

REPORT OF PROCEEDINGS BEFORE

LAW AND SAFETY COMMITTEE

**INQUIRY INTO THE INCLUSION OF DONOR DETAILS ON
THE REGISTER OF BIRTHS**

At Sydney on Thursday 1 March 2012

The Committee met at 9.30 a.m.

PRESENT

Mr G. D. Barilaro (Chair)
Mr N. Lulich
Mr J. O'Dea
Mr J. T. Rowell
Mr G. Zangari

GABRIELLE CARNEY, Assistant Director, Legislation Policy and Criminal Law Review Division, Department of Attorney General and Justice, and

STEPHEN BRAY, Policy Officer Legislation, Policy and Criminal Law Review Division, Department of Attorney General and Justice, affirmed and examined:

CHAIR: Welcome, thank you for attending the public hearing of the Law and Safety Committee. This morning the Law and Safety Committee are looking at the inclusion of donor details in the register of births. The inquiry is examining whether the details of sperm, egg and embryo donors should be included on the register of births which is maintained by the New South Wales Registry of Births, Deaths and Marriages. Today the Committee is hearing from Government agencies and stakeholders, including the Department of Attorney General and Justice, the Registry of Births, Deaths and Marriages, the Ministry of Health and the Fertility Society of Australia. I now declare the hearing open and in opening the hearing may I remind everybody to switch off their mobile phones as they can interfere with the Hansard recording equipment. I now welcome our first witnesses Ms Gaby Carney and Mr Stephen Bray, representatives of the Department of Attorney General and Justice. Before we proceed do you have any questions concerning the procedural information sent to you in relation to witnesses and the hearing process?

Ms CARNEY: No.

Mr BRAY: No.

CHAIR: Before the commencement of questions would you like to make an opening statement?

Ms CARNEY: Thank you for giving the Legislation, Policy and Criminal Law Review Division of the Department of Attorney General and Justice the opportunity to appear before you today. The question as to whether donors' details should be included on the register of births is an important issue that is likely to be of significant interest to the community. The views held by the community on this issue are a vital and important consideration in the development of any policy in this area. This inquiry is an important mechanism by which these views can be gauged. The department does not wish to pre-empt the findings of the Committee and, accordingly, has not yet come to a view on whether donor details should be included on the Register of Births, Deaths and Marriages which I will refer to as BDM.

In essence this issue involves the balancing of the interests of donors, donor conceived children and the legal parents of those children. This issue is complicated by the fact that the interests of these groups vary depending on their circumstances. Some donors may prefer to remain anonymous. On the other hand, some donors may wish for the symbolic recognition of being included on the birth register and the donor conceived child's birth certificate. Some donors may even wish for recognition as a legal parent of a donor conceived child. Some parents will wish to be open with their child regarding the identity of their donor from the outset. Some may wish to inform their child once their child reaches a certain age. Rightly or wrongly, some parents may wish never to inform their children that they were donor conceived. Similarly, some parents may wish for the donor to have an ongoing role in their child's life whilst others may wish for their child never to have contact with their donor.

And of course, there are the interests of the donor conceived person. A donor conceived person may wish to access information about a donor to better understand his or her biological history or for other reasons, such as to obtain medical history information, address concerns about consanguinity or to help identify any half siblings. Some people may not wish to have the fact that they are donor conceived noted on their birth certificate, while others may wish to have the donor's role recognised in this way. The challenge is to develop an approach that strikes the appropriate balance between these interests.

If donor details are to be included on the register of Births, Deaths and Marriages, consideration will need to be given to the best mechanism to implement this. The implementation of any such proposal would be the subject of further discussion between the Department of Attorney General and Justice and other government departments. In particular the Ministry of Health currently administers the assisted reproductive technology [ART] central register and there are obvious links between the terms of reference of this inquiry and the ART register. If the Committee is ready I would be pleased to answer any questions.

CHAIR: You may have touched on some of the questions we have prepared for today. The New South Wales Government submission states that a sole repository of donor conception information would provide a streamlined service that would be more economical and user-friendly for individuals than two separate repositories of information. The Victorian donor registers were recently transferred to Victoria's registry of births. In your view what would be the advantages and disadvantages of transferring donor records to the Registry?

Ms CARNEY: Assuming that donor details are to be included on the Registry of Births, Deaths and Marriages, the advantage of transferring the ART register to the BDM would be that it would avoid the prospect of there being two registers maintaining the same information. If two separate registers were to exist this could create an additional administrative burden on government and may be confusing for donors or donor conceived people who may wish to access such information. Also, being able to obtain donor information from the one source would be more user-friendly. Donor conceived people are more likely to approach the Registrar of Births, Deaths and Marriages for information regarding their genetic origins, especially if they have not been informed by their parents that they were donor conceived.

The potential disadvantages of this approach are that there are some health related aspects of the ART register that may be better managed by the Ministry of Health. For example, under the Assisted Reproductive Technology Act the Ministry of Health currently regulates services provided by registered ART providers. If the ART register were transferred other aspects of ART such as the regulation of ART providers would need to remain with New South Wales Health. Similarly, if counselling is to be provided to donor conceived people when they are first informed that they are donor conceived the BDM may not be well placed to facilitate this.

If BDM were to maintain the ART register this may also require significant changes to BDM's operations. New relationships would have to be developed between the Registry of Births, Deaths and Marriages and the ART providers who collect information for the existing ART register. The ART register maintains medical information relating to donors. In the case of a medical emergency or life-threatening situation parents can apply to the Director-General of Health for identifying donor information. Alternatively, donor conceived people may access such information when they become adults. In contrast, other than limited information contained on death certificates, the BDM does not retain medical information. In certain circumstances the ART register may be accessed by donors, donor conceived people, siblings of donor conceived people and legal parents of donor offspring. In contrast, access to the New South Wales birth register is generally restricted to the person in respect of whom the entry is made, subject to limited exceptions such as parents applying for their child's birth certificate and in relation to births that occurred more than 100 years ago.

In Victoria the management of the equivalent of the ART register was transferred from the Victorian Department of Health to the Victorian Registry of Births, Deaths and Marriages in 2008. The Victorian Parliament's Law Reform Committee is currently examining the operation of the register since its transfer to the registry of births, deaths and marriages in its inquiry into "access by donor conceived people for information about donors". The Committee noted in its interim report that it had received several submissions that raised certain practical concerns regarding the transfer of the register from the Department of Health to the registry of births, deaths and marriages. The Victorian committee is due to hand down its report on the inquiry by 30 June 2012. I also note that there is a statutory review of the Assisted Reproductive Technology Act that is due to commence in 2015.

In short, we cannot say at this stage whether the Department would support or oppose the transfer of the ART register to the Registry of Births, Deaths and Marriages. Any such proposal would need to be the subject of detailed discussion between the Department of Attorney General and Justice, the Ministry of Health and the Registrar of Births, Deaths and Marriages. The findings of the Victorian Parliament's Law Reform Committee's inquiry may also be instructive. We also note that if it is not possible or preferable for the ART register to be transferred to the Registry then the Ministry of Health could simply provide BDM with relevant information from the ART register as and when required. This would also ensure the veracity of the information provided to the Registry. Alternatively, legal parents could have the option of voluntarily providing such information with the donor's consent.

Mr NICK LALICH: Some submissions to the inquiry have argued that including donor's details on the birth certificate of the donor conceived child may create confusion in terms of legal parentage. Given that donors are not legal parents and have no parental rights and responsibilities what comments do you have on the issue of legal parentage?

Ms CARNEY: Section 11 of the New South Wales Status of Children Act and section 69R of the Commonwealth Family Law Act provide that there is a rebuttable presumption that a person is a child's parent if the person's name is entered as the child's parent in a register of births, deaths and marriages. On the other hand, section 14(2) of the Status of Children Act provides that where a child is born as a result of a fertilisation procedure the woman's husband or partner, including a same sex partner, is presumed to be the parent of any child born as a result of the procedure provided that he or she consented to the procedure and any sperm donor who is not a husband or partner is presumed not to be the parent of the child. These presumptions apply to fertilisation procedures are irrebuttable and will prevail over any conflicting rebuttable presumptions. The position is similar in the Family Law Act. One of the rationales for this is that if the situation were otherwise it could be a major disincentive to donating sperm, as this would attract legal parental responsibility.

We are not aware of any suggestion by this inquiry to record the name of a donor in the register or on a birth certificate as a parent of the child. However, even if this were to occur any presumption arising from it in relation to parentage would be overruled by the irrebuttable presumption that the person is not the parent of the child. In any case such concerns could be avoided by using a term other than "parent" on the register. In relation to donors a term such as "donor" would probably be more appropriate.

Finally, we are not aware of any current proposal to accord donors with the presumption of legal parentage and this would appear to be the outside the scope of the inquiry. However, I do note that where a sperm donor seeks to have a formal role in a child's life there are alternative mechanisms to achieve this. A sperm donor can apply to the Family Court for a parenting order provided that they are concerned with the care, welfare or development of the child. Parenting orders deal with aspects of parental responsibility, for example, with whom a child can live and who is to be responsible for the day-to-day care of the child. For example, in the case of *AA v. Registrar of New South Wales Registry of Births, Deaths and Marriages*, the case that prompted this inquiry, the donor did in fact have a parenting order that allowed him contact with his child.

Mr GUY ZANGARI: Some of the submissions received by the Committee have advocated the recording of donor information on birth certificates on a voluntary basis, only with the consent of the donor and the child's legal parents and without any legal presumptions arising. This would allow for the symbolic recognition of biological parentage without affecting legal parentage. What is your view of that proposal?

Ms CARNEY: The Department does not have a formal position on whether donor details should be included on the BDM register and would prefer to hear the views of the community and the findings of the Committee. However, where the donor and the legal parents both consent to donor details being included on a birth certificate the arguments in favour of doing so are stronger. The qualification that we would add to this is that due account also needs to be taken of the best interests and wishes of the child. Given that birth certificates are used as a primary source of identification, there is a risk that including donor details on the face of a birth certificate could stigmatise a child. At the very least it is arguable that once a child reaches a certain age, account should be taken of whether the child wishes for the birth certificate to continue to note the details of the donor.

Furthermore, consideration would need to be given as to what would happen if a donor and the legal parents initially agreed for the donor to be included on the birth certificate but the legal parents or the donor later wished for the donor's details to be removed from the birth certificate—for example, if their relationship ceased to be amicable. In other words, whether or not consent should be irrevocable and, if not, what would be the framework for adjudicating the matter? Regardless of what would happen to the appearance of the birth certificate in either of the above scenarios, one would expect that the birth register itself would retain details of the donor. The birth register is a snapshot of the child's birth at that time.

Mr JAI ROWELL: The Law Society expressed the view that the register of births should include all the parents a child could have, such as a donor, but that this information does not need to appear on an official birth certificate. It notes that in certain circumstances it may be possible for a child to have several parents—for example, egg and sperm donors, surrogate mothers and legal parents. Can you comment on the argument that donor details should appear on the birth register but not on the birth certificate, and would there be any legal issues or barriers to the proposal?

Ms CARNEY: There do not appear to be any legal barriers to information being included on the birth register but not on a birth certificate. A birth certificate certifies some of the information that is contained on the register; however, it does not contain all information that is contained on the register. For example, the weight of the child at birth, the place of birth of the child's parents and the existence of half siblings are some details that

may be contained on the birth register but will not be included on a birth certificate. If donor details were not contained on a birth certificate this may allay any concerns that including such information would stigmatise a child or otherwise infringe their right to privacy.

On the other hand, this approach may not completely satisfy the desires of some donors who want the symbolic recognition of being named on the birth certificate. Furthermore, if parents do not inform their child that they are donor conceived the child may never think to ask for such information from the birth register. The same issue arises under the current ART register. Including reference on a birth certificate could be a way of ensuring that parents tell their children of the fact that they were donor conceived.

In Victoria a donor-conceived child's birth certificate has the same appearance as that of a naturally conceived child. However, if a child applies for their own birth certificate in their own right after they turn 18 they will be issued with a separate addendum that indicates that further information is contained on the BDM register. The child may then approach the register and be provided with the details of their donor.

Mr NICK LALICH: The New South Wales ART register began operating in early 2010 and records all donor-received births from that date. However, information about donor births before that date is obtained on a voluntary basis. The issue of whether donor registers should operate retrospectively was raised in several submissions to the inquiry. What is the view of the department on the issues raised by retrospectivity of donor records?

Ms CARNEY: Of course the Department supports existing arrangements in which donor information from births before 2010 may be provided to the ART register on a voluntary basis. The Department does not have a formal position on whether identifiable donor information should be provided on a mandatory basis for births before 2010; however, we suggest that the issue be approached with great care. As a general principle retrospective legislation that derogates from existing rights reduces legal certainty and undermines the rule of law. Strong justification is required in order to retrospectively impose an obligation or adverse effect on rights and liberties since fairness requires that the legal rights and obligations governing certain conduct be known at the time the conduct occurs. Many donors would have donated on the condition of anonymity. To reverse this position through legislation is likely to cause concern for those who donated anonymously. Many such people may have donated on an altruistic basis and could feel legitimately aggrieved by such a prospect.

On the other hand, if it is accepted that there is an interest in donor-conceived people being made aware of the identity of their donors, it must be accepted that that this interest remains regardless of whether a child was conceived before or after 2010.

It may be that an acceptable compromise would be for non-identifying details of pre-2010 donors being made available to donor-conceived people. However, prior to the establishment of the ART register in 2010 there was no government-controlled register resulting from ART in New South Wales, so any attempt to enforce the provision of donor details would rely on those ART providers remaining in existence and maintaining records of those donations and the births that resulted. Therefore it is not clear how effective requiring retrospective disclosure of donor details would be. If the retrospective disclosure requirements were imposed on donations made through private or non-medical arrangements this problem would be even further exacerbated, as it is very unlikely that there would be accurate and verifiable records of these births.

CHAIR: The Registry of Births, Deaths and Marriages operates on a cost-recovery model, whereby fees paid by its customers fund its services. However, the New South Wales Government's submission notes that this practice may discourage donors from placing themselves on a voluntary register kept by the Registry, as the NSW Ministry of Health waives fees under the current system. Can you comment on that at this point?

Ms CARNEY: The Registrar of Births, Deaths and Marriages may be in a better position to address this question, and I note that he will be speaking later today. As a general point I note that the argument in favour of waiving fees would be based on a concern that the charging of a fee may act as a disincentive to voluntary registration. If a fee were to be set at a modest level this may not impact on registration decisions. Having said that, I note that under existing arrangements on the ART register no fee is charged and similarly in Victoria we understand that no fee is charged for adding donor details to the voluntary register.

Mr JONATHAN O'DEA: I have three questions flowing from what you have presented to the Committee this morning. First, in the context of quoting the legislation on presumption of parentage you

referred to sperm donors but not to egg donors. Is the situation different between the two? If so, how is it different? If it is not different, is there a legislative oversight?

Ms CARNEY: I believe the position is the same, actually. Section 14 (3) of the Status of Children Act states: "If a woman (whether married or unmarried) becomes pregnant by means of a fertilisation procedure using an ovum obtained from another woman, that other woman is presumed not to be the mother of any child born as a result of the pregnancy."

Mr JONATHAN O'DEA: So there is a similar provision to that which you quoted before in relation to sperm. Thank you. The second question relates to the rights of the donor-conceived person—sometimes referred to as the child. In debates on similar or related issues Parliament has made it fairly clear that it generally sees the interests of the child as predominant. I am not saying that that is necessarily reflected in the legislation in a black-and-white sense, but in your reference to balancing the interests of different parties in an appropriate way is there any legislative basis at the moment for regarding the interests of the child or donor-conceived person as greater than the interests of any of those other parties? If so, can you point us in that direction?

