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LAW REFORM COMMITTEE

Inquiry into Access by Donor-Conceived People to Information about Donors

Melbourne— 17 October 2011

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Professor D. de Kretser

The CHAIR — Welcome, Professor. My name is Clem Newton-Brown. This is a joint Parliamentary Committee, we have both parties here. You met Russell Northe, Anthony Carbines and Jane Garrett, and Donna Petrovich should be coming soon. As you're probably aware you are protected by privilege here but not outside the room. What we've been doing is basically asking witnesses to just talk us through their submission and we'll fire questions at you as they arise, if that suits you.

Prof DE KRETSER — Yes.

The CHAIR — If you could start with your name and address and who you represent and then launch into it.

Prof DE KRETSER — Sure. Professor David de Kretser. Do you want my home address?

The CHAIR — Business address is fine.

Prof DE KRETSER — Monash Institute of Medical Research, Monash Medical Centre, Clayton, Victoria.

The CHAIR — Do you want to talk us through it?

Prof DE KRETSER — Sure. You've got my submission. I thought it might be useful basically to talk a little bit about my background and my involvement in the area because basically until I became the Governor it was part-time research and the other time predominantly dealing with the management of infertility with a major focus on men. I'm an andrologist, which is the male counterpart to a gynaecologist. I've been doing that since 1967 so I've seen quite a lot of changes over that time. I spent two years in the United States from 1969 to 1971 working in a unit at the University of Washington, which was in endocrinology but also dealt predominantly with a lot of male reproductive problems. Since coming back to Melbourne I've been in academia but also having an interface with seeing patients in this area.

As I was briefly mentioning before, it's been a changing field and perhaps I should say right at the start, that even today, in 50 per cent of the men that would walk into a clinic with a low sperm count or low movement of sperm, you don't know the cause. Basically if you have a broken car that you don't know the cause you've got to change a lot of parts to try and fix it. Unknown causes of sperm number reduction, motility, shape which cause infertility still remain a big enigma. If you go back to the time when I came back from America, I would say we only knew 20 per cent of the causes so there's a 30 per cent gain over that period of time.

In many instances for the infertile male with low sperm counts there's no treatment, you can't increase your sperm count, you can't increase motility. In 50 per cent, yes we can, if some of them are genetic causes such as missing genetic information from the Y chromosome, which accounts for about six to 10 per cent of men who have very low sperm counts. Obviously those men can't do anything, other than trying to find sperm that might be present in the testes, and I'll come back to that in a moment. So basically when you see a patient with infertility as a couple, the couple obviously is very frustrated, there's sadness, there's hostility, shame, sometimes all of those things are together. There's an inability to share with others because of societal expectations, and that obviously has changed from the 60s to now. Who is to blame is sometimes a challenge to marital harmony. So that's the sort of mix of emotions that one is dealing with in patients such as this.

For the male partner, if he is the person who has the problem, there is a sense of "I'm a failure", a confusion between infertility and the issue of virility, leading sometimes to problems of sexual dysfunction and impotence. Depression, difficulty of accepting adoption or donor insemination, but the latter, I guess, provided the man and the couple with the opportunity to have a baby and a choice of keeping it secret. Adoption, I guess, is more a public disclosure that there is something wrong with that couple. So those are the dilemmas, and much of the time, one spent in dealing with couples was partly counselling, taking them through these sorts of issues, trying to say: well, this is what we can do, this is what we can't do. And I'll come back because things have changed a bit, even though we can't actually treat the man I think you will see a progressive decrease in the need for donor insemination for the community and I will come back to that.

The CHAIR — Just coming back to your comment about couples perhaps choosing to keep it secret. What percentage of couples would do that, is there a change over the years?

Prof DE KRETSER — I think there is. It's a very hard thing. As a physician you counsel them, you say it's much better to be open, their choice, and all of that depends on their upbringing, the family situation, sometimes the casual comment of a grandparent: "when is it going to happen?" They don't realise that a comment like that is like a shaft into somebody who is actually working through these issues of infertility, because it's not something that people put out there as a flag, it's not like you've got cancer or this disease or that disease.

