles—No, not in Tasmania, the ACT or the Northern Territory. Western Australia has Adoption Jigsaw and ARCS, the Adoption, Research and Counselling Service. In South

Australia there is PASS, the Post Adoption Support Services, in New South Wales there is PARC, the Post Adoption Resource Centre, and in Queensland, effective in February this year, there is PASQ.

CHAIR—Are they in each sense funded by their relevant states?

Mr Coles—They are at least partially. Some have to raise fees for service to make up the balance.

CHAIR—Thanks very much for your submission and thanks for the work that you do. It is appreciated.

Mr Coles—Thank you.

[4.39 pm]

ALESI, Ms Rita, Manager, Counselling Psychologists, Monash IVF, Victorian Infertility Counsellors Group

TOME, Ms Marianne Therese, Manager, Counselling Department, Melbourne IVF, Victorian Infertility Counsellors Group

CHAIR—Welcome and thank you for being here. We have your submission and we have identified it as No 68. Are there only changes or alterations?

Ms Tome—No.

CHAIR—We invite you to make an opening statement and then we will have some questions.

Ms Tome—Rita and I are here today on behalf of the Victorian Infertility Counsellors Group, a group of approximately 25 social workers and psychologists who work in the assisted reproductive field. We are representing the views of the Victorian Infertility Counsellors Group and these views are not necessarily those of our respective employers. We would like to highlight the following recommendations that we addressed in our submission.

We recognise the right of all donor conceived individuals in Australia to have access to information about their biological parents and genetic siblings. We also recognise the rights of recipients and donors to also have access to such information. We believe that access to such information should be through a national central register such as that established in Victoria. Victoria has led the way in setting up a system to facilitate information exchange and preservation of donor records through the central donor register and this has had much success in providing donor conceived individuals with information about their genetic history and linking donors, recipients and donor conceived children where requested. In practice, a system which is only a voluntary register provides only hit-and-miss access to information for parties involved. For this reason we advocate a central register based on the Victorian system.

We understand the donors who have donated prior to such legislation being enacted have done so with the belief that their donation was anonymous. We therefore believe that donors should be contacted in a respectful and confidential manner that acknowledges the context in which they originally consented to donation. They should be able to consent to the release of any information and have control over what information is released. Melbourne IVF is the only clinic in Victoria that provides donor linking to anonymous donors and our experience of donor linking has been largely positive due to the careful and sensitive process we follow. We have found that donors are in most cases willing to at least provide information for the donor conceived child and have welcomed such contact.

We believe the counselling support is a core component of the establishment of donor registers and donor linking. This counselling should be mandatory, include facilitation and be available to all parties. We recommend that it is preferable to establish a system where those seeking information from the registers are supported to think through their motivation for making the application, to think about what they hope to achieve through making the application and preparing them for possible outcomes. The person whom the request is being made about can then be approached by a donor linkage counsellor who can inform them of their options, including the particular details of the request for information, support them in their decision-making and facilitate any contact or sharing of information between the donor and donor conceived person. A comprehensive counselling service ensures that information is provided in a supportive and comprehensive way that maximises successful outcomes for all parties involved. This counselling support should be provided in an integrated way and tailored to individual needs.

Counselling and education should also be available to support parties post donor conception, to support parents in parenting a child that is not genetically theirs, in assisting parents in telling children of their donor conception and to assist children in dealing with learning that they are donor conceived. The Victorian Assisted Reproductive Treatment Authority's Time to Tell program is an important component of this education and support in Victoria. In fact, at their last seminar they had 170 people attend and had to close the books. They have now got a waiting list for the next one. It should be noted that in Victoria that is no longer a body to provide this comprehensive counselling and support service and as such it is currently being performed in a haphazard way dependent on the goodwill of private clinics. It is therefore essential that such a service be provided through a central body with suitably qualified and experienced counsellors in the donor conception field.

CHAIR—Thank you very much for that and for your thoughtful the submission. We appreciate it very much. You covered in part your view on the retrospectivity. I just want to drill down on that. You said that the donor should be willing to make available what information he or she saw fit. Would you provide us with details of that. Obviously, from the donor recipient's point of view, they may or may not want to find as much identifying and non-identifying information as possible. We are talking about a retrospective approach here, so how far do you think we should go as legislators? What do you mean when you talk about providing what the donor would like to provide?

Ms Tome—Currently in Victoria, when those born post 1998 turn 18 they can access information about their donor and they will be given the name of the donor. The donor will be contacted and asked if they want to provide any further information. They can then agree to provide telephone numbers, email addresses or other further contact details, but they do not have a say over whether their name is provided. We agree with that.

