

CORRECTED VERSION

LAW REFORM COMMITTEE

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

Melbourne — 5 December 2011

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Witness

Mr D. Adams.

The CHAIR — Damian, thank you for coming today. My name is Clem Newton-Brown. I am the Chair of the Law Reform Committee. This is a joint parliamentary committee. Jane Garrett, the Deputy Chair, is an apology for this afternoon. Anthony Carbines, Russell Northe and Donna Petrovich are here. We are gathering information. We have been given our terms of reference by the Parliament. We are gathering information and as a committee we will jointly put together a submission to the Parliament. We may or may not recommend changes to legislation to address some of the issues that we have discovered in the course of speaking to people like you. Thanks for coming in today. Everything is being recorded. You will get a transcript, and you can check the accuracy of that when you get it. You have parliamentary privilege in the committee but not outside the committee room. Please start with your name and professional address and the basis of your being here to give us evidence, and then go through what you wanted to tell us.

Mr ADAMS — My name is Damian Adams. I am a medical research scientist. I have been working in science for over 15 years. I have worked with obstetricians in the field. I am also doing a PhD on the outcomes of donor conception. I have talked at conferences. I have done numerous media appearances on donor conception. I provided evidence at the Senate inquiry. I provided evidence for court proceedings on donor conception. I am also a father with children, so I know what it is like to have children. I have also been through fertility treatment, so I know what that is like as well. I have been pro and con donor conception. I have been on both sides of the fence. I have lived and seen everything to do with it.

I would like to thank you today for letting me come to present. I know that you have already heard from several other donor-conceived people, and I hope you take their message to heart because it is they who are the experts in this. While parents are the experts in what it is like to be infertile and the clinicians are the experts in what it is like to treat infertility, it is us who live this every single day of our lives and know the true outcomes of it. I thought for a long time about what I would present to you today, and it would just have been a little bit simple for me to throw at you my life story, because my life has been anything but simple. That would also neglect to show you all of the research and everything that I have done in this field.

The single biggest thing in my life that has shaped my perspective on being donor-conceived was the birth of my own children. It was after my daughter was born. It was a similar thing that many other parents might experience when they are holding their child for the first time. You are looking in their eyes and they are looking in your eyes and you just have this absolutely overwhelming experience of love and pride. I do not think there are ever any words that can describe what that feels like. It was at the same time that I realised the strength of this biological connection, and that no matter what could happen to me from that day on, whether I might be killed or my wife and I might divorce or separate or something might happen, that I would always be her father and nothing could ever change that. It was simply because she was me and I was her. It is that phrase, 'Blood is thicker than water'. It is just an inalienable truth.

Then I came to think about how if she ever grew up not knowing who I was that was a concept that I just could not bear to think about and how that would have devastated me, and then I came to realise how that actually resembled my own life and that for no reason or fault of my own I had been deprived of the exact same thing that I had with my daughter. What should have been an extremely happy and joyous time in my life became extremely dark, and it has left me scarred for life.

I have been searching for this genetic connection for 21 years, and so even though my perspective changed completely when I had my children, I had always been curious to know who my father was.

I know this is a Victorian inquiry, but in South Australia I was entitled to non-identifying information when I was 16. The clinic told me that there was no non-identifying information for me, because I was conceived at a time when it was still in its infancy. Over several more applications for information over the years — I too had a health problem for which I needed to get a health history — I kept on receiving different stories from the clinics: they were destroyed, they were lost, they did not know where they were. There was a distinct lack of consistency in what they were telling me. It was not until we made an application through freedom of information that we found out that records did in fact exist. I had been continually lied to over a number of years. That story is not unique. So many other people that I have spoken to have experienced the exact same thing.

It is these stories, not just my own, that make so many of us very cynical of the clinics. We find it hard to trust them and what they have done over the past. It is this genetic link that I was looking for that is vitally important

for people as human beings. It gives us a sense of heritage, our identity, where we come from and also our health history that is vital in looking after our health. For myself, while it is difficult to put into words what that information would provide for me, what I have been deprived of is that basically half of myself is missing. It is those questions that most people have — who we are and where we come from.