Coming back to, if you like, the history of donor insemination. Prior to the 1970s adoption was available relatively easily therefore DI was really practised occasionally; there wasn't any organised clinics. There would be, if you like, messages that would go around in the medical community — it was predominantly obstetricians and gynaecologists who were dealing with the couple that so and so might actually provide donor insemination but nothing definitive.

The CHAIR — DI is direct insemination?

Prof DE KRETSER — Donor insemination, sorry. I guess one of the big changes was the availability of sperm freezing, and that made a big difference, rather than the use of fresh semen samples. With time, waiting lists for adoptions increased, due to the availability of oral contraceptives and intrauterine contraceptives, less children were available, so the waiting list started to increase very, very significantly and that put pressure, if you like, for organised donor insemination programs.

I came back from America in 1972. There was a little bit of practice in an informal way in terms of using donor insemination but then in about 1977 the late Bryan Hudson, the late Carl Wood, John Leeton and myself actually set out to formalise and try and set up a program and to have it on a professional basis with a sperm bank and with a nurse practitioner who would work in the area.

The CHAIR — Why was there a move from fresh to frozen; just because you could?

Prof DE KRETSER — Yes. Very good reasons in that it means that you can store sperm, you select your donor more carefully, you can do tests — and of course HIV started to come into the area. There was always a risk of STDs in terms of gonorrhea in particular, syphilis less commonly, and so it meant that you could screen the donor for all of those issues and then progressively genetic testing became available to do a karyotype to look at the chromosomes of men who were going to be donors, and so it became a much more professional service. Initially there wasn't a counsellor but progressively we realised that it was important to have a counsellor and so there was a social worker who was hired to work on a consultancy basis in that area.

The CHAIR — Are you able to explain — digressing a little bit — to a non-scientific person, how it is possible for something living to be frozen and then come alive again when it thaws?

Prof DE KRETSER — Okay. The leaders in the sperm freezing area was obviously the domestic cattle industry in particular, and we learnt from them about the fact that you could freeze sperm and store them in liquid nitrogen for as long as you like. There's samples, I think, that have been stored for 25 to 30 years and so on. I guess that was really to show that it was safe and the cattle industry obviously led that area but we learnt from the cattle industry. There was a lot of work in America on sperm freezing. When Alan Trounson came back from Cambridge, again he had experience in sperm freezing in the domestic industry, cattle industry, and he was again a valuable source of knowledge in addition to developing IVF programs and donor insemination.

Basically that's the sort of background and the evolution of DI, and really, you know, progressively there was more counselling, adoption and donor insemination. Questions arise: do you talk about that with your family? Yes, you should. Should you talk about the donor? And then there was the issue of recruitment of donors and initially, I guess, we were working in a society where access to records about adoption was not available. That changed over time and consequently that influenced the issues about donor insemination and should the donor be counselled, therefore, that at some point in time, his identity might reasonably be passed onto offspring that arose. You know the dates from which counselling was available and that that changed to actually telling the donor that he would be donating on the premise that information about his identity would be available to his progeny later on.

I said that the donor insemination pressures are going to decrease, and the reason for that is the ability to take an egg, to pick up a single sperm and to inject it in to achieve a pregnancy, intracytoplasmic sperm injection — or ICSI as it's called. That technique really revolutionised the whole area. For instance, there is a genetic condition that causes male infertility called Klinefelter Syndrome where a man instead of just having an X and a Y chromosome, which makes him a male, a man with Klinefelter's Syndrome has an extra X chromosome — two Xs and a Y — those men have testicles about the size of a pea.