CHAIR—What are they required to provide at this stage?

Ms Tome—They do not have a choice over whether their name is given, so, when a child reaches the age of 18 and requests information about their donor, the name of the donor will be given to them. Then the donor is advised that this information is being accessed and they can agree to give further information to assist in that contact.

Ms Alesi—There is a legal obligation on the clinics to provide information to the central register regarding the donor's details as well as the recipient's details and information about the pregnancy and the birth of the child. The consent form that the donors complete at the beginning of the counselling process includes identifying information, which is their name, date of birth and address and information about their ancestry, their parents details and so forth, as well as non-identifying information, which could be things like hair colour, eye colour and medical history. That information is held by the clinics until such time that a pregnancy occurs. Once a pregnancy occurs, information about the donor, the donor code and the recipient's details are then forwarded to the central register. When a birth occurs, that birth is linked to that particular donor.

Ms Tome—And we can provide that non-identifying information to the recipients and the donors at any time. We need their permission to provide any identifying information.

CHAIR—When did that become part of the law?

Ms Tome—In 1998. When they turn 18 children born post 1998 will be given at least the name of the donor. For those born between 1987 and 1998 the donor's information is on the central register but the donor can give permission as to whether any identifying information is released and what information is released.

Ms Alesi—You need the donor's consent to release information for those between 1988 and 1997.

CHAIR—You have reflected on the law in Victoria. What is your view with respect to access to information prior to that period?

Ms Tome—We think it is important and works well. We are concerned about those born pre 1988. They do not have that right of information. There is no central register for them, so they rely on people putting information on the voluntary register or the goodwill of the clinics to provide that link. At present only Melbourne IVF provides donor linking for those conceived before 1988.

Ms Alesi—I think the concern for clinics that take on that role is funding and resourcing. It is a very time consuming process. I can probably tell you here and now that at this point the clinics will not fund that.

Ms Tome—Unless we change them and they are given—

Ms Alesi—Yes; that is another story. Good luck.

Ms Tome—We do fund it at Melbourne IVF, but—

CHAIR—You are telling us about the Victorian law. I am interested also in your view as the Victorian Infertility Counsellors Group.

Ms Tome—We do agree with the right of the child when they turn 18 to have access to the donor's name and that that is not the donor's choice, but we do respect the rights of donors who donated under previous legislation where they thought that their donation was anonymous. We think that needs to be carefully managed and that they should have control over whether information is provided and the type of information provided. Speaking on behalf of Melbourne IVF, we contact donors, as I said, where donor conceived children were born pre 1998. In managing that we have really good outcomes. Donors at least will provide information. They may not necessarily want contact with the donor conceived child, but they are willing to answer questions and provide information. And often that is all the donor conceived child wants. They want to find out that missing information about their background and their genetics. They do not necessarily want a new relationship. Some do, but, by and large, they are very happy just to get information.

Ms Alesi—The key thing is how that process is actually managed. I can imagine that lots of donors who, for example, donated 20 years ago would be quite anxious that there will be a flood of people knocking on their front door. The reality is that, when people are making applications, it takes time for them to process and come to terms with the information they are given. That might take months—often it takes years. Similarly, we can provide an education service for those donors through education campaigns. Also, in making contact with them and following up in the future, they will have time to adjust to the idea and what the requirements might actually be when a request is made of them.

Ms Tome—The legislation has coloured the way we prepare donors for donations. We make it very clear that, inevitably, a donor conceived child will try to contact them when they are 18. We prepare them for that so that, when they donate, they know that this is the most likely scenario. We are now finding that a lot of the recipients—single women and same-sex parents especially—want information from the donor before the child turns 18.

Ms Alesi—Very early, actually—like one year or six months old.

Ms Tome—We facilitate that. When the ITA was involved they had a letterbox drop and they would exchange information between donors and recipients without either party having to be identified. That was working quite well. We do not have that process now with the new legislation, but we do that. Sometimes the recipients will want to provide a photo and a thank you letter to the donor to say, ‘This is what your donation has resulted in.’ The donor might want to respond back. Or it might be that the child has turned four and is asking where their daddy is and what he does. They might want some more specific information, and ITA used to make that contact on their behalf. Often they are not ready to disclose who they are but they want this information and the donors are willing to give it.

CHAIR—This is particularly the single women and lesbians?