Ms CARNEY: In terms of ART procedures?

Mr JONATHAN O'DEA: In this context or, indeed, if you aware in any other context. From my experience I can only point to statements made in Parliament, which are indicative I think rather than binding. That is perhaps a question from left field but if you have any insights I would appreciate it.

Ms CARNEY: I think we may have to take that one on notice. I cannot think of any legislative provisions in New South Wales that make that statement but we can certainly look into it and get back to the Committee.

Mr JONATHAN O'DEA: That would be great.

Ms CARNEY: Under the Family Law Act I know there is a principle of the best interests of the child but we can do further work and get back to you.

Mr JONATHAN O'DEA: My final question relates in particular to the Victorian jurisdiction. I think it useful to be aware that there is a Law Reform Committee report imminent at the end of June. I personally see that there might be some desirability in having consistency of law between different jurisdictions. Do we have any insight or indication of what that report is likely to say or any indication from that jurisdiction as to its experience to date?

Ms CARNEY: There was an interim report that was released by the Victorian Parliament Law Reform Committee in September 2010 I understand and there were a number of submissions received in that process, which I believe are up on the website. The interim report covered the issues that have been raised to date. I think it made one or two recommendations and then noted that it felt the issue needed further consideration.

CHAIR: Did the Department of Attorney General and Justice make submissions to that?

Ms CARNEY: Our department?

CHAIR: Yes.

Ms CARNEY: No.

Mr JAI ROWELL: Are there any other issues that might not have been covered today that you think might be relevant for the Committee to consider at a further point in time?

Ms CARNEY: I think we covered them in the opening statement really. We covered the point about the range of varying interests involved, and we will be very interested to hear what the Committee recommends.

Mr JAI ROWELL: I thought Mr Bray was going to say something in relation to Mr O'Dea's second question. Do you want to elaborate on anything?

Mr BRAY: No. I was going to suggest that the position in relation to the best interests of the child would probably depend on the legislation, but I think it is probably best that we take the question on notice to see if there is any sort of overarching principle that might run across several pieces of legislation.

Mr NICK LALICH: We have talked about a donor child or artificially-conceived child reaching a certain age and having the right to ask if he wants to know who his biological parent donor was. It could be 18, 16, 21 or whatever age may be set, but some children are far ahead of their years in age. For example, when I was at school there were some people who were only 14 but had the mind of a person of 18. What if you have a child at 14, or even a child of 13, who hits high school and wants to know who his or her donor parents were and they have a psychological problem—he or she really needs to know? On medical grounds do you find a problem with he or she being given that information or do you think it should be set at a certain age before that information can be requested?

Ms CARNEY: I think that will be one of the issues that the Committee will be grappling with, because different jurisdictions have taken different approaches on this. For example, in Western Australia I understand a child is able to make an application at the age of 16, whereas in Victoria a child is able to make an application from the age of 18. There may also be frameworks in place for parents to make applications prior to that time before the children are able to on their own behalf.

Mr NICK LALICH: What if there were medical grounds and a doctor was saying, "We really need to know this because of the child's psychological condition." I am concerned because the Committee has to make a decision on 16, 14, 18 or whatever, and if there is a child who wants to know earlier because it is causing them a problem psychologically, it would be remiss of the Committee not to look at it and say under medical circumstances that information should be given earlier.

Ms CARNEY: We could certainly take that on notice and spend some time looking at the other jurisdictions and the models that are operating at the moment and come back to the Committee.

CHAIR: Thank you for appearing today. The Committee may wish to send you some additional questions in writing, the replies to which will form part of your evidence and be made public. Would you be happy to provide a written reply to any further questions?

Ms CARNEY: That is fine.

(The witnesses withdrew)

GREGORY CURRY, Registrar, Registry of Births, Deaths and Marriages, and

DEBORAH JAYNE LEYSHON, Manager, Registrations, Registry of Births, Deaths and Marriages, affirmed and examined:

LISA ANNE KARAM, Manager, Amendments, Registry of Births, Deaths and Marriages, sworn and examined:

CHAIR: I welcome representatives from the Registry of Births, Deaths and Marriages. Thank you for appearing today before the Law and Safety Committee. Before we proceed, do you have any questions concerning the procedural information sent to you in relation to witnesses and the hearing process?

Mr CURRY: No, I do not.

Ms LEYSHON: No.

Ms KARAM: No.

CHAIR: Would you like to make an opening statement before questioning?

Mr CURRY: No.

CHAIR: Could you give us an overview of how births are recorded on the births register and what information you record on the register that does not appear on the birth certificates?

Mr CURRY: The birth registration process essentially begins when a child is born to a mother and the mother, the parents, are given a form called a Birth Registration Statement, which is provided by the hospital or the midwife, and the parents are required by the Act to complete the form and forward it to the Registry of Births, Deaths and Marriages within 60 days. When the registry receives that form we check that form against the notification provided separately by the hospital or the midwife and where those details are correct those details are entered on the register.

CHAIR: In relation to that, what proof is required to verify the information that has been provided?

Mr CURRY: Do you mean as to the identity of the parents?

CHAIR: Correct.

Mr CURRY: The identity of the parents is crosschecked against the information separately provided by the hospital, but where registration occurs within that 60-day period, in this State we do not routinely check the identity of the parents; we do not require them to provide forms of identity. Where a birth is registered outside the 60-day limit then we do seek further identification from the parents.

Mr NICK LALICH: Could I just follow on from that? You know it is the mother because she went to the hospital and had the child, but how do you know if the father is not just some boyfriend mum has picked up in between, conceiving the child with another person? If you are not checking that how do you know that that is actually the father? The mother is saying it is until she gets sick of that bloke or whatever and then she moves on or he gets sick of her—whichever way. Do you ever crosscheck that to make sure?

Mr CURRY: Apart from checking against the hospital records?

Mr NICK LALICH: Yes.

Mr CURRY: Both parents are required by law to sign the birth registration statement and in the normal course of events that is what happens. Where there are no father details, for instance, we make inquiries of the mother, and although it is a requirement under the Act that the father has to sign the form, the practicalities are that there are limits as to how deeply we can inquire into the personal affairs of people.

Mr NICK LALICH: Are you able to tell the Committee how the information that appears on New South Wales birth certificates is different from that in other Australian jurisdictions?

Mr CURRY: The information in New South Wales is very similar to that which appears in other jurisdictions throughout the country. The format and layout differs and some items placed on birth certificates at different times have been removed. So there has been some variation over the years. Basic information such as the name of the child and the names of the parents is quite consistent across all the jurisdictions. Debbie, would you like to add to that?

Ms LEYSHON: Not at all. I agree with what the Registrar is saying that although the format may appear differently it is pretty much the same information that is being recorded or printed.

Mr JAI ROWELL: I understand that you are conducting a review of birth certificates. Could you tell us what the review will cover and how it will be conducted? For example, what consultation will you undertake?

Mr CURRY: The review that we are planning, to give the Committee some background and perhaps refer to an earlier question as well, where there is some dispute over the contents of the register those matters can sometimes be heard by the Administrative Decisions Tribunal. In a matter approximately one year ago a member of the tribunal made some observations regarding the format of the birth certificate to the effect that the format had been unchanged for some years, and although that was a side comment in the matter at hand we looked at that comment and when we examined the issue we found that we had not changed the format of the birth certificate for approximately 50 years. The only change we could identify was that in the early 1990s where we had previously recorded details of previous children of that marriage we changed the word "marriage" to "relationship", and that prompted us to consider that it was appropriate that the format be reviewed.

The consultation that we are proposing to undertake would include parents groups, medical organisations, providers of assisted reproductive technology services, organisations providing counselling, other departments such as Centrelink, Immigration and Citizenship, Human Services, law enforcement agencies, the Australian Bureau of Statistics, the Ombudsman, the Anti-Discrimination Board, the Law Society, the Bar Association, community legal centres, maternity hospitals, the Department of Health, midwives and doctors, demographers, medical ethics committees. We hesitated to proceed to the consultation phase when we became aware of the Committee's work and thought it prudent to just hang back a bit where we were.

Mr JAI ROWELL: My second question is in relation to staffing matters. I have a friend who was down at the Registry of Births, Deaths and Marriages a little while ago this morning and he said there were eight people at the counter. If there were significant changes made to the recording of information on birth certificates would there be a need for additional staff? Do you see that as an issue?

Mr CURRY: We do see that as an issue. The Committee would be aware that we do not receive funds from Treasury, so we have to fund all the costs of our operations and our capital program from providing goods and services. At this point we are probably not in a position to say what impact it would have, of course, but my expectation is that where additional work was required that we would have to look at whether we could do that within our existing resources or whether we would need to increase those.

Mr JAI ROWELL: Could you take that on notice and report back to the Committee at a further point?

Mr CURRY: Yes, we would be happy to do that.

CHAIR: In relation to the previous question about your current review and how you are awaiting the report of this Committee—we are hoping to report by midyear—what is the time frame for the review that you are conducting at the moment?

Mr CURRY: We have not set a time frame. We did intend to complete it around midyear. We have some flexibility about that. We expect to commence our consultation phase shortly.

Mr GUY ZANGARI: The Victorian Registry of Births, Death and Marriages manages the donor registrations in that State. In Victoria, birth certificates of donor-conceived individuals have an addendum attached indicating further information is available. Are you able to provide further details or comment on Victoria's system and what are your thoughts on whether and how this could be implemented in New South Wales?

Mr CURRY: I do not believe it is for me to necessarily comment on the operations of another jurisdiction. I make the observation in general that it has been our practice in the past and it is quite standard for us to provide annotations on birth certificates. Typically, for instance, if a person changes their name during their lifetime an annotation will subsequently appear on their birth certificate. It may be feasible for us to include such an annotation, where donor details were available, to the effect that further details regarding the birth were available on application.

Mr GUY ZANGARI: Further to your comments about the annotations, could you give me an example of how an annotation is marked currently on the birth certificate?

Mr CURRY: It appears at the bottom of the birth certificate on the front and where it is extensive I believe it overflows onto the back.

Ms KARAM: It can go onto the back if there are multiple notations on the birth certificate.

Mr CURRY: It would typically be a very short sentence; for instance, it may be, "This person was previously known as..."—another name. Generally they are that brief. It is very rare they would flow over the page.

Mr NICK LALICH: Submission makers have proposed the retention of the existing ART register with the Ministry of Health, with the additional voluntary recording of donors' details in the birth register. What is your view on this suggestion?

Mr CURRY: There are functions that the registry is not equipped to carry out; in particular I refer to things such as health or genetic counselling and family counselling. We have a good working relationship with, for instance, the Department of Human Services in relation to adoptions, and in the case of adoptions where a person who was adopted seeks a copy of their original birth certificate supply authority is provided by the head of the Department of Human Services, which arranges support for that person. That is something that we are not equipped to do but the division of labour, as it were, works quite effectively. Once we get that supply authority we can proceed to issue the original birth certificate. In terms of the central ART register operated by Health, I believe there are functions operated by the health department or affiliated with the health system which we are not in a position to operate. I am thinking of the type of counselling and genetic support that one would expect to be provided to someone who was seeking details of their donor.

Mr JONATHAN O'DEA: The Law Society argues that the register of births should include all the parents a child could have, such as a donor, but that this information does not need to appear on an official birth certificate. They note that in certain circumstances it may be possible for a child to have several parents—for instance, egg and sperm donors, surrogate mothers and legal parents. Can you comment on the practicalities of donor details appearing on the births register but not on birth certificates?

Mr CURRY: Donor details could be recorded on the births register. The question as to whether it would appear on a birth certificate is at the discretion of the Registrar at the moment. I can require anything that is held on the register in relation to a birth to be included on a birth certificate. Whether donors would become parents or the equivalent of parents would of course be a matter for Parliament. The question that arises is the conditions under which access to that information would or would not be granted. I have briefly outlined the situation as it relates to adoptions. I think that could possibly provide a guide as to the type of regime which could operate in a similar fashion in respect of donors.

Mr JONATHAN O'DEA: Can you illuminate for us the different processes and perhaps inconsistency between donation situations which involve ART and those that are undertaken through more informal mechanisms, and some of the complexities that can arise in that situation?

Mr CURRY: A crucial complexity that would arise immediately is that at the moment parents are required by law both to jointly register the birth of a child. The question that arises immediately is that were such an informal arrangement made between three or four people, what level of compulsion should exist and rest with the donor or the parents to require the recording of that information. I point out also that the registry holds records in perpetuity. We have an obligation to ensure the integrity of the register. We would therefore take some steps, perhaps by statutory declaration, to obtain some level of confidence about the identity of the

donors. Earlier questions raised the steps we take to verify the identity of parents. I am aware of other jurisdictions in Australia that have a more stringent approach to that.

That question is under active consideration by the New South Wales registry. We expect we will in future seek a higher standard of identity checks on parents at the time of registration. This has been prompted by the general move towards greater identity security across the community. Returning to the question, the difficulties that may arise are, firstly, whether people would be required to register as donors and what sort of identity checks we would make on the identity of the donors, our access to that information and who would have access to that information and within what time frames. I was going to mention another aspect, but it will come to me shortly.

Mr JONATHAN O'DEA: While that is working at the back of your mind perhaps I can ask you this: Where a problem is identified, perhaps of the type Mr Lalich referred to earlier where there was a misapprehension as to who was the true father or a situation where the intention of the parties might change in relation to a donation, what is the scope for and the procedure to have paternity, in particular, changed? Does a person have to go through the Administrative Decisions Tribunal? I am aware that in some cases it goes to the District Court when there might be an element of contention. Do you have the discretion yourselves to make those changes without recourse to a third tribunal or court?

Mr CURRY: Thank you, you have hit upon the matter I was going to raise, which is the question of disputes, particularly disputes about events that may have occurred 15 or 20 years earlier. I will defer to Ms Karam who can perhaps shed further light on this.

Ms KARAM: We can add parentage details. Under section 18 of our Act we can add a father's details to a child's birth registration. We can do it under section 18(a), which means that both parents come to the registry and make an application. There is no dispute and there is only one person on the birth certificate so everybody comes in and does a statutory declaration and we make the registration. We can also do it by court order if a court orders the Registrar to include parentage details. The Registrar can also ask for DNA testing in some cases of dispute. There is also the option for a mother's details to be added to the birth registration of a child if there is already one mother on the birth certificate. We do it in a variety of ways. The disputes are often settled outside the registry. They can be settled in the Administrative Decisions Tribunal, they can be settled in court.

Mr NICK LALICH: Would that have to be settled through DNA testing? I do not want to cast aspersions on anybody but a prominent Federal member of Parliament paid maintenance for a child for some 20 years and found out later it was not his child. I take it his name would have been on the certificate. Mr O'Dea's question was a good one.

Mr CURRY: To add to Ms Karam's remarks, the issue of DNA testing can be interesting, to say the least, particularly as some of the testing that is done may not actually assist very much in determining who is or is not the parent. This is where the question of the difference between a donor and a parent may become much more important. Whether to add a parent or not could be quite a different matter to adding a donor or not if the donor is not a parent and therefore has none of the obligations and responsibilities of a parent. I do not think we have a settled view in the registry about whether a donor's details are in fact further details in relation to the birth.

Ms KARAM: Case by case.

Mr CURRY: We have to look at issues on a case-by-case basis where disputes arise. It is always preferable that the parties resolve them before they come to us. We have some discretion in some specific areas. Very often the matters have to be adjudicated by a court.

Mr JAI ROWELL: What about the method of the donation? Are there any challenges that arise? I understand some of those donations can be rather informal and might give rise to a party thinking it was a donation whereas it might actually be becoming a parent.

