CORRECTED VERSION

LAW REFORM COMMITTEE

Inquiry into access by donor-conceived people to information about donors

Melbourne — 8 September 2011

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Mr D. Fixler, Public Interest Law Clearing House.

The CHAIR — Welcome, everybody. You are probably familiar with the structure of the committees. This is a multiparty committee set up by Parliament. We have been given references by the Parliament to investigate, and this is the first one we are doing in this Parliament. All evidence taken at this hearing is protected by parliamentary privilege, as provided by the *Constitution Act 1975*. It is further subject to the provisions of the *Parliamentary Committees Act 2003*, the *Defamation Act 2005* and, where applicable, the provisions of reciprocal legislation in other Australian states and territories. That means you are protected by parliamentary privilege here but you are not when you go out of the room, so please be aware that when you anything you say outside this room you are liable for your own comments. This may be particularly pertinent given this is an issue the media has interest in, so just be aware of that if you are asked to comment further on your submissions.

Our first witness is Mr Fixler. Could you please give your full name and address?

Mr FIXLER — My name is David Fixler. I am representing the Public Interest Law Clearing House, PILCH.

The CHAIR — In what capacity are you representing PILCH?

Mr FIXLER — I am a secondee solicitor to PILCH from the law firm Corrs Chambers Westgarth. I am simply representing PILCH's position on the issues.

The CHAIR — All evidence is being recorded and will become public once it is compiled and released. You have provided us with a detailed submission. Thank you very much for that. Could you take 10 or 15 minutes to talk us through it? After that we might like to ask a few questions.

Mr FIXLER — Just to provide you with a little background about PILCH, we are a provider of pro bono legal services. We do this in part through a referral scheme whereby law forms such as the firm I work for agree to accept referrals for matters. Two of those matters have involved clients who were conceived using gametes donated prior to 1988, which is essentially why we decided to make a submission. We assisted both of those individuals in advising them, and representing them in the second case, on their ability to obtain access to information about their biological fathers. The first of those clients, who was referred to us in 2009, was Ms Lauren Burns.

The CHAIR — Before you go into the detail of that perhaps we could clarify — you are a secondee to PILCH?

Mr FIXLER — That is correct.

The CHAIR — Your evidence is representing PILCH's position?

Mr FIXLER — That is correct.

The CHAIR — What was the process that was gone through to come up with, 'This is our position as PILCH'?

Mr FIXLER — We of course conferred with PILCH regarding the outcomes of the cases we conducted for them. In consultation with PILCH they decided that they had identified flaws in the current system that they felt should be brought to the attention of the committee. On that basis they felt it was appropriate for them to make certain submissions as they arose on the issues that arose directly from their experience in conducting those cases.

The CHAIR — Your firm handled both of those?

Mr FIXLER — I had carriage of both of those while at the firm in my capacity as a secondee to PILCH.

The CHAIR — Thank you for that.

Mr FIXLER — In the first of those cases, which was referred in 2009 while the old legislation was still in force — that is, the *Infertility Treatment Act* — the client was Ms Lauren Burns. She had first written to the Infertility Treatment Authority, which administered the voluntary register prior to new legislation coming into force in 2010, and asked the authority to assist her in obtaining access to information about her biological father.

In her instance the Infertility Treatment Authority had access to and control over records containing that information which were held at the Public Record Office. She had written and made that request and the ITA responded that they could not assist her in approaching the donor seeking his consent to the release of that information. She subsequently came to PILCH and PILCH advised her on her rights. At the same time she wrote to the doctor responsible for assisting her mother in undergoing the infertility treatment procedure which resulted in her conception and the doctor agreed to use information he had in order to approach the donor and see if he would consent to the release of identifying information so that they could establish a relationship.

The CHAIR — Did the registry have the information available but was not prepared to use it?

Mr FIXLER — Our understanding is that the Infertility Treatment Authority had access to that information but would not use it to approach the donor in order to seek his consent.

The CHAIR — So Ms Burns was aware that they held that information?

Mr FIXLER — That is correct. As a result of the approach by the treating doctor in her instance to the donor, the donor gave his consent to the release of that information and she managed to establish a relationship with him.