Ms Alesi—They seem to be more interested in information because there is a not a male father figure on the scene for those particular families. They want to give as much information to the child as possible and at as early an age as possible. I come from Monash IVF clinic. We do not provide that service as intensely as Melbourne IVF does. Under the previous legislation, the system with the Infertility Treatment Authority worked quite well for us. We would refer 99.9 per cent of our requests to the ITA to facilitate and manage the information requests and also to facilitate the counselling issues that might come up with those people too. They had very experienced counsellors with many years of experience in infertility issues. So that worked quite well for us as a body.

CHAIR—That was at Monash?

Ms Alesi—Correct.

Ms Tome—Yes. And we used ITA too—and successfully. For those who wanted early contact we might do the exchange of a couple of photos or letters. But, once we realised this was something they wanted to be ongoing, we would refer them to ITA, who would manage that for them.

But **Ms Alesi**—And it could be a long-term relationship—it could be months or years.

Ms Tome—And we have lost that flexibility under the new legislation, which is a real shame.

CHAIR—You mentioned single women. What proportion are married heterosexual couples, single women or lesbians? What is the proportion of each?

Ms Alesi—The majority are heterosexual couples—at least 60 per cent.

Ms Tome—We have more of a same-sex population.

Ms Alesi—We certainly have same-sex couples and single women but I would say at least 60 per cent from our clinic anyway are heterosexual couples needing donor sperm—or, for that matter, donor sperm. We have about half and half with same-sex couples and single women—roughly 20 per cent each.

Ms Tome—That half of ours would be evenly distributed.

CHAIR—And yours would be a majority?

Ms Tome—No, I think it would be equally distributed across same-sex women, single women and heterosexual couples.

CHAIR—In equal proportion across the board?

Ms Tome—Do not quote me, but yes.

Ms Alesi—We are talking about all donors—donor sperm recipients, egg donor recipients and embryo recipients—so a high proportion would be heterosexual couples.

Ms Tome—Absolutely, yes.

CHAIR—Moving on to counselling, I have one question about the cost. Are you able to shed some light on who should pay for counselling?

Ms Alesi—It is controversial because the majority of clinics are owned by private equity companies. The focus has very much change from how it was 10, 15 or even 20 years ago. These clinics are run as businesses. For the services we provide in our clinic certain counselling is funded as part of patients' treatment cycles, up to a certain point. Then anything above and beyond that, even with our current patients, is fee for service. I do not think our clinic would be able to manage that, even potentially for past patients. They would be looking at that on a fee-for-service basis, if the clinic were to take that on board.

CHAIR—Most clinics are private or for profit?

Ms Alesi—Correct.

Ms Tome—Yes. I would say they are all like that in Victoria now.

Ms Alesi—Yes—all buying each other out.

Ms Tome—We have provided the service free of charge up until now. We are about to start. We will do some of the donor linking and the organising for free but if they come in for specific counselling around preparing, for making contact with their donor, we will now be charging for that.

CHAIR—How much broadly, per hour?

Ms Tome—Seventy-five dollars per hour.

Ms Alesi—Ours range from $100 to $150 per hour depending on the service. If they are patients, they may get a discount service at $100. For issues above and beyond that on a longer term we will be billing them at an hourly rate, which is still a lot cheaper than the general public or people in private practice where people can pay up to over $200 per hour.

CHAIR—How many are there in your counselling group?

Ms Tome—About 25.

Ms Alesi—Yes, 25 or so. The two biggest clinics are Melbourne and Monash. City Fertility Centre has a counsellor and there is Ballarat as well.

CHAIR—You are representing Victoria?

Ms Alesi—Correct.

CHAIR—Are there like groups in other states and territories?

Ms Tome—Yes, there are. We are also part of ANZICA—Australian and New Zealand Infertility Counsellors Association. We meet regularly and have a committee and there are groups within that.

Senator CROSSIN—Are you members of the Fertility Society of Australia?

Ms Tome—Yes. ANZIC is a subgroup of FSA.

Ms Alesi—Part of the requirements of membership of ANZICA is that you need to be a member of the Fertility Society of Australia.

Senator CROSSIN—Do you have a representative of your group on their board?

Ms Alesi—We do.

Ms Tome—Yes.

Senator CROSSIN—So you would be aware of the Victorian inquiry into—

Ms Tome—Yes.

Ms Alesi—We are. We have made submissions to that too.

Senator CROSSIN—You might want to let your president and vice president know about the inquiry. They were not aware of it today when we asked them about that—not at all.

Ms Tome—Members of their board are definitely aware of it.

Senator CROSSIN—Do you have anything to do with RTAC?