Mr CURRY: That does not arise at the moment. As I understand it, under the law in New South Wales at the moment a donor is not a parent and therefore someone who was a donor, even if they came forward and all parties agreed that they were a donor, could not be added to the register as a parent of a child. I am not aware

of any case where parties have come forward and requested us to add the details of a donor to an entry in the birth register. I do not know whether Ms Leyshon or Ms Karam knows of any.

Ms KARAM: No. In the AA case — can we talk about that? There was only one parent on the birth certificate and then a father was added and then the father was deemed by a court to be a donor. It is difficult to determine.

Mr CURRY: The situation has not arisen as yet where we have had to consider an application by a donor to be added as a donor.

Mr NICK LALICH: Some submissions advocate a system of recording donor information on birth certificates on a voluntary basis, only with the consent of the donor and recipient parent and without any legal presumption arising. This would allow for symbolic recognition of biological parentage without affecting legal parentage. Would this raise any particular difficulties for the registry?

Mr CURRY: I guess the comment I would make on that would be that the birth certificate to date has not been a "conception certificate". It is a record of the birth of a child. It is silent as to how that child was conceived. Again, referring to the question of adopted persons where in the normal course of events an adoptive person, if you like, their origins, the fact that they are adopted does not appear on their birth certificate and there is a regime in place where they can obtain an original birth certificate. I mentioned earlier that we are reviewing the content or the format of birth certificates.

One of the possibilities, options we have discussed is whether in fact we use or adopt different types of birth certificate, one of which would be a certificate of the birth of a child and another certificate which would be more of a historical origins certificate where it would contain details of, if they were adopted, their birth parents as well as their adoptive parents. It seems to me that a similar regime in relation to donors would be feasible and subject to a proper regime in place about the release of such a certificate or access to such information. I think that would address privacy concerns in relation to inclusion or not of a donor details on a certificate. So basically we could have two or three different types of certificates, one of which would be available through, if you like, a different application channel. It would have different checks in place. A certificate could have access to that.

Mr JONATHAN O'DEA: Just to clarify and drawing a parallel with an adoption situation, and recognising the astute observation, you said it is not a conception certificate, it is a birth certificate. In a situation where there are adoptive parents at birth, are those parents ever recorded on a birth certificate and the natural mother and/or father treating themselves as donors?

Mr CURRY: They are not treated as donors at the moment. I will ask Ms Karam to provide further information.

Ms KARAM: An adoptive person in New South Wales has two birth certificates. They have what we call their pre-adoptive birth certificate, which contains the details of their birth parents. Once the adoption is finalised in the Supreme Court and the registrar is notified of that adoption being finalised, then they are issued with their birth certificate which has their adoptive parents on it. If the person wishes to get access to the original pre-adoptive birth certificate the process that Mr Curry described, where the department—they approach the Department of Human Services, are given a supply authority. All the counselling and support services are handled there in the adoption unit. Then the registrar issues the pre-adoptive birth certificate. Does that answer?

Mr JONATHAN O'DEA: When there is a post-adoptive birth certificate is there an asterisk?

Ms KARAM: No.

Mr JONATHAN O'DEA: What indication is there, if any, that it is in fact a post-adoptive birth certificate?

Ms KARAM: There is no indication. There is no visible identifier that this person is an adopted person. There are obviously flags within the registry system to alert staff. Those pre-adoptive records are restricted to staff who are working with adoptions. So we have levels of privilege within our system.

Mr JONATHAN O'DEA: Could you conceive a situation where a pregnant mother might say "I'm not only happy to give up this child for adoption. I'm prepared to treat myself as a donor" and perhaps the natural father treating himself as a donor? It seems to me as though it is not too much of a logic leap to envisage that as a situation, given where we are with the myriad of other potential formulas.

Mr CURRY: If I could perhaps come in on that, I agree it is largely a matter of semantics as to someone in that situation if a woman has decided to make a child available for adoption. Then in effect it is a different—at the moment it is described differently to a donation of a gamete. Although much of the discussion and literature around donors is about sperm donation, of course there are egg donations as well. I would agree with the proposition that this is largely semantics from the point of view of the child. As the child is born there is a regime in place called adoption and qualitatively it seems to me to extend that to donors is not a great step. It does not seem to be a big step further back in the production chain, you might say.

CHAIR: We asked this question earlier to the Attorney General's Department but I think it is more important that we ask you. The Registry of Births, Deaths and Marriages operates on a cost-recovery model whereby fees are paid for customer-funded services. However, the New South Wales Government submission notes that this practice may discourage donors from placing themselves on a voluntary register kept by the registry as the Ministry of Health waives fees under the current system. Can you comment on this point?

Mr CURRY: I do not think that any modest fee should discourage someone who is motivated to become a donor. The fees that the registry charges are for its other products and services, are competitive and around the middle of the range across all of Australia. So we do keep our costs down and ensure that our fees are as low as they can be. In terms of the type of fee that could, would or would not be charged, it is important to remember that there is no fee for registration. We do not charge a fee to register a birth. We do charge a fee for a certificate. I believe it is an open question at the moment as to whether we would charge a fee for including details about a donor. It is a matter that yes, we would need to look at that and a question on notice about the likely quantum and we can respond in perhaps further detail later on, but my view would be that any fee that we would have to impose would be quite modest.

Mr GUY ZANGARI: Some submissions to the inquiry have raised privacy concerns about the suggestion of including donor information on birth certificates and that it may disclose a person's donor conceived status. What is your view on the privacy issues raised by such information appearing on birth certificates?

Mr CURRY: I agree that there are those privacy issues and that the privacy of the donor is certainly one of those issues. Of course, the donor has other children perhaps, a partner perhaps and their own family. So the privacy issues are actually broader though I agree there are privacy issues to be dealt with in relation to including those details on a certificate. As I mentioned earlier, a birth certificate is a certificate concerning the birth of that child, not about the conception of that child. While we could hold and manage information about donors, as we do about birth parents or surrogates at the moment, we have protections in place to ensure that access to that information is controlled. So one consequence of including donor details on the register would be that we would need to establish a similar regime in regard to access to those details.

Mr JAI ROWELL: Are there any services currently provided by the Ministry of Health in relation to the donor registers that your office would have difficulty in providing?

Mr CURRY: Yes.

Mr JAI ROWELL: Care to elaborate?

Mr CURRY: The registry does not provide counselling or support services. In the case of adoptions, as I think you all heard, the Department of Human Services operates a specialist adoption unit which provides those services in respect of adoptees and they do so prior to information being released by the registry. A similar approach could be taken in regard to donor conceived people.

Mr NICK LALICH: The Fertility Society of Australia has submitted that both the Ministry of Health and the Registry of Births, Deaths and Marriages are experienced in records management and dealing with confidential information that would be required to maintain donor details. However, they express the view that neither agency has the resources to fully cater to the needs of customers and clients in relation to assisted reproduction, for example, in terms of providing public information and counselling. What is your response?

Mr CURRY: The registry does have experience in managing information about civil registration and dealing with confidential information. For instance, we maintain records of adoptions and do so in a confidential manner. We could not provide services relating to counselling or public education. That is outside our area of expertise.

Mr GUY ZANGARI: We are here as a result of the submission made to the inquiry regarding the removal of the detail of the father on the original birth certificate. I want to ask about the process by which the removal of any such detail occurs at the Department of Births, Deaths and Marriages. Obviously applicants have their motives but it is a very sensitive area. Can you further elaborate on those details being removed and the processes by which that occurs at the department?

Mr CURRY: I will ask Ms Karam to respond to that question.

Ms KARAM: In the case of a father being removed from a birth certificate and a mother being put on a birth certificate, that can only be done by court order. In the case of a father's details being removed from a birth certificate and another father's details being put on it, that can be done by court-ordered DNA testing.

Mr JONATHAN O'DEA: Are there any circumstances ever in New South Wales where more than two parents can be registered on the birth certificate?

Mr CURRY: No. There are only two parents.

CHAIR: Thank you for appearing today in front of the Committee. The Committee may wish to send you some additional questions in writing, the replies to which would form part of your evidence and be made public. Would you be happy to provide a written reply to any further questions?

Mr CURRY: Yes, I would be happy to do that.

(The witnesses withdrew)

LEANNE O'SHANNESSY, Director, Legal and Regulatory Services, NSW Ministry of Health, and

GREG McALLAN, Associate Director, Legal and Regulatory Services, NSW Ministry of Health, affirmed and examined:

CHAIR: Do you any questions concerning the procedural information sent to you in relation to witnesses and the hearing procedure?

Ms O'SHANNESSY: No.

Mr McALLAN: No.

CHAIR: Do you want to make an opening statement?

Ms O'SHANNESSY: No.

Mr McALLAN: No.

CHAIR: Will you provide an overview of the process of gathering and recording information in relation to ART treatment and births both before and after 1 January 2010?

Mr McALLAN: Since 1 January 2010 when the assisted reproductive technology commenced the ART providers are required to notify the Ministry of Health when a donor-conceived child is born, when there is a live birth of a donor-conceived child. Of course, that meant that it was only conceived from 1 January so there were no births recorded up until about September, and from that date, the ART providers are required to give us information on identifying and non-identify information about the donor or the later information about the offspring. When this child reaches 18, maturity, they can access identifying information about their donor from the registry on application.

For children conceived before that date there is a voluntary register. It is the same register basically, and it is the same information that can go on, but the information that goes on is given voluntarily by the donor and the donor can stipulate the level of information that is going to be disseminated later on. So it could go to the parent, it could go to other offspring of the donor or it could go to that donor-conceived child. The donor may only consent to non-identifying information going out, for example, medical information or physical characteristics information. That is the major difference between the voluntary and the mandatory. With the mandatory, the offspring has complete right to all that information once they reach the age of 18 years.

Mr NICK LALICH: How many donor-conceived births have you registered since the inception of the registers, both in terms of the voluntary register and births, and births occurring after 1 January 2010?

Mr McALLAN: After September 2010 basically, we have had 296 births to date which is pretty much 200 a year and it has maintained that pace the whole time since September. In terms of voluntarily provided information, we have had nine donors volunteer their information and two donor-conceived offspring. We have not had any offspring that were not donor-conceived looking for information and looking to register information. Parents cannot register information. They can only get non-identifying information from the register. We have had 10 surrogate births registered since the Surrogacy Act commenced.

Mr NICK LALICH: You said there were two donor-conceived births and 10 surrogate births. That is not a great number but would it fluctuate and be greater?

Mr McALLAN: It is early days.

Mr NICK LALICH: I am not trying to belittle it by saying it is not a great number. A person still has the God given right to know where he is from and who he is from but it is not a huge number: it does not go into the hundreds?

Mr McALLAN: No. You will find that in places such as Victoria that has had it running for decades, it is still in the hundreds of registered volunteers. It is always a struggle, I understand, to get men, particularly who have donated under anonymous conditions to volunteer their identifying information. I might go into another

question, if that is all right, about an awareness campaign? At the moment we are running an awareness campaign through Infomed and being distributed is a brochure, which I think has been tendered, and posters. The campaign has only been running for about three weeks and so far about half of the 800 clinics which subscribe to Infomed have taken up the posters. We have not had a huge increase in inquiries at all. In fact, it has pretty much been stable but that is expected apparently, according to the ART providers, there is often a long take-up period for any advertising that they do to acquire new donors.

Mr NICK LALICH: Is a background check done on a sperm donor to ascertain whether he has a criminal record?

Mr McALLAN: My understanding is that donors are thoroughly checked medically and counselled as well.

Mr NICK LALICH: As far as a criminal record is concerned as to whether they are paedophiles? Are they then screened and removed from the register? Do you want their type of genetics to carry on?

Mr McALLAN: I am not sure that they screen for social characteristics such as that. I am not even sure if they do a criminal record check. But I know that they do genetic testing.

Ms O'SHANNESY: I think the focus is on the medical issues. I think you will probably be hearing from the fertility society and it would be most of its rules that would be followed. That might be a question they could answer.

Mr McALLAN: Their accreditation rules.

Mr JAI ROWELL: What is the process for accessing information on the ART registers? What support services do you provide?

Mr McALLAN: We have a whole suite of application forms for different types of applicants because there is different information that can be accessed by different people. As I said, parents can access non-identifying information so there is an application form for that. Generally though parents know non-identifying information about their offspring because that is partly the way they choose the donor, that is, through the non-identifying information on characteristics. At the moment there are no children who can access the mandatory register, obviously, they have to be of the age of majority so they do not access anything at the moment. Donors can apply for non-identifying information on the mandatory register but we so far have not had any inquiries about that.

In terms of the voluntary register, what we get from the offspring and the donors is all information that they know, particularly in terms of their ART provider, if they had them. If they do not know their ART provider we go to all ART providers—of which there are only about 17 so it is not a major issue. They are aware that we will go to all of them as well. If the ART provider identifies that they did have that donor donating they get back to us with non-identifying information which can then be matched should an offspring puts in an application. That is how we get a match out of it. We have not had many applications on the voluntary side so that really has not been tested as a method as yet.

Mr JAI ROWELL: What support services do you provide?

Mr McALLAN: We have trained staff—not in terms of counselling. It was never envisaged, as my understanding of the second reading speech, that counselling would be provided by the State. Counselling is mandatory but it is a private arrangement and it is privately funded.

Mr JAI ROWELL: How do you tick off that counselling has occurred?

Mr McALLAN: The ART provider has to provide that counselling and tested when it puts in the information about the live person. That is how we know that it has occurred. Also, ART providers have been providing counselling mandatorily under their accreditation for about six or seven years. They are very used to that process.

Mr JAI ROWELL: What are the main issues for clients that arise in providing those support services?

Mr McALLAN: The inquiries we have had are mainly around the intricacies of the legislation because there are a lot of exemptions under the legislation. For example, women who want to continue families using the same donor, who would not otherwise have ticked all the boxes under the new legislation, are allowed to continue to use that donor but there are all sorts of intricacies there in terms also of export and import of gametes. They are the sorts of questions that we have been mainly getting. We have had had one question from a donor recently saying that there was too much red tape but that was mainly around the 100-point identification that we require. It is very personal information that we are registering as true, and we want to know that they are the person, and this person had issues about that. I feel in this case that that sort of red tape is warranted.

Mr GUY ZANGARI: This committee has received a few submissions proposing the retention of the existing ART registers with the Ministry of Health with the additional voluntary recording of donor details on the births register. What is your view on that suggestion?

Ms O'SHANNESY: I think that moves into the next question in relation to the Government's submission. Our view probably would be that a sole repository is a better system. Where that sole repository goes obviously is a matter for discussion of the Government as much as anything else. I do not know if Greg has any ideas of advantages or disadvantages.

Mr McALLAN: Disadvantages would be double handling of data, just in terms of administrative efficiency; it is not particularly efficient to have it in two places. Another disadvantage is that it adds to confusion for the clients about where to go. Logically, you go for birth information to Births, Deaths and Marriages. On the other hand, we have already got this up and running. In that sense, I am not sure what other resources we would require to make an arrangement with Births, Deaths and Marriages if it was decided to put it on their register as well.

Ms O'SHANNESY: Obviously you would be asking Births, Deaths and Marriages similar questions. I would say that there is a view from both of us that it does not quite fit with our core business. We are a Ministry of Health. We are not a register of births. I think there may be a concern from them, which they can express if they have it, about the nature of the information being very health related and a bit of discomfort there. I think there is a view from both agencies. We are not quite sure where it would fit, but as you see from the Government's submission, we all agree for the community, putting aside our little bureaucratic views, it probably would be better to have it in one spot. Then it is just a discussion obviously for your thoughts and probably for government to think about where that might best sit and also, as it grows in the future, what it will be expected to do might be a factor in that as well.