Just as an aside, despite having testicles of that size, 50 percent of those men go through life without ever being diagnosed, simply because no one has examined their testicles. You couldn't miss it if you did. Until sperm injection became available, there was nothing you could do as these men had a zero sperm count. Then people were taking men who had low sperm counts and doing biopsies of the testes and actually extracting sperm, injecting those sperm into an egg and showing that you could achieve a pregnancy. And then doctors — I would have thought almost cowboys — decided to take a tiny little testicle like that and to dissect it and see whether you could find sperm. Believe it or not, in about 40 per cent of those men with testicles of that size you could find a few sperm. Even for that sort of man now there is the possibility of actually fathering a child. Today, something like 30 per cent of all IVF cycles are for male infertility; in other words you are putting a woman through a program of significant stimulation of the ovaries and collection of eggs basically for a male problem. But what the use of IVF has done is to drop the need for donor insemination if a couple elects to go down that pathway.

It's now a changed society. Adoption records are available, and this is why I think we're having these debates and issues of a person's genetic inheritance. Just one aside, without necessarily in any way downplaying the importance of your genetic inheritance, a study in East London of blood group of families — I've got the reference and I can give it to you — showed that in 30 per cent of cases there was no way that the father could have been the father of the child. That was an extraordinary sort of percentage of cases so there's a lot of people out there who don't actually know about their genetic inheritance. That's an aside, that's background information, and partly that came out in the discussion about donor insemination in about 1973 in the UK because in the UK effectively couples who had donor insemination were actually falsifying information that was given to the Registrar of Births saying that the husband was the father of the child and the reason for bringing out these issues was that there are other things that can mess up the Registrar's records, such as what happens occasionally.

That's the background, I hope that's of some help; I'm happy to take any questions in that area and then you have my submission which pretty much says it is important, it's a changing scene. I am now the Patron of VANISH, which is the organisation which you are aware of. On one occasion I've contacted the donor where I was the physician who organised and counselled the couple. That particular donor was willing to meet his offspring, and it's been a great success. I wrote to him initially and I said: "you participated in a program at Prince Henry's Hospital some time ago at such and such, would you contact me if you're interested in finding out some more about it". He did, and I was able to initiate that exchange of information; he met with a counsellor after that, he made his information available, met with what was his daughter.

Mr NORTHE — Just the last part of your evidence there, Professor, you mentioned the 30 per cent figure of those persons thinking that who their real parents are may not be the case. Through this scenario that we're playing out, if you had a voluntary register otherwise to try and link a donor-conceived person with the sperm donor, what mechanism should be in place, do you think, to make sure that we are absolutely getting this right? It was suggested through Professor Kovacs when he tendered evidence about making sure it had a DNA match because the last thing anybody wants to see happen here is that we think we're putting two people in contact with each other and it doesn't work out to be the case. When you're talking about putting measures in place and making the contact, should there be other aspects of that that we need to consider?

Prof DE KRETSER — I think that's probably a very rare occurrence in the infertile couple. They go through an extraordinary journey together and if somebody wanted to cheat, it's possible to cheat. They go through a long process, they go through counselling, they go through all of these issues, I would have thought the risk of that would be pretty small. One of the suggestions that I think I put in my submission was that to try and deal with the issue of where we have no records of donor insemination and people are falling through the cracks, it's not unreasonable to have some publicity around the area and to ask donors who might have donated in the early days whether they would be willing to put themselves on a register and actually give a sample of DNA and similarly if progeny are looking for their donor father that they would actually do the same and the DNA can then be matched up and provide that opportunity. Then that way you still retain the confidentiality issues between the doctor and the person who was recruited to donation, the conditions that existed at the time, but also still giving the opportunity if a donor feels that they would like to take responsibility and somebody who is seeking to identify their genetic inheritance.

The CHAIR — Professor Kovacs, who you are probably aware of the case where Narelle Grech has requested information. It seems that she's gone through a similar process that you went through to getting your records back from the Registrar, was it?

Prof DE KRETSER — Well, actually some of the records from Prince Henry's Donor Insemination Program they've actually remained separate and one of the suggestions I have made is that those records perhaps should be incorporated into a register under appropriate conditions of confidentiality.

The CHAIR — You obviously had no problems getting hold of your records?

Prof DE KRETSER — I have the records of the patient I saw, my own clinical notes and things like that, so then I was happy that I had been the doctor who was involved in seeing the infertile couple and identifying the issues.