Ms Tome—Yes. We work under the RTAC guidelines.

Senator CROSSIN—Are you on RTAC?

Ms Alesi—No. RTAC is now run separately. Previously there were counselling representatives on RTAC, as well as medical and nursing representatives. Now it is run by the system where we have an auditor appointed to the clinic and there are key criteria we have to meet to ensure—

Senator CROSSIN—Who physically makes up RTAC? Who is on that committee?

Ms Alesi—Good question. A lot of it has changed.

Senator CROSSIN—Are there counsellors on that committee?

Ms Tome—No, not now.

Ms Alesi—The system has changed quite a lot in terms of how the auditing is done.

Senator CROSSIN—Yes. We went through that today.

Ms Tome—But FSA has input into RTAC, don’t they?

Ms Alesi—Yes.

Senator CROSSIN—We explored that connection today. We are trying to explore how effective it is.

Ms Alesi—That is interesting.

Senator CROSSIN—Yes. I share your view.

Ms Alesi—I think it is important to have input from all departments and all representatives. We all provide a unique professional background. We are a unique industry because we combine psychologists, social workers, scientists and medical people all working together in the care of one couple or one person. Our points of view in managing patient care can come from very different perspectives.

Senator CROSSIN—So you think this area would benefit from national legislation and oversight?

Ms Alesi—Yes.

Senator CROSSIN—Why do you say that?

Ms Alesi—Because at the moment I think there are inconsistencies in terms of where children are born and what rights they have to access information about their donor origins, and also for the prospective parents. We have single women and same-sex couples from interstate who come to Victoria for treatment because we do have registers and they like the concept that there is the capacity for their children to access information in future. The other issue is being able to manage donors and manage the families formed from a single donor, particularly sperm donors more than egg donors.

Senator CROSSIN—I want to ask you about that. You have come up with the number of 10. Why 10? Why not six or 12? A lot of people are saying five.

Ms Tome—There is a scarcity and as we said this is more related to sperm donors. It is hard to get sperm donors because it is an altruistic donation. Five is a more popular figure in other areas but we would not get the donations we need.

Senator CROSSIN—So are you saying that if you do not pay the donors they will not donate?

Ms Alesi—No.

Senator CROSSIN—What are you suggesting?

Ms Tome—We do not advocate for paying sperm donations by any stretch of the imagination. We strongly support altruism and we think it works. We are able to manage with the limit of 10 families and with the number of donors we have, we are able to manage the demand for donors and we feel quite comfortable with the current program.

Senator CROSSIN—Most people are suggesting five to us. They have not had a figure of 10. Are you suggesting that if it were lower, there would not be enough sperm donors?

Ms Alesi—No and the way donors are recruited may change. At the moment, the majority of sperm donors are altruistic so they are recruited by the clinics. For example, in our egg donation program, we have very few altruistic egg donors. The majority of people coming through our program will recruit their own egg donors. They will either advertise, once they have permission from the health department, or they will ask a family member or a friend. Interestingly, a lot of women are getting egg donations through that path because there is a limited supply of egg donors. The fear the clinics have is, if the number of women who can benefit from a sperm donor is reduced, there will be greater demand and much less supply. That is where the anxiety is coming from. That is not to say that it cannot be managed in a different way.

Ms Tome—We do believe numbers should be limited. There is a lot of talk about consanguinity and making sure that genetic siblings do not meet. Our argument is more based on the complexity for a donor conceived child to comprehend. The more families created, the more complex it gets and issues of identity and belonging become more complicated.

Senator CROSSIN—Which is probably why people have gone for give.

Ms Alesi—Yes. Getting back to a national register, having a central register in Victoria enables all those who donate in Victoria—they might go to Monash five times, they might go to Melbourne five times or they might go somewhere else—the central register can say, ‘There are X number of registered births for that person.’ So once they reach the maximum, they have to be pulled from the clinic and they cannot be used for any new families. So if that person goes interstate, potentially you could have 100, 150 or 200—who knows.

Ms Tome—We know of some people who quite like the idea of doing that.

Senator CROSSIN—Your submission does touch on some interesting areas in respect of the importation from overseas.

Ms Alesi—Yes.

Senator CROSSIN—Today we heard from the society you belong to, the Fertility Society of Australia, that every lot of sperm which comes in from overseas can only be used by the clinics if the donor in the home country has agreed for his information to be released. You are saying here that you should ban importing gametes from overseas where the information about the donor cannot be provided for clinical records. FSA was saying today that none come in unless they get that guarantee. So what is happening?