Mr JONATHAN O'DEA: Who pays for the existing system within NSW Health?

Mr McALLAN: It comes out of the private health care unit's budget.

Mr JONATHAN O'DEA: So it is met by the taxpayer?

Mr McALLAN: The register is, yes.

Mr JONATHAN O'DEA: That is different to Births, Deaths and Marriages, which is self-funding.

Mr McALLAN: I will just add to that. There is actually a fee of \$50 for applications, but due to the low numbers of applicants for the voluntary register we are waiving that fee at the moment.

Mr JONATHAN O'DEA: In one sense you are quite happy to give it up because you will save some money, which is not necessarily a bad thing. If it were transferred to Births, Deaths and Marriages, what is the approximate cost at the moment of running that service?

Mr McALLAN: It is minimal cost to us at the moment. I would say it is maybe one full-time equivalent position.

Ms O'SHANNESY: Perhaps we could come back to you if you want the specific information. That might be helpful.

Mr McALLAN: Yes, and we could give you a more accurate number.

Ms O'SHANNESY: If it does transfer, I think they will take the money.

Mr JONATHAN O'DEA: If an ART provider goes bust or otherwise ceases operation, what happens to the records they keep?

Mr McALLAN: That would be the health information records that they are obliged to keep. I am not sure under the ART Act if they are obliged to store them. I know that under the Private Health Facilities Act if a licensed private health facility goes bust—and most of them are actually licensed private health facilities—or whatever, they are obliged to find somewhere to keep those records as health records have to be kept. That is the other issue: ART providers are required to keep them for 50 years at the moment. So after 50 years they are gone anyway.

Mr JONATHAN O'DEA: If responsibilities are shifted to Births, Deaths and Marriages we have to be careful to make sure that some of those obligations that might at the moment marry in more with Health are not lost in the transfer. Perhaps you could take that on notice, give some thought to that information and get back to the committee?

Ms O'SHANNESY: I think we could give you something more comprehensive because there are also provisions under the health records privacy legislation but, as Greg said, if they are licensed facilities, that licensing obligation remains with Health. So their obligations to retain the records will continue.

Mr McALLAN: We would presume that their obligation to make and maintain records would be under the ART Act.

Mr JONATHAN O'DEA: You mentioned or suggested that perhaps the information actually collected before 2010 as opposed to that collected after 2010 has not really changed much, if at all. Is that being accurate?

Mr McALLAN: I am sorry; I am not following your question.

Mr JONATHAN O'DEA: The actual information collected to the extent that it is or has been collected—

Mr McALLAN: You mean by the provider?

Mr JONATHAN O'DEA: By the provider, has not really changed?

Mr McALLAN: Has not changed a great deal.

Mr JONATHAN O'DEA: What is the minimum level of information that was collected in the past and how is that changed now? I am just trying to reconcile that with your earlier comment suggesting that it has not really changed.

Mr McALLAN: I would have to get back to you on the exact changes that have been made, but I know that part of the consultation on the 2007 Act was with the providers and they would want some parallel with their accreditation requirements as well. Basically, the difference will be between the National Health and Medical Research Council requirements and the requirements under the ART Act. My understanding is that they are quite similar, but I can provide the exceptions for you on notice.

Mr NICK LALICH: Are there any particular difficulties that may arise by transferring responsibility for registering donor details to the Registry of Births, Deaths and Marriages? Would such a change have any wider impact on the ministry's current role in assisted reproductive technology?

Mr McALLAN: I cannot speak for Births, Deaths and Marriages, but from our point of view, with those low numbers there is not a great deal of difficulty transferring the data. I cannot imagine the data would be difficult to translate. You would have to change forms. You would have to change websites. It is all basically administrative changes. Our role still maintains and we would be the register for the ART providers and, obviously, that would remain our role under the Act.

Mr JAI ROWELL: I understand that the information relating to private donor conception arrangements, which occur outside of ART clinics, cannot be registered. The New South Wales Government

submission suggests expanding the voluntary register to include private arrangements. What is your view on the practicalities of that proposal?

Mr McALLAN: I do not think it is hugely practical in terms of verifying the information that is tendered. It would have to be quite a complex system of mutual consents between the parents and all donors for that kind of information to be registered. It would be a can of worms.

Ms O'SHANNESSY: I think the issue is that by having it through the providers you have what is a relatively objective party with some clear rules. If you translate that to the private arrangements, you will have to have processes in place, if we really wanted to do that, that would have to be testing what you can now accept from the provider.

Mr McALLAN: Yes. At the moment under the Surrogacy Act we register whatever information the intended parent wants to give us and under the Act we are not obliged to test that information at all. That gets tested in the Supreme Court when there is a parenting order made.

Ms O'SHANNESSY: I guess the alternative is that you have to then recognise, if you did it in a more simplistic fashion, that there would have to be an understanding that that information is not as reliable or that it is simply a record and then there is a question about how valuable it is, if that is the case.

Mr McALLAN: To the child when they are 18.

Ms O'SHANNESSY: Yes.

CHAIR: Do you have an idea of the mix or the split between registered providers and private arrangements?

Mr McALLAN: Private arrangements are unknown.

CHAIR: Is there any data available to tell us?

Mr McALLAN: It is not something that is ever kept. You could do tallies of advertisements in private publications, but that would give you an indication of the kind of market but not necessarily the take-up.

CHAIR: Because we do not know what is happening with private arrangements, it would be difficult for a government to propose a way forward to collect that information if it is only small? I am trying to work out if it is worth the resources to collect that information if it is happening only on a small scale.

Mr McALLAN: My understanding is that it is not happening on a small scale.

CHAIR: So there is an understanding?

Mr McALLAN: It is an exponential on the registered providers.

Ms O'SHANNESSY: Would the providers be the people who could give a better comment on that?

Mr McALLAN: Yes, they probably could because they are aware of the private market.

Mr GUY ZANGARI: Several submissions to the inquiry raised whether donor registers should operate retrospectively. What is your view on the issues raised by retrospective access to donor details?

Mr McALLAN: Retrospectivity cannot happen under the current legislation without consent of the donor. Do you mean like compulsory or global retrospectivity that anybody could access the details or data with the ART provider? Once again, I think they probably are the better people to ask that question. I know there would be a lot of push-back from some providers on the basis that they acquired the information based on anonymity.

Mr NICK LALICH: The Fertility Society of Australia has submitted that the Ministry of Health and the Registry of Births, Deaths and Marriages have experience in records management and dealing with confidential information that would be required to maintain donor details. However, it expressed the view that

neither agency has the resources to fully cater to the needs of customers and clinics for assisted reproduction, for example, in providing public education and counselling. What is your response?

Ms O'SHANNESY: I will start off and Greg might have a more operational response. I think it is really quite difficult to answer that question in the absence of what sort of counselling and services they have indicated they consider adequate. I guess our view is probably that for the purposes of the Act and what we have in place, we think the resourcing would be adequate as it is, but it is a bit hard. I was going to say, How long is a piece of string? It is a bit difficult to comment on that in that context without knowing exactly what the proposal may or may not be.

Mr McALLAN: It depends how Rolls Royce you want the service to get. In Victoria they will give you a list of counsellors, but it is private; you pay. It is privately paid for. We do not give a list. On our website we refer people to ANZICA, the infertility counsellor association and it can nominate someone for you. But we do not think it is proper for us to be nominating approved counsellors. In Western Australia you get one counselling session and then after that you pay. So the service is not Rolls Royce in any jurisdiction, as far as I am aware. I think also in terms even of adoptions here, it is user pays for counselling sessions. As it is not an illness as such, it does not attract free treatment.

Mr NICK LALICH: Is counselling outside the scope of, say, medical practitioners?

Mr McALLAN: I am not competent to reply to that one.

Mr NICK LALICH: A doctor could give them that information for a consultation fee?

Mr McALLAN: Like a Medicare arrangement. I think the providers and some of the other support groups might have a different view on the expertise needed in the circumstance.

Mr JONATHAN O'DEA: Going back to the previous question on potential retrospectivity. The Attorney General's department suggested that it may be possible to make details that are not identifiable available where possible: What is your response to that suggestion?

Mr McALLAN: On the register? In terms of practicality or just straight to the provider, do you mean?

Mr JONATHAN O'DEA: The question has been raised in a number of submissions to the inquiry whether donor registers should operate retrospectively. When you were asked about retrospectivity in terms of access to donor details you indicated that might be problematic. One suggestion that has been made, particularly by the Attorney General's department, is that it might work if the details were not identifiable. In other words, the donor could not be identified but some of the characteristics or some of the health related information was made available where possible. I am asking for your response to that suggestion on that issue?

Mr McALLAN: At the moment my understanding is that if any parent or child goes to an ART provider they will give them that information. The ART providers, during our consultations, were saying they were more than willing to help on any aspect they could except for giving over identifying information. I do not think it is particularly practical to get all the information—except donor information—matched with offspring on to the register. That would be a much larger task than we are doing now. Basically, in terms of searching out all the records there will be different sorts of records and they will not be uniform as are the records coming to us now. We would have to translate them into a common form.

Mr JONATHAN O'DEA: It comes back to the question of what might happen to the ART records if the operation had ceased.

Mr McALLAN: Yes.

Mr JONATHAN O'DEA: In either case, whether or not the central register is run by yourselves or births, deaths and marriages, that sort of information would not be practical to be kept on that central register?

Mr McALLAN: I would not say it was not practical. It is a question for Government what resources it wants to allocate. It can be done.

Ms O'SHANNESY: The ART providers have shown there is no issue, and they are willing, to provide that information. It is a matter of weighing up the value of doing it the other way. It may be expensive to do it.

Mr JONATHAN O'DEA: The ART provider in practice is happy to provide any information except that which may identify the donor. You may not have the answer, but is there a compulsion of any type upon the ART provider or is it relying on the ART provider's good will?

Mr McALLAN: You would have to ask the ART provider. My understanding is that the RTAC (Reproductive Technology Accreditation Committee) accreditation requires them to give that information. The fact that they have processes in place to give over that information would be audited.

Mr NICK LALICH: My understanding is that in 1972 they started a process that from every child born a blood sample was taken from their heel for medical purposes and to keep it as a DNA record. Do we do that or is that just a story?

Mr McALLAN: I do not think there is a DNA record kept. It is just for phenylketonuria and other genetic disorders.

Ms O'SHANNESY: The little card with the heel prick is retained.

Mr NICK LALICH: That is only a heel print; it is not a blood sample?

Ms O'SHANNESY: It is a blood sample. They take the heel and they prick it and place it on the card.

Mr McALLAN: It is for phenylketonuria.

Mr NICK LALICH: You could use it for DNA purposes in perpetuity or for the life of that person?

Ms O'SHANNESY: It is highly confidential. I cannot tell you how long it is kept. There have been some privacy issues. The police would like to get access to that information. There is a memorandum of understanding with the Police Service but the police have never had access to it. This is all off the top of my head from several years past when we worked on looking at the privacy issues associated with it. I cannot recall now, but I think we had a finite time put on how long they were kept.

Mr McALLAN: You would not need it for that long.

Ms O'SHANNESY: It was the late 80s and early 90s when the privacy laws came in. We had to look at whether it complied with the privacy laws.

CHAIR: The Committee may send you further questions in writing which will form part of the evidence and be made public, are you comfortable with that?

Ms O'SHANNESY: Yes.

(The witnesses withdrew)

JOHN ANTHONY McATEER, Deputy Privacy Commissioner, Information and Privacy Commission NSW, affirmed and examined:

CHAIR: Welcome and thank you for appearing today before the Law and Safety Committee to give evidence. Do you have any questions concerning the procedural information sent to you in relation to witnesses and the hearing process?

Mr McATEER: I have no questions.

CHAIR: Before commencing questions do you wish to make a brief opening statement?

Mr McATEER: I would like to inform the Committee that the function and role of the Privacy Commissioner of New South Wales is to protect the privacy of persons generally and specifically to ensure compliance with the information protection principles and health privacy principles as they relate to the New South Wales public sector and, in respect of health, in respect of all health service providers operating in New South Wales.

Mr JAI ROWELL: Your submission states that including donor details on birth certificates would mean that donor-conceived individuals would not be able to prevent this information from being viewed as birth certificates are frequently used to establish identity. You suggest that individuals should be able to decide whether they wish to withhold this information from their birth certificate. Will you please expand on that point?

Mr McATEER: The concern of the Privacy Commission and the Information and Privacy Commission in respect of the proposal can be best summarised by my answer to this question—that is, historically, and at an increasing rate, the birth certificate has become a form of identification verification rather than in practice the document that the Births Deaths and Marriages Act refers to: Being a recording of particulars relating to births and other particulars as prescribed by the regulations for individuals born in New South Wales. To illustrate this point—and it is referred to in my submission—I am sure the Committee would be aware of the 100 point identification check that organisations, companies and government requires to prove identity when opening a bank account, applying for a passport, et cetera. There are three documents listed which provide 70 points out of the 100 points: a birth certificate, issued by a State or Territory, a citizenship certificate or a passport.

I am assuming that everybody who is a lawful citizen of New South Wales either possesses a birth certificate, or there is information in the registry, or they have obtained citizenship which is linked to an overseas form of birth certificate. For the purposes of my submission, we would submit that 100 per cent of individuals in New South Wales would have a birth certificate. The current data from the Department of Immigration is that only 48 per cent of the people in Australia hold a passport. That immediately shows the weight placed on the birth certificate over the other primary form of high value identification document. The citizenship certificate—in the brief time I had to turn my mind to this—I do not have any figures on but I am assuming it is only people who are not legally born in Australia who have an overseas birth certificate who would have a citizenship certificate. I personally was born in New South Wales. I do not know whether I could also apply for a citizenship certificate to complement my other primary forms of identification.

The point I wish to make to the Committee is that I would hazard a guess that less than 48 per cent of residents of New South Wales possess a certificate of citizenship. Only 48 per cent of the Australian population possesses a passport. It is fair to say that one-third of the Australian population reside in New South Wales and, in the absence of any evidence to the contrary, I would suggest that half of the population of New South Wales possesses a passport but 100 per cent, or close to it, possess a birth certificate. As the Committee would know, it is mandatory in order to apply for a Medicare card that when a child is born the birth must be registered first. So there is a very high uptake as prescribed by the legislation.

The point I am heading towards is that, if this primary source of identification document: a birth certificate, includes by way of annexure, addendum or some marking or notation that indicates there is further material available then that may, as an unintended consequence of the practical use of it as an identification document, indicate to the reader, the third party, that the person was essentially the result of assisted reproductive technology that they were brought into being, that they have a donor, that they may have been brought up in a certain sort of adult-child relationship—that is, two parents of the same gender, single parent

with a donor through a private arrangement et cetera. Now our concern is that those are matters—before we get on to issues of genetic health, which I think the later questions address—are really the sole province from a day-to-day practical point of view of the individual in whose name the certificate is issued.

If I were to present with a document to Roads and Maritime Services to obtain a driver's licence or to a bank to open a banking account and there is an annexure or it says "incomplete record" or an addendum or even an asterisk or some code, in operational experience third parties will understand what that means and they will be able to say I had an unusual parentage or childrearing experience. Not saying there was anything inappropriate about those experiences, but to identify that perhaps I was brought up by two men or two women or I was brought up by a single father or single mother. I think it is more the single mother issue because by looking at the Registry of Births, Deaths and Marriages Regulations the birth mother is unable to remove herself from the birth certificate if she is applying for registration of the birth whereas the father is not always registered.