The second case we have handled regarding the same issues was that of Ms Kimberley Springfield, who was referred to us in 2010. She was conceived at Monash IVF, and in her instance the records containing identifying information about her donor were held by Monash IVF. She had written in the first instance to her mother's treating doctor, who also had access to those records, asking him whether he would assist her by approaching the donor and seeking his consent simply by acting as an intermediary. The doctor in that case refused to assist her on the basis that donors were guaranteed confidentiality. As a result she made a similar request directly to Monash IVF asking them if they would assist her by using the information they had to approach the donor and seek his consent to the release of information to her, and Monash IVF similarly informed her that they could not assist her for the same reason.

The CHAIR — Did they believe that it was a breach of confidentiality for the approach to be made by a third party?

Mr FIXLER — From our recollection, I do not believe that they said it was a breach exactly; they simply said that they could not assist her in light of confidentiality — that the donor was owed a duty of confidentiality. On that basis they refused her request.

The CHAIR — Is it your view that the confidentiality was not breached by a third party approaching and asking whether they would be happy for their confidentiality to be breached and whether they consented to it?

Mr FIXLER — From what we have seen in these instances and the limited agreements between clinics and donors that we have been made aware of — and we have only been made aware of a few written agreements — none of them that we have seen so far guarantee the donor the right not to be contacted at all.

Ms GARRETT — Can I ask what terms were in those ones that you have seen? Were they mainly oral, do you think?

Mr FIXLER — The agreements that we have seen, I believe, are annexed to the submission made by Lauren Burns to this Committee.

Ms GARRETT — Yes, that is true.

Mr FIXLER — I believe there are three agreements there. They simply provide a right to maintain the donor's confidentiality. In most cases the right that is expressed in there is directed more towards the patient than towards the donor. But what was said to the donor in the context of making the donation, we simply do not know. As the committee under the previous Parliament noted, there is a lot of anecdotal evidence that they were guaranteed certain rights, perhaps orally. As a result of the refusal by Monash IVF in Ms Springfield's instance, Corrs wrote to the Registrar of Births, Deaths and Marriages under the new act, who is responsible for administering the voluntary register, and asked the registrar to write to her biological father to inform him about the voluntary register. In that request Corrs, on behalf of Ms Springfield, noted that the registrar has an express power under the *Assisted Reproductive Treatment Act* to publicise the register and in the event that the registrar did not have direct access to that information in order to send the letter, it requested in the alternative that the registrar forward that letter to Monash IVF seeking that it use the information that it had in order to send the letter.

Ms Springfield's request was refused by the registrar on the basis that she said she did not have the power to write directly to the donor under the act. As a result Ms Springfield commenced a proceeding in the Victorian Civil and Administrative Tribunal seeking a review of her decision. That application was dismissed on jurisdictional grounds but a senior member of the tribunal in that instance noted that at least the request by Ms Springfield that the registrar forward a letter to Monash IVF seemed to have some merit. But obviously the tribunal could not decide the issue because it found that the decision was not reviewable.

From those experiences PILCH has identified a number of what it believes are deficiencies in the current system. The first being that medical practitioners who have access to records and medical clinics that hold records do not have a uniform policy as to how they deal with requests by pre-1988 donor-conceived persons for access to identifying information or other information. From the perspective of donor-conceived persons, it creates an injustice or an inequality, and it is an arbitrary distinction. Their success — as the difference between Ms Burns's experience and Ms Springfield's experience indicates — largely depends on who the treating doctor was and what their approach is.

The second issue that PILCH has identified is that the registrar, or at least the Infertility Treatment Authority before the registrar, would not engage in the practice of using information in its possession to approach a donor upon request by a donor-conceived person in order to seek the donor's consent.

Finally, as Ms Springfield's case indicated, the registry is even unwilling to use what PILCH believes is its power under the *Assisted Reproductive Treatment Act* to write to donors in order to inform them about the voluntary register upon request by a donor-conceived person, including by asking the relevant medical clinic to forward that request along if it did not have the information at its disposal.

Noting those deficiencies that PILCH has indicated and recognised, as the Committee has recognised in its interim report, there is a need to balance the rights of donors who were guaranteed certain rights when they made their donation regarding confidentiality against the rights of donor-conceived persons to obtain information about their genetic identities. We say that there are a number of rights that are reflected at least in the Victorian Charter of Human Rights that are consistent with each of those rights and that an appropriate balance has to be struck between the two. In particular there is a right under the Charter in the interests of protecting families and children and cultural rights which PILCH says from its experience cannot be fully recognised if there is no right to access that information. Of course PILCH does not say that these are absolute rights, but it is a right that is recognised in the Charter that merits consideration. The other right that PILCH has identified is the right to equality before the law. In terms of this right, from the perspective of donor-conceived persons who were conceived prior to 1988, there is an arbitrary distinction from 1988.