I used to be grateful and happy for my existence in being donor-conceived, but now all I feel is sorrow, not just for my loss but also for my children, because what has affected me will also affect them. It has multigenerational effects. Also, I personally feel like a fraud in my own name. I am nothing like the other Adamses. While I love them unconditionally like my maternal side, we lack that similarity, and so I have always felt that my place in the family was not quite as secure as the others, even though we have still had good relationships, it is just that bonding that people have when they are the same.

Part of this fraud occurred because of the state. The state was complicit in creating a fraudulent birth certificate that contained false and misleading information. A birth certificate was originally created as a factual document. It was originally created for taxation purposes, but also as a truthful and accurate record of your lineage. If we continue to put deceptive information on that, we allow parents to perpetuate this fraud and deceive their children. I feel it is vitally important that we remove this level of secrecy and deception that is occurring. As we can see from research that is currently being conducted, the majority of parents still do not tell their children. I think everybody knows that if we keep secrets in a family, it places that family construct, that foundation, on shaky ground. If we are to have truthful birth certificates, I feel that will add another layer of information access that will be there so that it will be easier for the child to find out the identity of their family.

You may have noticed these large mutton chops that I have on my face at the moment. I originally grew them as a set of props for the conference I was at this week at which I spoke. I was originally going to put up a slide of the X-Men character Wolverine. He has similar chops. I am not sure if you are familiar with the character, but basically he was created in a lab by a bunch of scientists. I too was created in a lab, except by a bunch of clinicians masquerading as scientists. They conducted what I class as a medical experiment in social science, and a very poorly conducted experiment at that, because they did not do a critical analysis of similar disenfranchised people, where people have been deprived of similar things, such as adoptees. They kept very poor records, and looking at my records I can see that I had two lots of records — I had postnatal records and the treatment records. These are the ones I obtained through freedom of information.

The postnatal records follow very good clinical practice. They were massively thick. They can be used as a doorstop — stop the door opening. It was every single detail that you need so you can follow clinical practice and make sure somebody is healthy, and if something goes wrong, you can follow what has gone wrong.

The treatment records were on scrap bits of paper and contained a donor code, the date and not much else. I can tell you that does not follow clinical practice, and as a scientist who does experiments every single day it sure as hell does not follow scientific practice. Not only that, there has been a distinct lack of research into the outcomes of donor-conceived people, particularly the physical outcomes. We are starting to do more research into the psychological outcomes, but there is a dearth of information about what happens to adults.

I believe donor conception is a misnomer because, if we are to donate something, we are to freely give something without accepting anything in return, but that is the exact antithesis of what happens in the donor conception practice. The industry likes to class it as a reimbursement, but it is a financial transaction. Money is changing hands, which makes it essentially a payment. One of the single biggest issues that every other donor-conceived person I speak to has with their conception, apart from being deprived of their kinship, heritage, identity and all those other things, is basically that their existence has been denigrated and commodified. We are commodifying human life, which is extremely dehumanising.

Whether we offspring were extremely wanted and loved has no bearing on our ability to feel the pain of our kinship separation. On our behalf, before we were even conceived, it was decided which connection would be important to us and which one would be simply disposable. It is this fact that makes donor conception hypocritical.

As I mentioned before, I have done lots of talking in the media or at conferences about donor conception. Something that happens not only to me but to other donor-conceived people is that when we express these views we often cop abuse that we are ungrateful and are trying to ruin it for the infertile. What these people

often fail to understand is that we do not talk about it because we enjoy it; we are doing it because we are trying to provide a voice for those who cannot speak — the young offspring and those not yet conceived. If we do not speak out about this, no-one will.

The CHAIR — Just to clarify, is your position fundamentally against the idea of donor conception, or is it that there is not the right framework around donor conception?