In essence that is the point: The day-to-day use of a birth certificate is for a private purpose in order to conduct commerce, provide access to provision of services and to do matters on a daily transactional basis. The New South Wales driver's licence has become a de facto Australia card as well, but the Committee may know that it is only worth 40 points. A birth certificate and a licence will get you over the hurdle. So the point I am making is that in the vast majority of instances where people provide 100 points of identification to do business with government or corporations their birth certificate will be produced.

Mr JONATHAN O'DEA: I understand the point you are making but can I put a slightly contrary proposition to you and ask you for a comment?

Mr McATEER: Sure.

Mr JONATHAN O'DEA: A person has the right to know certain information about themselves. If there was not at least an asterisk or some indication to put a donor-conceived person on notice of some line of inquiry themselves they may well go through their lives not knowing that information; it being in many cases important information for them to know or, one may argue, they have the right to know. Secondly, there is other information already on the birth certificate—for example, their parents' name, which might be ethnic sounding. One might say the fact that they were born overseas or of a particular ethnic background might also be a little bit sensitive, or a profession that is recorded. Perhaps they have come from a working class background or, dare I say it, might be the son of a lawyer or politician heaven forbid. There is potentially sensitive information already there. I want to put those two propositions to you and get your response.

Mr McATEER: I think they are valid points. One might argue that to place a value judgement on a person's ethnicity because of their name or something of that nature then that would apply to the individual as well as to the other persons named on the document.

Mr JONATHAN O'DEA: They may have changed their name to get away from it.

Mr McATEER: They may well have. I would submit that is a more, I suppose, subjective and benign privacy aspect in respect of the personal information of the person. The issue about genetic information we will come to I am sure. Matters relating to whether they were a child born from a donor, we would submit, are more intrinsically privacy related than the occupation of a parent or the type of analysis of the ethnicity of the individual that could be placed by examining the surname. There was a period I think where religion was recorded on birth certificates—I seem to remember seeing my birth certificate and there were two letters there. The fact that a person might have a name that might in a Christian context be the name of a Saint might tell the reader something about the ideology of the family or something of that nature.

Yes, that information is available. The important thing is, in my experience, there is a birth certificate extract and a full birth certificate. My own birth certificate even had the name of a witness at my birth—a nurse—and all those sorts of things. I was born in the 1960s and things may have changed since then. I must admit I have not looked at a lot of birth certificates in my time: I have looked at a lot of death certificates in my time. Those are all valid points. We support the proposal that people should be able to obtain information about their parentage and their circumstances—I note the Commissioner for Children and Young People said from the age of 14 in certain circumstances but definitely from the age of 18—and in principle we are aligned with the Government's position, which I understand was through the Department of Premier and Cabinet's submission to

this inquiry, but where that information would arbitrarily through form be disclosed to third parties we have concerns.

CHAIR: Taking that into account, as well as your comments about the birth certificate being a primary piece of identification and then looking at the Victorian Registry of Births, Deaths and Marriages, who now include an addendum to the birth certificate of donor-conceived individuals; do you have a problem with that?

Mr McATEER: On the questions on notice I have two ticks and the word "better" written next to that proposal. I think that is better than the very general proposal that the terms of reference refer to. It did not specify exactly how this would operate in practice and we looked to making a submission solely on the privacy issues. The only query that we would hold in respect to that is I made reference to an asterisk earlier. I remember many years ago having access to the legal practitioner rolls as they are now called and there would be asterisks against so many names, maybe 10 per cent of the names, and that indicated that the person had made a disclosure and the people working in that registry did not really need to know or had no right to know that they knew that they had made some disclosure to the boards of a matter—it might have been a conviction that was capable of becoming spent or it might have been some sort of charge.

I do not know the figures but when I saw the rolls there was a large number of these asterisks—it may have been 5 per cent or 4 per cent of the people on the rolls but the rolls were very long; they are a historical document—and that told the reader something about the person, because they knew the meaning of the asterisk. The roll did not say, "The applicant has made a disclosure to the boards"; they knew that that is what the asterisk meant. The Victorian example, I am not sure how it works in practice, but if there was some way where a bank teller or a registry officer in a motor registry or even a person at the passport office would not be able to glean that there was further information available that was irrelevant to proving the identity of the person, that would be preferable.

I am not quite sure how that would work. There is talk of a separate sheet in the Victorian example. My concern would be if at the bottom of the front folio it said "Further attachment" or "More information available". We can have good training of people in the public sector, and hopefully in the private sector, where they can know that whenever they see that they place no regard on it because it has nothing to do with establishing the bona fides of the person applying for the service. But I think, as delegated Privacy Commissioner, I would prefer to see a way of working through that sort of example.

Mr GUY ZANGARI: If I could ask a question about working through that example that you have provided regarding the asterisks, but also looking at the rights of the child in knowing parentage and origins? What ways to move forward could you suggest where if there is no marking on the certificate on the front page that information could then be available as such, but solely for the child when they become of the age where they would ask such questions about origins and parentage?

Mr McATEER: I see Mr Curry gave evidence before me. I do not know what he had to say but, I am thinking back to my own example, I think my birth certificate is in a single folio—I think it is foolscap because that is the way that it was done and if I wanted to get another one I am sure it would be an A4 size. The example that I would envisage would be one where a person who was authorised to apply for a copy of the certificate from the Registrar, presuming that to be—and I am not sure what the rules are, but I am a parent of children so I applied for the registration, paid a fee and received a certificate; so, in effect, I applied for the certificate, once it was available, for my children. Other persons obviously can apply—the person to whom the certificate relates. I think I said that if I could not get a birth certificate I am sure I could go along and apply for one and satisfy the Registrar of certain documents.

Presuming there is an appropriate limitation on who can apply for a birth certificate—I am not talking about a warrant or some coercive instrument from the Crown—to apply for it as a client or customer, my view would be that in such an example the document should have two folios in the envelope that are not affixed in any way to each other and when arriving at a banking institution or a motor registry I just bring the front folio. We are talking about adults at law—persons who are over 18 years of age—and we all have personal documents and papers that we have to keep safe and from time to time we misplace them and have to reapply for them. So the information or the knowledge would continue to be available to the person to whom it was relevant.

I do not particularly think there is a privacy issue about the parents because they know more about the circumstances of the child coming into being than the child did at the time—the child has no cogent knowledge of those matters—and, having known one thing, those parents cannot have that knowledge removed from them.

So there are no privacy issues because the disclosure was already made appropriately, that the birth parents or the donor information was available. That would be a way that a person could manage their own privacy because one of the risks in modern society and the amount of information that government and the private sector are collecting is that there is no way to verify one's identity without providing more and more information because of the nature of the information recorded in the document.

Somebody raised earlier—it might have been Mr O'Dea—about the other information that is on a birth certificate. To prove your identity, in essence, unless it is a matter of some great importance, it is neither here nor there to bank X or motor registry Y who your parents are or what their names are or what their occupations are or how old they were when you were born—from memory, other siblings are listed as well—that is immaterial to bank X or bank Y. I think that aspect illustrates the problem with these documents becoming a form of identification when that was never the intention; it was information held in a register for the Crown, to be accessed by the person to whom it related and other people where there was a lawful basis. That is the primary purpose. I think the judge said something in the case that caused this inquiry to commence about the function of the register. I do not know if that answers your question but it is a suggested approach.

CHAIR: You have put forward a good argument in regard to the debate over an Australia card.

Mr NICK LALICH: The New South Wales Government submission states that a sole repository of donor conception information would provide a streamlined service that would be more economical and user-friendly for individuals than two separate repositories of information. The Victorian donor registers were recently transferred to the Victorian Register of Births. In your view what would be the advantage and disadvantage of transferring donor records to the registry? This may also answer question number 4: In terms of the proposal to transfer donor records currently held by the Ministry of Health to the Registry of Births can you identify privacy concerns that might occur? I think that is the same as the previous question.

Mr McATEER: Yes, I think they are linked. The current privacy law prohibits such a thing, but obviously arising from the government bringing legislation in to move ahead with the proposal, if that is what happens obviously that gets around the legislative impediment, because at the moment it is basically impermissible for a government agency to transfer data to another government agency which is personal or health data unless a whole lot of criteria have been met—the first one obviously being consent. I think for what we might call broadly benign data—statistical or just general information of a historical nature—it is not information in the provision of a health service or a primary purpose; it would be for a secondary purpose or maintaining a different register. So the legislation would need to address that, and I am sure it could do it quite effectively.

The only other issue is that once two databases are held, notwithstanding the client/consumer convenience of a one-stop shop, as referred to in the DPC's submission, the New South Wales public sector is bound by the information protection principles and once a second agency has a whole lot of data it is obligated to put all these other steps into place concerning security, accuracy, relevance, up to datedness or currency of other data. So, following on from the District Court decision obviously, the Registrar of Births, Deaths and Marriages had to amend the data to make it up to date in that case because that was the order of the court, in effect. So those obligations flow across. They are particularly onerous because—I used that word "benign"—the data is generally benign; it is just factual information. It might be sensitive, as I said in my answer to the first question, but it is, broadly, basic data.

The Victorian example, I am not sure what role the donor registries still play, if any, or whether they are the recipients of that data and they then transfer it to their Registrar of Births, Deaths and Marriages, the advantages are that potential clients would be able to know that there is one place they can go to for all that information. That would assist applications under the Government Information Public Access Act in the sense that they would only have to make an application, if it had to be made through that method, to one organisation rather than potentially sending it to two or three organisations to work out who holds what data. So there are some benefits to consumers there, and that ties in with some of the philosophy of the Government Information Public Access Act to make accessing information easier and information more open and more transparent.

There are obviously fiscal advantages in that Births, Deaths and Marriages is currently set up to provide a number of products to authorised clients as well as maintaining a register. It has systems in place. I realise there are some issues with national registration at the moment and interfacing with those registries, and, based on the Victorian experience and the current matter before New South Wales, the other States and Territories are, no doubt, from time to time looking at similar issues. These arise in our early twenty-first century western

society and they will probably arise to a greater extent because my understanding is, through technological reasons and also through a changing in social attitudes, that formalised situations of parentage, donor, et cetera is becoming more and more prevalent, common.

The only disadvantages would be that if the information was somehow compromised then there are two places or two opportunities for the information to be compromised. So that gets back to the information protection principle about the security. The privacy concerns about transferring it to the Ministry of Health held by the ART Registrar and the other ones, the New South Wales experience would touch on some of the things I raised just a moment ago. I do not think the transfer is problematic, I do not think the proposal is problematic, and my general answers touch on that initial issue that I raised in the submission about this, for want of a better expression, ancillary use of certificates. In common usage that is the majority of transactional uses of those certificates and that is the day-to-day issue. So what happens in the registries, there was an Auditor-General's report about the electronic information about 10 or 12 months ago, but other than that I think broadly the New South Wales sector is performing as well as can be expected in respect of keeping the information secure and making sure that it is only used for the purposes for which it was collected.

The Committee may be aware of the document verification service which is currently being trialled and is proposed to be rolled out in different areas. We are currently having a debate in the different jurisdictions and the different privacy areas about the expansion of that service to the private sector. So there is always that issue that whilst the Ministry of Health and the Births, Deaths and Marriages registry in New South Wales might be appropriate places to hold information and to transfer it to, we have to be mindful of operational and functional creep, and if these proposals or proposals of a similar nature were to expand further into other areas there may be risks. But I do not think in respect of those two entities that there is any great risk.

There is a concern if there is duplicating of the information. I think the real issue though is that the medical information would probably need to be retained by the Ministry of Health or its subsidiary, and the demographic and statistical and identification information would be retained by the Registrar of Births, Deaths and Marriages. So there probably would still need to be the two holdings. The issue I mentioned about the legislative impediment is something that will have to be overcome by the proposal. I do not see that as problematic; it is just that currently it is impermissible at law. There are a couple of other questions that you can take me through if you want.

Mr JAI ROWELL: I will ask one. Submissions have also raised the ability of donor-conceived people to obtain access to genetic information, for example for medical treatment in case of genetic diseases. Do you have any comments on the legal and privacy issues this raises?

Mr McATEER: As I understand it, there is discussion at government level to look into putting donor registries to one side in respect of the incidents we have all encountered where, for example, a person is diagnosed with a virulent form of cancer and the person who is diagnosed with it discusses it with maybe their daughters and as a result they have an invasive medical procedure to lower their risk of developing this cancer later in life. As Deputy Privacy Commissioner my view is that along the lines of what is in the Health Records and Information Privacy Act, the legislation and any policy proposals need to move towards the disclosure of genetic information where it is reasonably believed by the organisation, say, the health provider—or available in the register—it is necessary to lessen or prevent a serious threat to life, health or safety of a genetic relative of the person.

Historically, there have been problems where adopted children have developed conditions in the middle of their lives that were quite unusual at that age—maybe unexplained cardiac problems not meeting any of the other criteria and there was an assumption there was some genetic issue—and it is impossible currently to find out what the genetic history is. The electronic health records proposal ultimately will go some way to that for all of us, but for those of us who currently do not know their parentage it is problematic. This proposal will assist with that in some ways because it will make the parentage clearer and will give some information. The issue about how the circumstances might arise is a bit tricky. The question refers to medical treatment in the case of genetic diseases. I do not know how that would work in practice. If an individual in the future—and assuming this information is available—has no contact with the donor would they be able to identify aspects of the donor's medical history in order to obtain a diagnosis or be examined or treated? There are problems there. Presumably if due to the information contact is made and rapport is established between the younger person and the biological parent it would be a matter between the two of them to give consent.

There is definitely a need, with the advance of medical technology, to in effect lower the privacy protection in a serious threat to life, health or safety. The issue has to be with the medical technology; by the time it is imminent the medical profession has lost the race. It has to be earlier on. That is a proposal and a policy consideration that is much broader than the terms of reference of this inquiry, but it illustrates the same point—finding out genetic information about yourself through finding out about the genetic information of someone else. I suppose my answer might be that from a lowering of privacy of a third party there is a public interest benefit in a proposal where there is a genetic basis for disclosing information or to be able to access information. It could well be that there is nothing genetic in that parent. It may be the other parent or some environmental factor. Who knows? I am not a medical person.

Mr NICK LALICH: But you are not going to know that unless you have that history.

Mr McATEER: The issue is how one obtains the history. The register is a portal but it does not give the detail.

Mr NICK LALICH: You know the reason for this inquiry is the case that has been mentioned. I take it the Supreme Court ruled that the record be changed to remove the father's name.

Mr McATEER: I think it was the District Court.

Mr NICK LALICH: The District Court, sorry. As the Deputy Privacy Commissioner do you think that even though the court has ruled that the record be changed, the original record should still be retained so that if that person—the child born by artificial means—wants to know later in life the original record can be given to him? Do they destroy the original document just because the District Court says the birth certificate should be changed so as not to reflect the donor's name?

Mr McATEER: I cannot remember all the facts of the matter but the person whose name was ordered to be struck from the register provided biological material for the child. This proposal, as I understand it, would ensure that their information would be potentially available to the child. This touches on the other questions about retrospectivity. I do not know enough about the facts of the matter. I have read the decision and I know the circumstances but I do not know the time lines. I cannot remember how old the young person was at the time of the court case—whether they were 5, 10 or 20. The current Assisted Reproductive Technology Act, or ART, is administered by the Minister for Health and her ministry as a provision relating to matters where conception occurred on or after 1 January 2010. To answer your question, assuming the young person in that court case was conceived prior to that time—knowing court delays as I do it is probably a fair assumption to make—I am not sure whether they would be captured in this matter retrospective to 1 January 2010. I will say something in a moment about matters that pre-date that—matters pre-1990 and matters during the 1990s.