The CHAIR — Is there a difference between your situation and Professor Kovacs in that he's tried to get his records and can't get them, he's been told: no, they're confidential.

Prof DE KRETSER — I don't think that that's right. He actually ran the Donor Insemination Program with a couple of other people at Prince Henry's so my understanding is the records from that clinic are there. Before that clinic was set up, there would be no consolidated records.

The CHAIR — You were in the same clinic?

Prof DE KRETSER — Yes.

The CHAIR — Who did you apply to to get your records, or did you obtain a copy of the records yourself?

Prof DE KRETSER — No, I don't have the records of the donor insemination, who is the donor and things like that, actually they were maintained by Prince Henry's Hospital Donor Insemination Program, and Professor Kovacs would know where they are. I'm just trying to think what procedure I actually followed. I think I did it finally through the social worker, but the records are available because that was how I found the particular person concerned.

The CHAIR — What year was that?

Prof DE KRETSER — Now you're pushing it. I wouldn't have a clue, quite frankly.

The CHAIR — Five years ago?

Prof DE KRETSER — When I made contact with the donor?

The CHAIR — Yes.

Prof DE KRETSER — Basically about a year and a half ago.

Mr CARBINES — Thanks, Chair. With regard to confidentiality arrangements at the time for those couples entering the program, what's your assessment at that time of what was driving that or what assurances the program was trying to give to couples who entered the program?

Prof DE KRETSER — Donor confidentiality or the confidentiality related to the couple concerned?

Mr CARBINES — I think both really, what was trying to be achieved out of that?

Prof DE KRETSER — I guess if I see a couple with infertility then those are very personal conversations that we have and they would be bound by the confidentiality of a doctor/patient relationship. There would be notes kept in my files, which belong to the patient now, and are accessible to the patient only. The discussions about whether they discuss their infertility situation with their family and so on, again, openness to me is very, very important but many of them in the early days felt that they couldn't discuss those issues and hence they elected to maintain that degree of secrecy. Again, if you go back to the time I started practising in this area, many women were investigated extensively before a sperm count was even done on a man.

Mr CARBINES — Different time.

Prof DE KRETSER — Indeed. So that's the sort of background and we've moved a big deal from there. The clinic at Prince Henry's always saw the couple. We had five consulting rooms, there was a gynaecologist, urologist, and I'm an endocrinologist, all consulting on the same — we ran on Tuesday nights simply because we wanted to offer a service to the community that was a one stop infertility shop so that you had both the husband and wife who were seen together. That's, to me, the best way to practise reproductive medicine.

Mr CARBINES — And given your role you've had less of a role with those who are choosing to be donors through the program than you would have been with couples seeking — —

Prof DE KRETSER — Yes, we would talk about that and in the initial period there was advertising for donors and progressively that involved counselling and progressively the changing conditions about donating. Initially it was in confidence and the donor was guaranteed that that would occur.

Mr CARBINES — Chair, if I could ask: on that matter then, was there much discussion with your colleagues in setting up arrangements around a confidentiality arrangement for donors or do you think that that was just the base case that was seen as reasonable to start with?

Prof DE KRETSER — I think we basically picked that up from the American scene and the UK, but the Americans had actually developed it further.

The CHAIR — Were the donors actually after that at the time or was it something which the team sort of presumed that this will increase our chances of finding people, that if we put it out there that this is all going to be anonymous, we don't have to worry about it in the future, or was it something that the actual donors were very concerned about?

Prof DE KRETSER — I think it was probably our perception that people would want that confidentiality and I guess when the issue of compulsory counselling was proposed we were quite concerned about whether there would be donors who would put their hand up under those circumstances, but we were quite surprised that people were willing to do that.

Ms GARRETT — Just a couple of questions. With regard to the centralisation of records and integrity of information, which obviously appears to be of paramount importance, some of the evidence before the inquiry has talked about people's concerns regarding steps that are taken to contact donors and needing to know that everything that could be done has been done. Do you have a sense of that level of transparency and the steps to give the donor-conceived individuals some real comfort that the steps have been taken, because I know you've had that success regarding assisting the donor-conceived individual?