The CHAIR — So with the rights of equality before the law are you still talking in the context of the Charter of Human Rights?

Mr FIXLER — That is correct. From the perspective of donor-conceived persons there is no reason why somebody who was born using gametes after 1988 should be treated by the law substantively differently from somebody who was conceived using gametes before 1988. That represents an inequality from their perspective. On the other hand, PILCH acknowledges that there is a right to privacy, that donors were guaranteed some form of confidentiality even though it is unclear exactly how far that extends and there is nothing that has been brought to our attention that indicates that that would extend so far as to not contact the donor under any circumstances. But in the interests of that right it does seem appropriate from our experience that donors would need to be asked for consent before their information is released. It is for that reason that we support a position that is consistent with the position that was recommended by the Victorian Law Reform Commission in 2007, which was not included in the *Assisted Reproductive Treatment Act* but would require the Infertility Treatment Authority or whichever body is now responsible — in the current circumstances the registrar — to assist in facilitating requests for information, including by contacting donors, through clinics where necessary, in order to seek consent.

The CHAIR — In relation to your comments, which were confined to the Charter of Human Rights — as you are probably aware, that is under review at the moment — if there is no longer a Charter of Human Rights, would that influence your position?

Mr FIXLER — As far as our understanding, the rights in the Charter ought to be recognised. We regard them as fundamental human rights. They are not strictly enforceable; we acknowledge that the rights, even as they are currently recognised, are not absolute and must be balanced against each other. We simply rely on the Charter in terms of identifying that these are rights the Victorian Parliament has recognised, and, consistent with those rights, we believe the current system ought to be changed. If the Charter is repealed, we would still maintain that those rights ought to be recognised.

It is based on those experiences and with those policy considerations in mind that we have made three recommendations. The first is that the *Assisted Reproductive Treatment Act 2008* be amended so that power is expressly conferred on treating doctors and medical clinics which have access to identifying information to enable them or to encourage them to facilitate requests, including by writing to donors directly. We have said that, obviously, because in our experience there is an inconsistency in the way that some clinics are happy to facilitate requests and others are reluctant to. Similarly, from our experience with Ms Burns and Ms Springfield, we have seen that some doctors are equally happy to facilitate requests and others are reluctant to do so. We believe that that would give both doctors and clinics a peace of mind in facilitating requests.

The CHAIR — So you are suggesting conferring a power but not an obligation?

Mr FIXLER — We would suggest a power for clinics and for doctors without an obligation. If we move to our second recommendation — that the registrar should have a statutory obligation to facilitate requests and that that should be an obligation on the registrar, including to assist doctors and clinics in that regard — at this stage PILCH's position is simply that that power should be conferred.

The CHAIR — But wouldn't you be in a position where people are then treated unequally depending on the attitude of the doctor?

Mr FIXLER — You would, but you would still have the benefit of relying on the registrar where possible to engage in that request for you and engage in facilitating that request for you in the event that your doctor or medical clinic is reluctant to assist you.

The CHAIR — Would the registrar hold all the information that the medical clinics hold? Could there be a situation where it is only the doctors who have the information?

Mr FIXLER — It is possible under the current system that the doctor or the medical clinic will have that information only, and if the registrar was under an obligation to facilitate a request, that would involve writing to the clinic and asking the clinic to facilitate that request for them. Whether the medical clinics should be under an obligation to forward that on — —

Ms GARRETT — To provide that information regardless.

Mr FIXLER — We have not yet considered or suspected that that might be appropriate.

Ms GARRETT — Just to tease that out a little more, would you see that, given your experience, as something that would happen if that path were gone down, within your recommendations — that there is an obligation on the medical clinics to assist the registrar? Would that go so far as to put an obligation on the medical clinics to provide the information up-front — all the information they have — to a central registrar?

Mr FIXLER — I suppose there are two ways in which it could be done: either there could be an obligation on the clinics to forward that request along — —

Ms GARRETT — Regardless of whether there has been — yes.

Mr FIXLER — The other alternative, having read a number of the submissions, is for the information to be located centrally and to be accessible, and PILCH does not have a view either way on how records are best to be — —

Ms GARRETT — Managed.