As I understand it a whole range of different things could have been recorded on the birth certificate at that time; for example, the gentleman whose name has been removed, as I understand it, was never required to be recorded at that time, but he was. It is hard to say because I would have a strong view about the accuracy of personal information having regard to the Births, Deaths and Marriages Registration Act and the associated regulation, if it was mandatory that that gentleman's name be recorded at that time. As I understand it, it is discretionary. The person applied for registration. There is something in the Act that I saw this morning that says if it is incomplete the Registrar can register the birth with the particulars that are there.

This is 2012 law: Both parents of the child make a joint application; one parent of the child makes an application and the other parent cannot join in because he or she is dead or cannot be found; one parent of the child makes the application for inclusion of information on the register and the Registrar is satisfied that the other parent does not dispute the correctness of that information. So it was not a requirement that his information be recorded. As I understand it, it was recorded and due to the ventilation of an argument to remove it the court looked at the available legislation and said it was permissible to remove it and in the circumstances the court agreed to it. One thing the judge did say, as I seem to recall from looking at the decision, is that he suggested a quick fix or a remedy to the situation—that there be an addendum or something of that nature.

CHAIR: I think he mentioned having a third parent identified on the birth certificate.

Mr McATEER: Okay, but it gets back to the issue I raised. From a privacy perspective the primary issue is that the certificate is about the person to whom it directly relates. There is third-party personal information on it—witnesses, next of kin, et cetera. If you are the first born, you have no siblings on your birth

certificate. If you are the second or subsequent child, siblings are listed whether they are still alive or not at the time of your birth. The same thing happens with death certificates but with death certificates it is a bit more problematic because with the average life in this country they will have been completed many decades, on average, after that information was immediate. It is difficult to answer, Mr Lalich, in the sense that it does seem a nonsense of a scheme for registration that biological material or identification that was placed on them—I am assuming in good faith at the time because the registration had to meet one of those criteria—can then be removed. But, in the same way as there is provision for matrimonial relationships and their termination, then circumstances can change. If a divorcee applies for marriage it will say on the application "previously married" and for a person who applies for marriage who has not been married, or at least not to their understanding, it will say "not previously married" or something of that nature.

These documents, as I understand it, are a registration holding of material at the time that the registration is created, but obviously there is provision to include other information at a later time if only because of the fact that the Registrar can register the birth and then complete other information subsequently when he becomes aware of those details. It is difficult to have a philosophical view about the court case in this context because I am trying to speak frankly about these matters but I do not have a good enough grasp of the background situation. I know there was a change in the dynamics of the adults in the relationship at different times in the child's life, but that is all I know so it would not be appropriate to say any more.

CHAIR: Another proposal is for donor records to be kept by the Ministry and reported to the Registry of Births for inclusion on the Register of Births. Do you have any comments on the privacy implications of this suggestion?

Mr McATEER: It implies a transmission of data but the other proposal in the question, of having them transferred, would be for existing matters. I am not sure how the Registrar of Births, Deaths and Marriages could actually be the primary collector of that information. I think it would always somehow have to stay tied to the Ministry of Health. As I mentioned earlier, donors have been around for some 25 years in respect of assisted reproductive technology—I am not talking about private arrangements; they have been around for many more years than that. It is really about the issue of how the data would be transmitted. One of the concerns I had about changes to the assisted reproductive technology register was the lack of consultation because there are three classes: There are people conceived from 1 January 2010 and there was a consent-based system for people conceived prior to that. So there has been a mandatory system in the past two years and there was a consent-based system prior to that. But prior to 1990 all gamete donations were given on the proviso of absolute confidentiality, and if the donor did not agree to that then their donation was not accepted. That is my understanding. I am sure the Health Minister's people could speak to that to a better extent.

The information is now included in the ART register but it cannot be disclosed without consent. What we are talking about here is information of more than one person. You need to get consent from more than one person and the very fact that you may be seeking to get consent could have a privacy implication on a third party's circumstances in life. I have been down this track with proposals or discussions about genetic information where I am not talking about a knock at the door by a stranger but you receive a letter from the Ministry of Health telling you that your material or your information has been put in a register. That may not be the best thing for an individual many years later in different life circumstances to receive that information. I think ideally it would not be retrospective but for the genetic issue which needs to be addressed by other legislation. It would not be retrospective beyond that 1 January 2010 date because that way there is implied or informed consent from all the parties without having to consent to that. It is the lay of the land legally, for want of a better expression. People who provide material for assisted reproductive circumstances now do that with their eyes open.

CHAIR: Thank you for your thorough responses today and for appearing in front of the Committee. The Committee may need to write to you with further questions and that will form part of your evidence and be made public. Would you be happy to provide a written reply to further questions?

Mr McATEER: Yes.

(The witness withdrew)

(Luncheon adjournment)

ELIZABETH MAVIS HURRELL, Board Member, Fertility Society of Australia, affirmed and examined:

CHAIR: Before we proceed do you have any questions concerning the procedural information sent to you in relation to witnesses and the hearing process?

Ms HURRELL: No, but bear with me as I have not done this before.

CHAIR: In what capacity are you appearing before the Committee?

Ms HURRELL: I am a counsellor with the fertility unit at Royal Prince Alfred Hospital but I am here today in my capacity as a board member of the Fertility Society of Australia.

CHAIR: Would you like to make an opening statement prior to questioning?

Ms HURRELL: I just want to make it clear that everyone knows that the Fertility Society of Australia is the peak body representing doctors, scientists, nurses and counsellors who work in IVF or assisted reproductive technology clinics through Australia. It has a function of maintaining standards of accreditation in assisted reproductive technology, as well as ongoing education and maintaining of standards within the industry.

CHAIR: So you do not represent the donors?

Ms HURRELL: No, I do not. I represent the professionals working in assisted reproductive technology.

CHAIR: The New South Wales Government submission states that a sole repository of donor conception information would provide a streamlined service that would be more economical and user friendly for individuals than two separate repositories of information. The Victorian donor registers were recently transferred to Victoria's Registry of Births. In your view what would be the advantages and disadvantages of transferring donor records to the New South Wales Registry of Births, Deaths and Marriages?

Ms HURRELL: On this point the Fertility Society does not have a strong opinion. We think it is sensible that there would be a sole repository and not two repositories but we do not have a strong position on this. We acknowledge that the Department of Health has a good record in terms of management of confidential information but also Births, Deaths and Marriages has experience in management of adoption records and so on, so both departments have relevant experience. Our concern is more about the resources available to whichever authority manages this information and the need for there to be utmost respect for privacy around these issues and the need for staff who are working in this area to be sufficiently trained and experienced in taking a sensitive view of what is very personal information. So I guess we are saying that whether these needs can best be managed by the Department of Health or Births, Deaths and Marriages is really up to the Government to decide. We do not have a strong view on that but we do think that appropriate resources need to be allocated to do this properly.

Mr NICK LALICH: You note that both the Ministry for Health and the Registrar of Births have experience in record management and dealing with confidential information that would be required to maintain donor details while expressing concern at their ability to provide adequate counselling to families and donors. Can you tell us about the counselling that donors and recipients receive at the moment? What additional counselling may be required to be provided by the agency that manages the donor registers?

Ms HURRELL: When I am talking about the counselling that is provided to donors and recipients at the moment I am talking about donors and recipients at the beginning of their treatment process in a fertility unit. Counselling is provided to all donors and recipients seeking treatment in any assisted reproductive technology unit. As I mentioned, all fertility units in Australia are required to comply with the RTAC code of practice which is a sub-committee of the Fertility Society of Australia. The Reproductive Technology Accreditation Committee has a code of practice by which all fertility units are accredited, which requires counselling prior to any treatment. A further requirement of that code of practice is that we all comply with the National Health and Medical Research Council ethical guidelines on reproductive technology. So they are the two frameworks that inform counselling in clinics.

What this means in practice is that if you have a couple presenting who need to use a donor because one of the partners is infertile, both the donors and the recipient couple will have at least two sessions of counselling before they commence treatment. The purpose of that counselling, which we call implications counselling, is to make sure that all parties are fully informed about the implications of the decision that they are making to be either a donor or a recipient, and to ensure as far as possible that they are making informed consent in proceeding to treatment. In fertility units we can work with patients who are using sperm donors, egg donation or in some cases embryo donation, and donation may involve using a donor who is known to the recipient couple. An infertile man could have his brother acting as a sperm donor or an infertile woman could have her sister acting as an egg donor, for example.

Some clinics offer donors—and this more pertains to sperm donation where the donors will be recruited by the clinic and their identifying information will be only available to a donor-conceived person when they turn 18 years of age. But whichever path we go down, the donors and recipients are all required to have at least two sessions of implications counselling. What happens in that process is that there is always a full and thorough discussion of the legal framework around acting as a donor and being a recipient of a donation. Within the clinic setting you are putting in safeguards that a recipient couple is always saying that they are taking full legal responsibility for a child born from the donation, though one of the partners may not have a genetic relationship with the child, and then the donor is consenting to his donation as a gift in a sense, or his or her donation, and the donor is fully aware that they will have no legal rights or responsibilities in relation to the child born.

The maintenance of clarity around those boundaries is very important. In the counselling process many other issues are discussed beyond the legal framework. For recipient couples there are issues around their history of infertility and their loss of fertility. There is discussion around the broader context of the family donation, around their choice of the donor and their relationship with the donor. Very importantly, there are discussions about how a couple who are recipients of a donation will disclose this information to a donor-conceived child as they grow and develop, and we talk about models for disclosure or telling a child about their donor conception. Counselling also addresses the stresses of the treatment process and also religious, cultural and ethnic issues that may arise in terms of the donation process.

In terms of counselling the donor, there are parallel things that are discussed. Particularly with a donor, there might be issues; if a donor has children of their own then any children born from their donation will have a genetic relationship with their children. So how that sort of thing is going to be managed is always discussed prior to treatment. One of the purposes of treatment is to give all parties the opportunity to consider all these issues and not to proceed to treatment if they do not feel comfortable about any of these issues. That is kind of the context of implications counselling. But through treatment there is also ongoing supportive counselling available to all parties if they request it.

Mr GUY ZANGARI: In your submission you make the point that access to donor information is dependent on the disclosure of donor conception and that a person will not seek this information if they are unaware that they are donor conceived. One means of encouraging disclosure by parents is to include a reference to donor conception on birth certificates. However, you note that this would raise some issues and concerns. Can you elaborate on the concerns you touched on in your submission?

Ms HURRELL: I would just like to acknowledge, my understanding of the case that has prompted this inquiry is that this is a case where conception was achieved privately so the safeguards offered by clinics were not available in that situation. The situation of that particular family is quite unique. One of the points I would like to make is that in working in assisted reproductive technology you are seeing a huge diversity of families with different needs, different expectations, different concepts of what a family means to them. You might be working with traditional heterosexual families where privacy around the issue of donation is very important to them, but we are also working with lesbian couples and single women in clinics as well.

The decision of most families to use a donor, however, is that it is a very personal issue for these families. By putting a donor's name on a birth certificate, we have concerns about the privacy of these families and the stigmatisation that could come about if a donor's name is on a child's birth certificate. That is not the sort of information that needs to be disclosed when you are taking the birth certificate along to register your child for the local soccer team or something. It is very private and personal information and in that sense we are concerned whether it is appropriate to put it on a birth certificate.

There is another aspect, however. The Fertility Society of Australia believes in the right of donor-conceived people to know their genetic origins. There is a body of research that suggests that in the past a lot of

parents have not informed their children of their donor conception. We think there would be some advantage in having something on a birth certificate that, I guess, in a way, states to parents that we have a benchmark that it is their responsibility to inform their children that they are donor conceived. If parents know that there is some sort of addendum or something like that on a birth certificate then they will have a sense of responsibility that they need to inform their children before they turn 18 years of age or whatever that they are donor conceived.

We think there is an advantage in having something like that but not the donor's details fully stated as with mother/father or mother/mother or whatever the case may be on the full body of the birth certificate. We think that having an addendum on a separate page could still be an incentive to parents to disclose the details of donor conception to their children but it would also respect the privacy needs of families to not have to disclose this information all the time. I realise that I was asked a second part to the question about the additional counselling that may be required provided by an agency that manages the donor registers, and I failed to answer the second part of that question so, if I could do that now just briefly?

CHAIR: That is fine.

Ms HURRELL: In a fertility unit we work with families at the point of them achieving a pregnancy using a donor. Down the track, as a child grows and develops, there are other counselling issues that may come up for families that are donor conceived. They relate to things like parents seeking guidance about how to disclose to a child about their donor conception. Some parents have a lot of anxiety about that, and it connects emotionally with a lot of issues to do with infertility. There could be counselling about donors making decisions about whether they want to put their details on a donor register, and donors often have to think about that in the context of their family, and the implications of their family.

Down the track there is counselling for donor-conceived adults in making decisions about whether they want to have contact with their donor, and what sort of contact they have with their donor, and that is complex because it involves the identity issues of the young people and information that they want to get about a donor. I guess in this process there is counselling that potentially could be provided in managing the expectations of all the parties concerned about the information that they will either provide or receive. Counsellors often play the role of a mediator too in terms of co-ordinating and sharing information and ultimately in the linking of donors and their donor-conceived offspring down the track. That is the second part of the question.

CHAIR: Is that counselling missing in New South Wales?

Ms HURRELL: It is missing, yes.

CHAIR: I know there is counselling prior to conception.

Ms HURRELL: Yes, I guess what happens is that some clinics do offer that but it is not a requirement of clinics to offer it. We will talk about this a little bit more down the track but in, for example, Victoria there are provisions made for that sort of counselling through an organisation called FIND (Family Information Networks and Discovery) that is subcontracted to provide that information or the Victorian Assisted Reproductive Treatment Authority [VARTA] that has staff that used to provide that information.

CHAIR: Is it responsible for the Time to Tell Program?

Ms HURRELL: That is correct. New South Wales does not have that level of counselling provided anywhere. As I say, individual clinics do. In my other role—I am not speaking in that role today—I do some of that work but I am limited by my other responsibilities and limitations of whatever is the policy of the clinic.

CHAIR: If more information were provided on a birth certificate it would put more pressure on parents to disclose to their child whether they were donor conceived and it would have to be hand-in-hand with greater counselling?

Ms HURRELL: Absolutely, yes. If that were going to be managed responsibly the two go together, yes.

CHAIR: You touched on following the Victorian model in relation to the separate addendum on birth certificates for donor-conceived people. Do you have any other comments in relation to the Victorian model that you might want to raise to this committee?

Ms HURRELL: The big difference between what is happening in New South Wales and Victoria is that Victoria set up some statutory authorities or responsibilities with staff with necessary skills to manage the sort of issues that arise in this highly sensitive area. New South Wales has tried to do it, in a sense, a little bit on the cheap and there has been no provision of those sorts of resources. What is currently happening with the New South Wales Department of Health and the register is that things are being managed administratively but not on those other levels that are needed.

The other concern of the Fertility Society is that in New South Wales there is no mechanism to consult with stakeholders, be they donor-conceived families or professionals within the industry who have a much better understanding of the sort of things that arise. You mentioned the Victorian Time to Tell Program, and VARTA has established a role in terms of community education, supporting families, mediating in donor linkages and so on. As I said, I understand that Find is now the organisation that is sub-contracted to do the counselling but I am sure you are all aware of a recent inquiry last year in Victoria that is looking at those things again and maybe there will be a shift back to just VARTA being a one-stop shop for managing these sorts of things. The bottom line is that the Fertility Society of Australia strongly supports the Victorian model.

Mr NICK LALICH: You stated that the donor's name and details should only be placed on the birth certificate with the approval of both the birth mother and the donor. Will you elaborate on that?