Prof DE KRETSER — I've only been approached on one occasion, that's my experience, so it's a bit hard for me to sort of comment on that. I guess some physicians may not wish to do that. I would find that surprising but people's personalities vary, I'm just trying to think if there is some way of guaranteeing a person who is interested in exploring that pathway that the steps have been taken.

Ms GARRETT — I suppose it starts with the integrity of the data with which you're dealing with, to go to your point about the centralisation.

Prof DE KRETSER — Yes. I think the data that would be kept would be, as far as I'm concerned, accurate; I don't think there's any doubt about that. It's obviously better if the enquiry is proceeded with the physician who was dealing with the couple at the time, just purely because of the relationship, provided they had a good relationship with their practitioner, rather than a third party intervening. I guess in the case that I was relating to you, the donor was aware that I was associated with the program at Prince Henry's and consequently recognised what it was all about when a surreptitious letter came about this enquiry.

Ms GARRETT — A further question regarding the issue of confidentiality. I think a lot of evidence before the Inquiry has focused on it's much better to have a voluntary connection between donors and donor-conceived people and that's a good start to any ongoing contact, but we have had some very powerful testimony from both donor-conceived children and from donors who in the space you get to where the donor does not wish to be identified, or doesn't even wish to have non-identifying information, and the child is very much feeling a huge hole in their existence because they know it's there, you can almost touch it, and that's been expressed in terms of a balancing of rights — the rights of the donor-conceived individual and the rights of the donor. Your submission talks about the paramount importance of confidentiality, that is your position that you're balancing those two rights?

Prof DE KRETSER — A donor who donated under those circumstances did so in good faith, that that would be respected; it's very hard to walk away from that.

Ms GARRETT — I suppose in the context, though, that there has been perhaps some unforeseen circumstances of the concerns of the people who were created, if it was the position of this Inquiry that at the end of the road there was a view that identifying information should be given, do you think that the veto on contact provision that exists with the New South Wales adoption situation where you can identify your birth parents, but if the birth parents choose not to be contacted there is some legal protections around that, do you have a view on that?

Prof DE KRETSER — I guess that's a sort of a halfway house, isn't it? Obviously in the sort of case that Gab Kovacs has been dealing with there was obviously a potential medical issue related to inheritance. I think it would need to be judged on the basis of each individual case. That's probably, if you like, sitting on the fence.

Ms GARRETT — It's a difficult issue.

Prof DE KRETSER — I mean, it is a dilemma; there's no question about it.

Mr NORTHE — Professor, just in terms of a voluntary register, just your thoughts on who might manage that one central body and who might have carriage of operating that? A subsequent question: in your submission you talk about running a media campaign to try and encourage donors and also donor-conceived persons to filter into the register, how would you actually tackle that as well?

Prof DE KRETSER — I wouldn't want to be coercing anybody to do that, I think it's just bringing it to the attention of people that this might now be available and some suitable publicity around that. There needs to be some organisation set up by Government if there is going to be a register and people can put their DNA, for instance, a sample sitting there and vice versa. It needs to be a reputable body who, if you like, has a legal framework to work under because it's a sensitive area.

Mr NORTHE — Just a subsequent question again. In terms of the donors themselves who might have at that time donated and wished to remain anonymous, do you think that they generally would understand the legal requirements that centre around them at the moment? I have asked this question a couple of times to people but I get a sense that maybe donors may not wish to come forward sometimes where they may think there's an entitlement to their offspring to tackle their assets or estates or otherwise. I might be wrong in that assumption.

Prof DE KRETSER — This is where you need, if you like, some person interposed between. In the case that I was talking about, a counsellor was made available and if there is a move to set up some form of structure to deal with this then I think there needs to be a definition of what the legal responsibilities, etcetera, would be as a result of a donor coming forward and being identified. I think that's probably only fair, otherwise you may well have people who are reticent to do that because of a perceived concern. I just sort of wondered how the particular person I sent the letter off to would have felt, but that person was quite happy to accept that possibility.