Mr FIXLER — Best to be centralised, with access by the registrar. PILCH believes that requests should be facilitated and that there should be sufficient obligations in place on whichever party to enable that to occur so that it could not happen that the registrar fulfils their obligation and that a request is not forwarded along because the clinic in the particular instance decides not to fulfil or satisfy the registrar's request.

The CHAIR — Given that the records, I understand, are patchy in that period, would you support the idea of a requirement for a central register to get all the information that everybody has — let us get it all into one spot so at least we know what we have and then proceed from there?

Mr FIXLER — PILCH's previous submission to this Committee, which was a submission originally made to the Commonwealth Senate inquiry, recommended that records be centralised. I believe in that case there was reference made to a national register, and I am not sure if that is what is contemplated in this particular instance. While PILCH is not well placed to comment on what would be the best method of centralising the records, it does seem that that would assist the registrar and clinics to meet the obligations we have proposed to enable facilitation to occur.

Mrs PETROVICH — Thank you, David, for your presentation to date. In relation to your recommendation 1 and in line with the questioning that is taking place, is that recommendation going to stand up to the test? It seems to me that currently we have disparate information, and if we deal with what we have at the moment, the individual agencies are conflicted in the respect that they have a belief that they have committed to protecting those people who were donors. That recommendation, it seems to me, causes a lot of conflict. Does it stand up? Should we be moving to a centralised and more controlled source of information?

Mr FIXLER — I think moving to a centralised source of information would obviously alleviate the problem entirely. We would hope that if information remained as it currently is and there was an express reference in the act enabling or encouraging the doctors and clinics to take action, they would have the peace of mind to do so. From our experience and from the correspondence that our clients have engaged in with doctors and with the Infertility Treatment Authority or with the registrar, unless there is an express power they are reluctant to act because they are concerned they may be breaching rights. That might assist in putting them at ease, and our hope would be that based on that alone, without an obligation, they would accede to that request.

Mr NORTHE — Thanks, David. Well done on PILCH's submission; I commend you for it. In respect of chapter 4 of your submission 'Right to Know vs. Right to Anonymity' — —

The CHAIR — Better get used to that!

Mr NORTHE — I know — remaining anonymous. From a practical viewpoint, if one is a donor, how do you protect the rights and privacy of the donor in making contact with them as the best method? Obviously there will be people who have donated and want to remain anonymous. How do you broach the subject of having that contact without breaching their privacy and so forth?

Mr FIXLER — I think the Infertility Treatment Authority, which existed before the registrar assumed the responsibility under the new act, had a considerable amount of experience in dealing with donors. It would be our view that, as we have said in the submission, guidelines should be put in place by the registrar or by whichever body is deemed to be the appropriate body to deal with these issues in order to support requests and ensure that they are made appropriately. From our limited experience, we have not identified that there has been an issue with doctors making an approach that is inappropriate, but of course we accept that a request would have to be made in an appropriate fashion, and this could be regulated partly by the act and partly in regulations or guidelines.

Mr NORTHE — To extrapolate further, from a practical viewpoint, what are some of the main examples of how you would do that? What might be the regulations to do that?

Mr FIXLER — Perhaps the guidelines would encourage or include a standard form of letter, along the lines the Victorian Law Reform Commission recommended, to ask the donor whether he would consent and encourage him to seek counselling that is perhaps available in order to better understand what his rights are and whether he would want to engage in that kind of activity and whether he would want to release some information — non-identifying information, perhaps medical information, or identifying information — if he chose.

The CHAIR — The problem, as I see it, in contacting someone out of the blue 20 years down the track is that while, yes, they might be happy to consider a request, the real problem comes when they have got a partner, they may have their own family, and then have something arrive in the mail. How do you do that? How do you initiate a contact without basically releasing the secret that may be there? One of the witnesses, Monash IVF, suggested putting out a letter along the lines of — —

Ms GARRETT — Please contact us if you had any contact with this clinic.

The CHAIR — Which is still difficult. My wife would certainly ask a lot of questions if she received a letter like that. It is a very difficult one, as to how best to do that.