Ms HURRELL: It goes back to what I was saying about the legal separation that the consenting process in clinics supports that. In patients coming through clinics there is a very clear delineation that the parents are going to be the recipients of the donation, and the donor is playing the role of a donor which comes with no legal responsibility. That delineation is very clear. We are quite concerned about what the legal implications might be if the donor's name appears on the birth certificate, and the sort of confusion that that might create for families who are using donor conception. We think it is really important to have very clear legal boundaries about that.

Earlier I spoke about the diversity of families we see. I guess there are some situations of which we are aware, and perhaps it applies more to lesbian couples and single women, where even though the donor has acted as a donor they might want to play a very active social role in parenting a child so that there may be situations where, if all parties are consenting, it may be in the interests of a child to have the donor's name on a birth certificate. Perhaps it is worthwhile to have a mechanism in those circumstances. We are quite clear that that is not going to apply to all the families that are using donor conception. We say that putting a donor's name on a birth certificate should not be forced on all families who have taken that legal responsibility to parent themselves.

Mr NICK LALICH: If there were a separate document, not the birth certificate, that had the donor's name on it, why cannot that be given to the child when he or she reaches the age of 18 or whenever, whether or not the mother consents? The child has the right to know about their biological father.

Ms HURRELL: Yes, they do. My concern about that is to imagine a scenario of an 18-year-old who applies for their birth certificate, who has not been informed of their donor conception, and gets a sheet of paper that has a donor's name on it.

Mr NICK LALICH: No, on a separate document, not the birth certificate.

Ms HURRELL: We are suggesting an addendum to the birth certificate that says that further information is available so that a donor-conceived adult—at 18 years a person is pretty young and impressionable—when applying for a birth certificate could then make contact with the authority that hopefully would have the staff to manage a situation like that sensitively. Hopefully it would be in a face-to-face situation and talk about this and help the young person understand about their donor conception.

Mr NICK LALICH: Do you think an addendum that says there is more information if the young person applying for a birth certificate wants to look for it would trigger their brain and cause them more problems? They might have only wanted the certificate to apply for a licence and their parents did not tell him or her about being donor conceived?

Ms HURRELL: Yes. I guess that we to put it in another framework—and there is another question later on about retrospectivity. We do not support retrospectivity. In New South Wales now laws are in place, and

families are clearly counselled about the rights of donor-conceived young adults to get information when they are 18.

If we look at this 18 years down the track, we are making an assumption that most donor-conceived young adults will be informed of their donor conception. So this sort of scenario is less likely to occur, but it does not mean that it will never occur. I would like to put it in that context too. Yes, I do think there would be problems. It would be very distressing for a young adult to get that information in that way and it would be inappropriate for a government department to give out that sort of information in such an insensitive way.

Mr GUY ZANGARI: Ms Hurrell basically has answered question six on retrospectivity in the issues she has raised.

Ms HURRELL: Yes, but can I be emphatic about that? The Fertility Society is really emphatic that we do not support retrospectivity. How can I put it? The whole use of donor conception, I guess, nowadays we do not have anonymous donation anymore. It is a thing of the past and we support openness and voluntary registers and so on, but we cannot change that past practice. It would be very wrong to force people who donated in the past anonymously to disclose this information. It would have negative effects for them and their families as well as the donor-conceived families who consented to anonymous donation in the past. I want to be really emphatic about that.

Mr GUY ZANGARI: Your submission proposes the establishment of a tribunal or an advisory body in relation to assisted reproductive technology. Can you elaborate on this point? For example, what would be the potential functions of this tribunal and its membership?

Ms HURRELL: We touched on this again when we talked about the Victorian model. As I said, in New South Wales at the moment the needs of donors and donor-conceived people, the register is kind of being managed administratively but there is an absence of any resources linked to that. It would be useful to have a tribunal or advisory body that has people experienced in working in assisted reproductive technology to manage the complex and sensitive requests that come up with donor conception. The models that exist in Australia already exist in Victoria and Western Australia too, as we have talked about, but I guess we advocate VARTA as the model that works well. We see the potential functions of a tribunal as being things like community education re donor conception, education for parents about telling a child, better coordination of information about donor-conceived adults.

As an example, there are records of doctors who worked with donor conception in the past who are no longer in practice that are in storage somewhere but not accessible to anyone. If there was a tribunal that could manage those sort of records, that would be another useful function of such a tribunal. We have talked about a tribunal or advisory body that can help manage donor linking and also just the better implementation of the Assisted Reproductive Technology Act. In terms of membership, we think such a tribunal should have the key stakeholders—consumers, donor-conceived families, donor-conceived young adults and donors—as well as some representation by the health professionals working in assisted reproductive technology and, of course, the government departments managing these responsibilities.

Mr JAI ROWELL: Private donor conception arrangements, which occur outside of ART clinics, cannot currently be registered. The Government's submission suggests expanding the voluntary register currently managed by the Ministry of Health to include private arrangements. What is your view on recording donor details for private conception arrangements?

Ms HURRELL: In a sense it is beyond the scope of our organisation. It is going to be very difficult to mandate something like this in a totally unregulated area. I am not quite sure how you could do it. We do not see any harm if both parties consented and were fully informed of the implications of having their names on a register. I do not see that it is a problem if the donor and recipient are both consenting to that. But I do not know how you would manage it. You would need to put lots of safeguards in place.

Mr JAI ROWELL: I guess one of those safeguards would be some counselling services and a few other bits and pieces along the way?

Ms HURRELL: Probably, yes. Provision of good information, most certainly. Private conception involves risks of lack of clarity about those sorts of boundaries. It involves clinical risks in terms of infection.

We are not saying that this is an area that should be encouraged but given that we know this is happening, then it is important to put these opportunities for registration in place if possible.

CHAIR: Thank you for attending today. We may need to send you some written questions.

Ms HURRELL: Fine.

CHAIR: That will form part of your evidence and will be available to the public. Are you comfortable with that?

Ms HURRELL: Yes.

(The witness withdrew)

CAROLINE ELIZABETH LORBACH, National Consumer Advocate, Donor Conception Support Group of Australia Inc., sworn and examined:

CHAIR: Can I welcome Mrs Lorbach. Thank you for appearing before the Law and Safety Committee. Do you have any questions concerning the procedural information sent to you in relation to witnesses and the hearing process?

Ms LORBACH: No.

CHAIR: Would you like to start with an opening statement?

Ms LORBACH: Yes, I would, thank you. The Donor Conception Support Group of Australia Inc. would like to thank the Committee for this inquiry and for giving us this opportunity to speak with you. The parents in our group are blessed that we have been able to have children even though we, as couples, are infertile. Raising our donor conceived children has taught us a lot. We have made realisations that never entered our minds before we had these children. We are here today to speak for those children. Within the Donor Conception Support Group we have a wealth of life experience in donor conception and it is from these experiences that I speak to you today. The Federal Government has sanctioned the practice of donor conception through Medicare and this has helped to create an estimated 60,000 plus donor conceived people. The governing of donor conception has been left up to the States and it is for the most part relatively recently that State governments have decided to look at this area, given that the practice of donor insemination has been carried out in Australia since at least the 1940s.

The self-regulating system of the past, and that currently in place, does not provide fully for the needs of donor conceived families. To try and compensate for this a small group of parents formed the Donor Conception Support Group in 1993. We were the first group in the world devoted to supporting families created from donor sperm, eggs and embryos. We are the only group of its type operating in Australia. At our very first meeting all of us agreed that we wanted to tell our children the truth about their conception. Truthfulness is one of the first important ethical lessons that most parents teach their children because we as a society understand the significance of honesty and the building of good relationships. However, up until the 1990s most of the families in the group had been told by their doctors that they should withhold this truth from their children.

Donor conception will always be a subject that is not openly spoken about while the country as a whole refuses to deal with the long term effects of withholding of donor information by clinics. When secrecy is operating there is a high chance of family relationships being damaged. Secrets prevent family closeness and prevent open communication. Australia has ratified a number of important international conventions. The two most important ones that apply to donor conceived people are the international Convention on the Rights of the Child and the International Covenant on Civil Rights. It is clear that donor conceived people, who are actively being denied access to information on their biological parents, are the victims of discrimination.

Some may argue that many people in today's society do not know a part of their heritage for a variety of reasons. However, their right to seek information is not denied to them through any legislative or regulatory framework or through decisions made by the medical profession. Within New South Wales those born before the enactment of the Assisted Reproductive Technology Act 2007 have no right to any information about their donor. Some were lucky enough to have some information about their donors—without identifying the donors—but very few have ever got to know the identity of their donors. Since the release of the 2004 National Health and Medical Research Council [NHMRC] guidelines clinics in Australia have supposedly moved towards a system whereby anonymous donors are no longer accepted. Children born after that date should be able to access identifying information on their donors. But because of the system of accreditation we have no way of knowing whether clinics are complying with these guidelines and the system is not retrospective.

The NHMRC guidelines state that the welfare of those born from reproductive technology is paramount. It states that the welfare of donor conceived people should be considered as more important than all others involved. If the welfare of donor conceived people is paramount then there should be no competing rights. The Donor Conception Support Group firmly believe that to withhold information about identity, medical history and relationships from people conceived by donated gametes is not treating their interests as a primary consideration. In fact, it is treating them in quite the opposite way by withholding from them rights that the rest of us accept as our due. The denial of such rights of access to one group can have severe adverse effects on their

perception of themselves and their position in the world. We are concerned that denial of rights purely on the basis of date of birth has produced a minority group afforded less rights than those of their younger counterparts.

CHAIR: Mrs Lorbach, your submission suggests moving the current donor register to an independent authority or to the Registry of Births, Deaths and Marriages. What are the benefits of moving the registers and what do you feel are the difficulties associated with the registers remaining in the current location?

Ms LORBACH: Currently they are within the private health care branch of the health department. Donor conception, unfortunately, is legislated for by the health department which our group believe is not necessarily the best place for it. We are dealing with issues that are not primarily health related. Yes, people within our group are denied access to full medical histories and that can have an adverse affect on them. We are dealing with social and emotional issues which are not dealt with best by the health department. We feel that moving the registers to births, deaths and marriages or to an independent authority would give a greater service to donor conceived families. We think it should be treated more akin to adoption.

Mr NICK LALICH: Your submission recommends that donor details appear on the birth certificate of donor conceived people. In New South Wales certificates currently contain information about legal parentage, as donors are not legal parents. Some submissions to the inquiry have said that there is potential for confusion about legal parentage and parenting rights and responsibilities if donor's details are included on birth certificates. What are your comments on that point?

Ms LORBACH: I do not think there would be any confusion if we moved to a model like Victoria where there is an addendum to a birth certificate. Once a person applies for their birth certificate they will be told that further information is available to them if they wish to access it. It is up to that person whether they want to access that information. The name of the donor would never appear on a birth certificate. We think that would be the best result.

Mr NICK LALICH: There would be a second certificate behind the birth certificate and it is up to the individual to look for that—but not on the birth certificate?

Ms LORBACH: No.

Mr GUY ZANGARI: Some suggestions propose following the Victorian model of having an addendum attached to the birth certificate stating that further information may be available when the individual named on the certificate is aged 18. What is your view of this proposal and what would be an adequate way to give donor conceived people information about biological parentage?

Ms LORBACH: As I stated, we think that model would be the best but it has the benefit that it will respect the privacy of all parties involved: the donor conceived person, the donor and the parents. The information that the child is donor conceived is not written on that birth certificate. It is up to the donor conceived people who they want to tell.

CHAIR: We heard earlier from a witness the concerns of having a second page to a birth certificate, the restriction to access until they are 18 years of age and then being confronted with the information that they may have been a donor conceived child. Do you have issues around that?

Ms LORBACH: There are issues around that and there is no perfect solution. What was done in Victoria, even before the legislation changed, to allow time for that to happen, was what they called the "time to tell" campaign. They went public to get parents who had not previously told children to look for information on how to tell those children—some of them would have been adults not children—and give them help on how to tell their children. There has been little research done in this country about how many parents are telling their children about their conception. Some people say the figure could be below 50 per cent. Part of the problem is where do parents in this State go for help on how to tell their children the truth? They come to our group. We are an unfunded volunteer base group which will probably be closing this year because we cannot get funding, we are having trouble, like a lot of volunteer groups, getting people to come forward to help. I have been doing this work for 20 years. I have a full-time job and I have raised three children. Why should it be left up to us to help parents tell children about their conception?

It is not necessarily a difficult thing to tell children the truth about donor conception but it is what comes afterwards: How you deal with the issues long term? How do you start talking to children when they are

getting into teenage years about when are they going to talk to a prospective partner about donor conception? I have been through this with two of my children so far. One did not know how to raise it and did not speak to his girlfriend about it for six months. She did not turn out to be donor conceived, but she could have been a donor conceived person who did not know the truth. There are major issues such as that long term. There is no one, apart from our group, supporting families in how to do things like that. How do you survive with only half of your medical history when the medical profession is telling us that getting family histories is all important? All I have been told about my children's donor's history is, "Nothing of significance." That was taken years ago when they donated and it is not kept up to date.

We have no way of knowing whether the family discovered things along the way. I know of one donor conceived person who was conceived in Victoria, who some of you may have heard of through the media, who has stage IV bowel cancer. She has looked through her mother's medical history and there is no evidence of any bowel cancer. She has been told it is probably genetic so she thinks it may come from the donor. They will not contact all the donor children who are her half siblings to warn them that they may have a possibility of bowel cancer. That is really scary. It should not happen to people in this day and age when we know so much about the genetic makeup of a lot of diseases.

CHAIR: You said that you would like to see a system where donors continue to add information as they progress through life.

Ms LORBACH: Yes, if possible. I think that would be a very good thing. They should be asked, encouraged and given the reasons why this may be important. They probably were not told that by clinics a long time ago. We need clinics to have a clear set of rules for what should be done when they recruit donors and things like that and things like that are not being done by clinics—they are not getting donors to regularly update information.

CHAIR: You represent donor-conceived individuals but do you also represent donors?

Ms LORBACH: We do have donors within our group, yes.

CHAIR: Are you finding that in this day and age donors would be more open to giving more information earlier on than what may have been done 10 to 15 years ago?

Ms LORBACH: Much more. The experience that has happened in other places that have changed to using identifiable donors quite some time ago, like New Zealand and Victoria, they have had no problem getting donors and they have actually been very encouraged by how many men are willing to update information, how many men are willing to come forward and share information with a donor offspring, but they have to be encouraged to that.

CHAIR: That would be non-identifying information?

Ms LORBACH: Yes, and identifying.

Mr JAI ROWELL: The Law Society expressed the view that the register of births should include all the parents a child could have, such as a donor, but that this information does not need to appear on an official birth certificate. It notes that in certain circumstances it may be possible for a child to have several parents—for example, egg and sperm donors, surrogate mothers and legal parents. Can you comment on the argument that donor details should appear on the birth register but not on the birth certificate?

Ms LORBACH: I think we discussed that before. We feel they should be in an addendum to a birth certificate. The other reason for that is that we firmly believe that all donor-conceived people should have the right to know the truth about their identity whether their parents tell them or not. This would get over the fact that some parents either are not telling their children because they do not know how to or because they are reluctant to do so. Some people say it should be the parents' right whether they tell the children the truth or not but once that child reaches adulthood whose information is that then? We firmly believe that that is the donor-conceived person's information and no-one should have the right to deny them that information.

Mr JAI ROWELL: Are you able to tell this Committee—obviously excluding names—of a case study where a child has found out through a normal process—their parents have told them—and how they might have

reacted as opposed to a child who found out accidentally particularly where the parents have not been willing to tell them and some of the issues that might surround that?