The CHAIR — So given that you're happy to do that, do you think that that is a model that we could look at putting some frameworks around such that the pre-88 contacts are made?

Prof DE KRETSER — To me as a physician that was the least that I could do, and I can't see any reason that other people wouldn't do the same provided it's done tactfully. I think Gab Kovacs has probably done it a few more times than I have.

Mrs PETROVICH — My apologies, Dr de Kretser, for my lateness today; I would have dearly loved to have been here for your full presentation because obviously your work is quite groundbreaking, but we have moved on and we're in a different space now I think, but from your understanding pre-88 how many people are we talking about? If we do actually establish a register, is it a really onerous task or is it going to be a Godsend for a few?

Prof DE KRETSER — I can't give you a figure on that but that should be pretty easy to find out because the records are available and there would be no problem for somebody to scan through the records and say: there's this number of cases that went through this year. They probably would have seen an increase and, as I pointed out before you came in, the need for DI is dropping away very dramatically because of the IVF program and the capacity to inject a sperm into an egg and achieve a pregnancy. This is something I would never have dreamed about. I gave you the example of a genetic condition called Klinefelter Syndrome, which when I was in practice before sperm injection came in I would have said absolutely no chance, nothing. With testicles that size, there is nothing. But when sperm injection came in, people went and actually carefully dissected that tiny testis and actually found few areas containing sperm, and these men have achieved pregnancies.

The CHAIR — Of the pre-88 donors, could you estimate how many donors we're talking about? Is it tens or hundreds or thousands?

Prof DE KRETSER — No, no. My guess would be a couple of hundred probably. But, again, it shouldn't be too much of a problem to find that out from the records that are available.

The CHAIR — What would your view be to be able to go back to those records and try to contact each of them to get them onto a database, do you think that would be useful, or should it only occur when you have an approach like you had from a donor child?

Prof DE KRETSER — Hard question to answer. I mean, approaching a donor when it's not imminent that a person is going to knock on your door type of thing might be a preconditioning, if you like, saying: look, things are changing, adoption changed, this is what the Committee is looking at, this is our preferred position, would you be willing to put your name? It would have to be done very discreetly, obviously. Probably might be beneficial if it came from somebody who the donor had interactions with at the time he donated, be it even the social worker who counselled the donor, or the physician concerned, rather than just receiving a letter.

The CHAIR — Any final questions?

Mr CARBINES — Thanks, Chair. We talked earlier about the role you played in making a connection through a donor-conceived person who approached you 18 months ago, roughly. What would be your expectation or your understanding in regard to clinicians even further in the future where donor-conceived people might want to make those sorts of inquiries where the clinician is not available, what do you think is a satisfactory way in which donor-conceived people can proceed to make those?

Prof DE KRETSER — So if the physician is no longer available or reticent to participate, which of the two?

Mr CARBINES — Well, they might be dead.

Prof DE KRETSER — Yes, sure.

MR CARBINES — What would you think is the most appropriate way in which those donor-conceived people can seek to make the same enquiries where the physician perhaps isn't available to do that?

Prof DE KRETSER — If the person who counselled them and recruited them was available that might be an appropriate alternative. It might have been a social worker who saw them, if it was during the time when that type of counselling was made available to the donor, otherwise there might be a couple of physicians who take this on as a task and obviously develop some ways of handling that and approaching that.

Mr CARBINES — Or perhaps then the custodians of the records of Melbourne or Monash IVF records and have those processes dealt with?

Prof DE KRETSER — I would have thought probably most of the clinicians who would have participated in those clinics are still available and still around. I don't think Carl Wood was particularly involved in dealing with the donor area so predominantly all of the gynaecologists and the small number of andrologists — we are small in number — are still around.

The CHAIR — Any final questions? Thank you very much, that was very helpful.

Prof DE KRETSER — Pleasure.

Witness withdrew.