Ms Tome—Victoria is a little bit different. We have to be able to put that information forward for the central register. They have to have counselling with a counsellor who works for a registered RTAC clinic. Also they have to be able to guarantee in Victoria that that donor will not be used to create more than 10 families.

Senator CROSSIN—Does the overseas donor still have to agree to their information being released to the donor conceived person?

Ms Alesi—If they donate in Victoria but that does not stop their sperm being imported to Queensland or somewhere else.

Senator PRATT—Are you saying that there is less sperm coming into Victoria from overseas because it does not meet this requirement?

Ms Alesi—We do not take any here.

Senator PRATT—And you do not take any which does not meet these requirements?

Ms Alesi—At the moment, the Victoria legislation says that you cannot pay for sperm. That is not under RTAC; it is under—

Senator CROSSIN—I understand what you are saying about Victoria but the Fertility Society of Australia led us to believe that it is not happening anywhere in this country, not at any clinic in this country, unless the overseas donor fills out a piece of paper which says that they are happy for their identity to be released to the donor conceived person.

Ms Tome—I cannot comment on other states but in Victoria we are not importing any sperm from overseas.

Ms Alesi—It may indeed happen in other states. The other issue is access to the information about a donor from another country. It is hard enough here and now, let alone for a young person to seek information from overseas.

Senator CROSSIN—But you must have a view that it is not happening in other parts of the country as it is in Victoria or you would not be making that recommendation in your submission.

Ms Alesi—I am aware that there are clinics interstate who do import sperm from overseas.

Ms Tome—But I am not aware whether they are getting that agreement. We have had sperm clinics contacting us saying that they want to import sperm and we say that we will provide whatever they need, that they will only give us donors who will allow their details to be recorded.

Senator CROSSIN—But nationally, importation of this product is unregulated?

Ms Alesi—The NHMRC guidelines—

Ms Tome—Yes, the NHMRC guidelines say that you cannot pay but we question how enforceable they are. FSA would have a better idea of what is going on Australia wide.

Senator CROSSIN—You might say that.

Senator PRATT—You are clearly associated with clinics that are trying to put together historical pictures for people over time, within a different set of laws. Do you have any awareness of what is happening for people whose records are perhaps no longer held by an active clinic, how the register might be supporting people like that? I certainly know that there are records in other states that are no longer held by clinics. I am not sure if that is the case here in Victoria. Who is facilitating access to those records for them?

Ms Alesi—ITA was previously.

Ms Tome—ITA used to but now, I do not know. Donors would have to put their information on the voluntary register and then, when a donor conceived individual wants to contact, they will be given that information.

Senator PRATT—But they would lose the benefit of a counsellor like you being able to contact that donor.

Ms Tome—Yes, but that is only happening at Melbourne IVF at the moment. ITA used to do that and they would prepare the donor conceived person for making contact. They would look at what they hoped to achieve from it. They would get them to put questions together, the sorts of things they want to ask. Then they would make careful contact with the donor.

Senator PRATT—Why was the decision made backwards as opposed to forwards?

Ms Tome—It was a legislative decision to move the register from ITA, which is now VARTA, over to Births, Deaths and Marriages and Births, Deaths and Marriages function purely as an information provision service. They do not have any of the other support to go with it. Donor conceived individuals who access the central register have to have one mandatory counselling session but that is a very general session; it is in no way providing them with the support they need to make decisions about making contact and support them through that process.

Ms Alesi—What has happened with the changes in the new act, with ITA being rebanded as VARTA, is that the functions of the previous ITA have been farmed out to different government bodies. So you have Births, Deaths and Marriages, you have doctor and family records and VARTA is retained as a community education component, which is valuable but nowhere near what was being done before.

Senator PRATT—What are your views about how demand for this kind of identifying and contact information is going to change over time?

Ms Alesi—I think it will more so because certainly in our clinic—and the same with Melbourne IVF—and in our professional group we educate people before they start the program, in terms of prospective parents. Probably in the last 10 or 15 years with the 1998 legislation there has been a shift in attitudes. That is also reflected at Monash where we run education seminars on a monthly basis preparing people. VARTA has been running education seminars and there is quite a volume of people attending wanting information, people who either have young children or they are currently pregnant or thinking about having donor conception treatment. You can see that there is a wider interest and a lot more openness within the community, through many years of those of us who work in the industry, as well as other supporting bodies around us.

CHAIR—On behalf of the committee, thank you for your evidence and for your submission.

Committee adjourned at 5.11 pm