Ms LORBACH: The vast majority of children in our group have been told very young. We told our children when they were toddlers. The results of that telling can be very varied. Everyone is an individual. Some donor offspring want desperately to know the identity of their donors, some want to meet that person and to see that person, some would like more non-identifying information, and some have absolutely no interest in their donors at all. My husband and I had three donor-conceived children—we had three different donors. Our children have been given some non-identifying information about their donors that we got from the two different clinics we attended. They do not at this current point in time have a great deal of interest in finding out information about their donors—my children range from 16 to 23—but they say they should have the right to it. What we have found in all the years of our group being in existence is that there is a variety of needs and wants that donor conceived-people have but I have never met a donor-conceived person who says they should not have the right to know or to be able to access information if they feel they want to.

I have also met donor-conceived people who have found out accidentally or been told by their parents in adulthood and a lot of them have found that very hard to deal with. One person put it as though he had been hit by a truck; that this truck had hit the brick wall of his identity and he had to start rebuilding that identity from scratch because everything he had been led to believe before was not true any longer. So he had to say: Now I have to decide how I feel about all of this. Who am I actually related to? He also had the problem that he knew there was a good chance that there were a number of half siblings out there that he did not know about and would probably never get to know.

CHAIR: If you do not mind me asking, how young were your children when you told them?

Ms LORBACH: Toddlers. The eldest was about two when we told him; the other two were probably even younger because they heard our discussions with him. So there was not really a starting point of telling with them; it was sort of a natural thing that they grew up knowing. We wanted to tell them very young so that they would grow never remembering a time where it was not part of their identity. That is what has been advocated in adoption: Adoptees are told as young as possible so it is part of their identity as they grow up.

Mr NICK LALICH: Do you feel at two the child comprehends what you are telling them? If I may ask, you said your children are now between 16 and 23. Was there any problem in telling them so that you felt you should not have done it at such a young age and perhaps you should have waited until later? That is a private question; you are not obliged to answer it.

Ms LORBACH: No, I am fine answering that question because it reflects the experiences of lots of other people as well. I do not think at the age of two they do understand. But we tell them: "Aunty May is having a baby; she is pregnant." They do not understand that at the age of two, so I do not see why this is actually any different to that. The reason for telling them young is so that they grow up always knowing. I will tell you how we told our children. We just told them that to have a baby you have to have a sperm from a father and an egg from a mother. In our family dad did not have any sperm so we went to a hospital where somebody gave us the sperm and that was how we had them—it was as simple as that. At the age of two we got no questions—very few parents ever get questions at that age. We repeated the story as the children grew because you want them to know that it is a topic that is open for discussion. We have had people in our group who have been told once at a reasonably young age—probably at about the age of seven or eight—and then the topic was closed from then on, which makes people feel ashamed or that there is something secretive about that information.

We told them and then we added little bits of information as they grew. Our first question did not come until our eldest was about five, when he asked why we had a support group. He was going to these picnics and he knew all the children were conceived the same way he was but he did not know why we needed it. We just explained to him that we wanted him to know other children who were conceived the same way because the majority of children were not conceived that way. He accepted all that information. We have not had any problem discussions in our house. I think any problems probably came from me not necessarily knowing how to broach certain subjects because we were the first people doing it in a lot of cases and people were learning from our experiences. I think our children are fairly well adjusted. As I have said, they do not particularly want to meet their donors but that may change in the future. I know donor-conceived people who had no interest in anything to do with their donors until they had children of their own and then they suddenly realised what their children were actually missing, as far as medical histories and genetic information was concerned.

Mr GUY ZANGARI: In your submission you say, "adoption has always been under the main control of government or religious welfare services, donor conception has been under the control of medical professional individuals and organisations." Further to that you said, "it is ironic that the culture of secrecy was being promoted in donor conception practices during the same period as the wall of secrecy was being broken down in adoption." From your submission and what you are saying here today there seems to be a large gap between adoption and donor-conceived people?

Ms LORBACH: I will take the first part of that question. Most adoptees were lucky enough to have records in existence because church organisations tended to keep them fairly well and governments tended to keep records very well; that has not happened in donor conception. I know of quite a number of donor-conceived people in their 20s, 30s and 40s who have been told that their records have been destroyed. They have no hope of ever finding out who their donors are or of getting any information at all bar what their parents may have verbally been told decades ago about the donor and may not remember. A number of those people are still actually fighting for the right to have access to that information even though they know they will never get it. They think it a principle that they should be given that right.

In donor conception, because it has been held by private individuals and companies they have been allowed to do what they like with those records. The records have never had a great deal of protection above and beyond what is given to normal medical records. That is part of the problem of legislation sitting within the health sphere as well: They are only governed by the laws that govern health records. These records go way beyond that. My children's records, and the records of thousands upon thousands of other donor-conceived people, are like birth certificates because they are what tell my children the truth of who they are related to. I am still trying to find out where my eldest son's medical records have gone. The clinic he was conceived at was bought out multiple times and was then also, as far as I know but I am trying to ascertain this, bought out by a pharmaceutical company. I do not think the best place for these records is a pharmaceutical company.

I do not think the best place for these records is any privately-owned company but they do make a huge amount of money from what they are doing. I read in the paper only this week that apparently IVF Australia and related companies could be up for sale for \$150 million. So it is not a small amount of money we are talking about. These clinics are not protecting records. We do not really know what they are doing with records because there is no transparency as to how clinics are accredited to Medicare funding. There is no report that has to go to Parliament for their Medicare funding. There is a report that has to go Parliament if you are using embryos for research. Under the Federal Research Into Embryos Act the committee that goes round all clinics and accredits them for their licences to research on embryos has to give a report to Parliament I think it is twice a year—that is Federal Parliament. Those embryos will never create human beings but there is no government committee that goes around clinics in this country to check how they are operating when they are creating living human beings. I find it incredibly sad that we give more respect to an embryo that is never going to create a human being than we do to what is being done to create human beings.

Mr NICK LALICH: A number of submissions received by the Committee propose the provision of counselling and support services. Where do you think this function should reside and what do you think are the requirements of a comprehensive counselling or support service?

Ms LORBACH: The reason for us so strongly suggesting that we need something in this State is because we were hoping that when the Assisted Reproductive Technology Act came into force there would be some form of counselling attached to the registers here; there is none. The people who operate the registers are not really trained in this area, as far as I know. The Victorian Assisted Reproductive Treatment Authority volunteered to help in the setting up of registers here and to give them its years of expertise; nobody took up that offer.

We also suggested that they go to the Post Adoption Resource Centre and get their experiences of handling birth origins information. As far as I know that offer was not taken up either. So we seem to have a group of people who are running a register—and I think they have two people running this register—and they are not getting an awful lot of people coming to it as yet, but they do not have training; they have no counsellors on board. They will not even suggest counsellors that people can go to; they suggest that people go to the infertility counsellors organisation, but those people are trained in infertility, they are not trained in birth origin information.

So people are left high and dry as to where they go for help and they are coming to our group—we are not trained counsellors either, we can suggest to people that they perhaps look to places like Relationships Australia, but at the moment there are no organisations that will help people who are struggling with this information except for us. We need something that is either a separate authority or resides in a place that may have experience with this sort of information, like the Post Adoption Resource Centre.

Mr NICK LALICH: In so far as the private organisations that have these fertility clinics, do you think that they should be compulsorily made to give a copy of that certificate to either the health department or to the Births, Deaths and Marriages? Who do you think should keep those records?

Ms LORBACH: Births, Deaths and Marriages because that information is just as important as their other birth certificates.

Mr NICK LALICH: Bring them all under the one?

Ms LORBACH: Yes.

CHAIR: Private donor conception arrangements which occur outside of ART clinics cannot currently be registered. The New South Wales Government's submission suggests expanding a voluntary register, currently managed by the Ministry of Health, to include private arrangements. What is your view on recording donor details of private conception arrangements? Also, because you are dealing with both donors and donor conceived individuals, those that you represent, do you have an idea of what the mix is or the split is in regard to those who are going through the ART or private arrangements?

Ms LORBACH: I could not give you a definitive answer on that, but we have people coming to our group who have used private arrangements or are planning to and now that a few more people are aware of the registers we are getting asked the question can they put their names on the register, and we tell them no, but I am also giving them the phone number of the register and saying speak to them as well. So we are getting people coming thinking even though they have gone through a private arrangement where they know that person they would like the safeguard of having information on a government register in case at some stage they lose track of that person, so there is somewhere if anything happens to them or their own private records that their children can go to find the information as well.

Mr GUY ZANGARI: The issue of whether the donor registers should operate retrospectively was raised in several submissions to the inquiry and your submission addresses this question in detail and you express support for granting retrospective access to donor details. Do you have any further comments on this issue?

Ms LORBACH: I would reinforce that we do not see why donor conception should be treated any differently to adoption, and adoption was made retrospective. People were concerned at the time that the floodgates would open and that there would be really serious problems, but it did not happen. We would suggest a system very similar to adoption where there is the possibility of contact vetoes. Victoria does not even have contact vetoes and they do not have a problem with adoption down there. But the one difference that we see between donor conception and adoption is numbers; the fact that a relinquishing parent may have relinquished one, two, three children; it is not often you get a huge number, but in donor conception those figures can be quite large.

I know of people in our group whose children have upwards of 25 half-siblings, so I think we need to have something in place to protect the donors from the fact that they could have a large number of people wanting to get in contact with them. I think you have to have some form of protection and I think contact veto is the ideal way to do it. We can also encourage donors to come forward and give more non-identifying information, which may mean that many donor offspring may not want to contact their donors because they have had their questions answered: Where did I get my nose from? I get it from my donor's grandmother who had a nose very similar. They may be able to have photos of their donors. They can find out about where they might get certain talents from. There are all sorts of things that could be done, but the right to have identifying information should be retrospective, as in adoption.

Mr NICK LALICH: This morning the Ministry of Health indicated that there are not a high number of donor-conceived people. They do not know about the number in private organisations because up until 2010 they have not had to notify them, but they are saying it is not a very high number. Do you find that through your

organisation where you get together with these people for barbecues and picnics that there are a lot of donor children?

Ms LORBACH: I do not know how the health department can tell you that because the problem is we do not know; records have never been kept of donor conception up until the last few years.

Mr NICK LALICH: I think it is the records they have.

Ms LORBACH: There are very few public hospitals that have done donor conception in this country. In New South Wales it was Royal Women's; Westmead has done a mixture of public patients and private; and Royal North Shore—I am not 100 per cent sure what their situation was, whether they were a public clinic, I know a clinic operated within Royal North Shore Hospital and I think it may have been private. But the only figures we have ever been able to get a vague idea of is from the 1990s when clinics were telling us they thought there were about 2,000 children being born per year. So we are talking about fairly large numbers, and Victoria and New South Wales would have had the most of any State in the country, but we really have no idea.

Mr NICK LALICH: So until we legislate that there has to be compulsory recording of this we are up in the air, and people like you who have had experience say—

Ms LORBACH: And even then we will never truly know because of the destruction of records.

Mr JAI ROWELL: I want to thank you for your open account of your story and the people who you represent. We have obviously covered a lot of issues today but are there any other issues that we might not have covered that you might want to raise with us or challenges that we should be looking out for?

Ms LORBACH: I think that the New South Wales Government really has to have a serious look at retrospectivity. It has been looked at in Victoria—they are the first jurisdiction in the world to be seriously considering retrospectivity. I appeared before their inquiry last year and it is an amazing thing for a committee to sit down and actually say, "Yes, we are thinking about this", because it has never even been on the table before as a suggestion, it has always been, "No, you cannot possibly do that", and we have always asked why not. We just kept getting told it would be a breach of privacy, and I think it was considered a breach of privacy of relinquishing parents in adoption too, but they were guaranteed in a lot of cases that their identity would never be known to their children, but it was. The world did not come crashing down and it helped a huge number of people work out who they were in the world and what their place was in the world, and it should be the same here.

I do not think the health department is doing a great job with the registers. We had huge problems with the writing of the information that went on the website where it was even down to the wording where originally they wanted to put up on their website that in the past some donors were anonymous. I got to the stage of saying to them, "You cannot rewrite history". In the past virtually every single donor was anonymous and you cannot rewrite history; you have to be honest about what went on in the past before you can move on. It was like denying a lot of people's experiences, because we had donor-conceived people come to us when we consulted them over these draft documents who were saying, "How can they say that? We will never know who our donors are; they were anonymous and our records have been destroyed". They were so angry that someone could even suggest that they write such a thing.

Advertising of the register is virtually zero. I have been led to believe that this month information should be going out to all GPs in New South Wales advertising the register. So they will get mini posters for their waiting rooms—

CHAIR: We were told earlier today that that has commenced.

Ms LORBACH: Good, because we do not get told anything. For some reason the register has stopped communicating with us. The only time I get information is when I ask them.

Mr JAI ROWELL: Are there any more effective ways you could see for that message to get out there?

Ms LORBACH: Do what they did in Victoria: they took out newspaper advertisements; they did online advertising. The information on the web for the register is hidden within the health department website.

In Victoria because they have an authority they have a stand-alone website, which is what we need so it is much easier for people to find. I battled for a long time the fact that when you search for the register you are getting old pages that were not even a new version of the website that we battled to get. So it has been a long battle and it is still not working very well, especially when people phone up the register and they do not have people on the line who are trained in birth origin information.

Even now I do not think they fully understand how scary it is for people to approach the register, especially when you have gone through the older system in clinics whereby you are told that your children did not need to know the truth, where, as in my case, when we tried to write letters to our children's donors to say thank you we had to go through a huge battle with two different clinics as to why we would want to do that. We wanted to do it because we wanted to say thank you for that gift of our children but we also wanted to make sure that the donors knew that children existed because in some cases clinics were not telling donors that any children had resulted from their donations, and we wanted to let them know that maybe in the future our children might have questions. It was a huge battle to get two clinics to do that because we were the first people to have done that with both those clinics.

With our first clinic—sorry, this is quite a complicated story—we asked for the letter to be sent on. The scientist who dealt with the donor said he would do that. He got back to us a considerable time later, after us reminding him, and told us that the donor was no longer at the address that they had on record and that he could do nothing further. So we left it for a few years and then there was something on television about donor conception and our eldest son said, "Do you think you could try and contact the donor again?" because he had seen on this TV program that a clinic in South Australia had helped a child get in contact with their donor, and I said, "Yes, we will try again". That scientist had since retired; the clinic counsellor was now doing any correspondence with donors and we asked her could she do more, could she do what Royal Women's Hospital have done for a family that we knew where they would look through electoral rolls and send out registered letters to every person of that name? She said she would have a think about that and she would consult the doctors, because the doctors have the final say—they are medical people, they are not experienced in this area but they get the final say in things like this, and still do.

When she went to the records she thought she would give it another go with the address that was on record—the one that we were told they could not find him at—and she found him, at the same address he had always been at. So we had been lied to by the clinic. That is not an isolated incident. People wonder why we are a little mistrusting of clinics and how they have kept records, and how they handle families who approach them to try to get information. I know of one family that got their children to undergo DNA testing to find out if they were actually full siblings. The clinic told them they were but the family did not know whether they were or not. There are lots of instances like that, which is sad. That is why we need better legislation to control what is happening to old records and we need it to be taken out of the health sphere.

CHAIR: Thank you for your submission and for attending today on behalf of Donor Conception Support Group of Australia. Thank you also for sharing your personal reflections and experience as it helps the Committee. We may wish to send you some additional questions in writing and your replies will form part of your evidence and be available to the public if you agree to that.

Ms LORBACH: That is fine. Thank you for listening.

(The witness withdrew)

(The Committee adjourned at 3.00 p.m.)