Mr FIXLER — Absolutely! From our experience we have only had one client who successfully managed to establish contact and, as I said, that came through the doctor directly. I am not certain exactly how he went about making that approach. I believe he wrote a letter, but we accept that there would be issues that would need to be considered. Our view is that a method could be found that would enable the donor to be asked for their consent in a way that is appropriate and that protects their right to confidentiality. Then at least if a request were made, the donor-conceived child would have the peace of mind to know that at least the donor was asked for consent and was aware they had the right to refuse or that they were happy to consent. In our view it is not an issue that is insurmountable.

Mr NORTHE — In terms of the voluntary register itself — and I guess we have seen the ITA evolve into the registrar — from PILCH's experience or your own experience, have we seen a decline in the services available through that? Or conversely, how can we enhance that register?

Mr FIXLER — Our understanding is that our clients, as they have said in their submissions before the Committee, preference was for the ITA, which offers certain counselling services and which has a small but specialised group of people who understand the issues. And when that is contrasted with our experiences with the registrar, the request that Ms Springfield sent to the registrar was refused, I suppose, blatantly and as a matter of course simply relying on legal advice, we imagine, without any sense of support.

Mr NORTHE — Without any support.

Mr FIXLER — Our understanding is also that the registrar does not offer the counselling services and a number of the other services that the ITA used to offer. Whether that could change, we simply do not know, but it seems, from our perspective, that the way in which the registrar has been treating its function under the new act has been quite administrative and consistent with its functions under the *Births, Deaths and Marriages Act*. Our view is that this is quite a different set of issues which require particular sensitivity.

Ms GARRETT — Obviously at the end of the day your submission recommendations are about facilitating in the best way possible that contact to give the donor the opportunity. But if the donor refuses and wants to remain anonymous, your submission accepts that that is a right that came about due to the circumstances. Have you found in your experience in acting for donor-conceived people that — and this may be difficult for you to answer — at best they are just seeking the opportunity to have the question put, and they understand the anonymity issue? Or have you found that is a mixed bag?

Mr FIXLER — From our experience it is very mixed. There are a number of donor-conceived people born prior to 1988 who are adamant that whether or not the donor consents they ought to have rights to obtain access. Equally, there are a number of others who simply want the peace of mind to know that the donor has been made aware of the possibility of obtaining consent. But at this stage the second group of donor-conceived people are frustrated in not even being able to ask the question. There is a constant uncertainty as to whether the donor is even aware of what is available.

In relation to PILCH's perspective, the view that has been taken is that it would not be appropriate, given that PILCH has simply provided referral services, to comment on whether all donors should have a right even without consent, so PILCH has decided to limit its submission in terms of promoting or in support of the recommendations that it has made.

Mrs PETROVICH — In light of that, and this may be well outside your parameters, we know that prior to 1988 record keeping was not good, and you have just said that people believe it is their right to know who their donor is. The difficulties are that we may not know or that those people may be unwilling. Those are the prohibitors. Would it be worthwhile having a program which asks for people to come forward to actually persist with that identification — those people who were donors — because they may not be aware that there is somebody looking for them? Would that assist and perhaps give these people some peace of mind, if we had a program that actually asked for people to come forward?

Mr FIXLER — Under the current legislation, and under the previous legislation that introduced the voluntary register, it was always contemplated that there would be a power for the body administering it to publicise it. From our understanding, they were very limited campaigns. One was called the Time to Tell campaign which involved advertising and making donors aware of the voluntary register. Our view is that if the donor was made aware of the voluntary register, that would have the same effect as what you are suggesting, because they would be able to come forward, but because the advertising is not targeted in any way it seems to have had very limited effect.

From anecdotal experience, many of the donors who have decided to give their consent in response to a request, when asked if they were aware of the voluntary register, have said, ‘No, we were not aware of it’. It seems that that kind of public advertising of the procedures that are available simply does not work, which is why in Ms Springfield’s case we specifically sought that the registrar write directly to the donor in question, to inform him of his rights under that act, which was refused.

Mrs PETROVICH — And have the various agencies — not the central body — been given that opportunity to participate in that targeted campaign?

Mr FIXLER — I am not certain as to whether or not they have been given the opportunity. Our request was directed towards the registrar. Our view was that the registrar, having the power to publicise, would be the appropriate body to direct our request. The clinics, in relation to our requests, have refused to act as intermediaries, and we did not think that they would be willing to engage in that process. But in our view the appropriate body to facilitate an advertising program about the rights under the act or a specific targeted program would be the body administering the voluntary register.

The CHAIR — As there are no other questions, we thank you very much, and also for your submission, which was very helpful.

Witness withdrew.