Mr ADAMS — That is a good question. As I mentioned before, I have been on both sides of the fence. Because there is a component that I call existential debt, I felt it was almost my duty to give back and donate myself, and I was this close to doing it. However, for whatever reason, I never got around to doing it, and now that I have had children of my own I realise it would have been the single biggest mistake of my life. Not only would I then have been perpetuating what has occurred to me, I would also have been depriving my children of knowing their siblings and continuing on that process. While I understand there is a complete rainbow of emotions — some people are completely happy with their conception and some are extremely traumatised — I think we always need to focus on those who are the most affected, because we cannot have one positive outriding the negative and cancelling it out.

Even with the best current practices, and even if the child knows, the way it is currently set up is that they are not entitled to obtain the identifying information until they reach 18 years of age. However, we know through prominent work, such as that from a world-renowned researcher called Erikson, that a critical period of identity construction occurs during adolescence. If we do not let people find out this information until they reach 18, they have missed the critical window of identity construction, so it needs to occur much earlier.

For me, being a father has now changed everything. Even though I have seen some people who have met their donors later in life and some are extremely happy with the relationships, what I have analysed about what happens with adoptees is that often these relationships can be strained simply because they have lacked the growing-up togetherness, so they are always struggling with this relationship.

Even if we come up with the ideal situation with donor conception, there will always be the risk — I like to class it as a possibility, because some people will be happy with it — that some are going to miss out on something. I always have difficulty from an ethical perspective saying that that is okay. I find that difficult, but I also accept that it is not pragmatic to say that this is going to end. People are always going to be doing it. While we are talking today about what happens in the clinical setting, people are doing it in private. I think we need to make sure that we have a good system in place where the rights of people are appropriately recognised and that protection is seen.

I would like to go on. We are having an inquiry here, so what can we do about it? The vital thing we need to do is make information retrospective. This is required to bring equality and bring the rights of the donor-conceived in line with every other Australian, because every other Australian has their right to access this information acknowledged. We have made this acknowledgement with the Stolen Generation, adoptees, wards of the state and the forgotten Australians. We are the only ones who are still second-class citizens. It will allow Australia, and in particular Victoria, to follow the articles of the United Nations Convention on the Rights of the Child, which Australia is a signatory to and has also ratified. If you analyse it and see how UNICEF has written a handbook on how it should be implemented, we do not follow it accurately.

I know there are some people who argue that this causes a breach of privacy to donors. However, this right in Australia has never been absolute. It gets overturned in the courts all the time, particularly when the welfare of the child is seen as paramount. I certainly did not agree to have my rights stripped off me, and neither did any of my fellow donor-conceived people. We are the silent third party to an agreement that directly affects our welfare. I feel that at no point should the desires of adults outweigh the welfare of the most vulnerable party, which is clearly the child, and that to continue to provide privacy protection is unethical.

We have seen retrospective access given in the past on a very similar topic — that is, adoptees. There was equally strong opposition to it at the time. There were a lot of fears about what it would do. But guess what: the sky did not fall down and the Chicken Littles had nothing to complain about. Their fears were not realised. As a society, even through research, we have now acknowledged that it has been an outstanding success, and there is absolutely no reason it will not be a success here as well.

The CHAIR — Do you see any differences in the analogy with adoption? Is there anything we need to consider that you would look at in a different way than you would with adoption?

Mr ADAMS — One of the primary things that is similar is that many of the adoptive parents were often promised privacy and that they would never be contacted. However, as I said, it has been seen as a success. In some places they did instigate a right of veto, but that has been overturned in most states now. Even when they did have the right of veto, very few parents ever exercised that right.

The CHAIR — Do you think the donation of sperm is akin to the donation of a live baby?

Mr ADAMS — It is different. There are some fundamental differences. As a society, when an adoption occurs and the parents are unable to look after that child, we recognise the tragedy of that, but when we do it intentionally to a child and deprive them of half their genetic heritage rather than both lots — we are stripping it deliberately — as a society we do not recognise the tragedy of that and we think it is okay, but it is not okay.

The CHAIR — Are you saying in your evidence that it should be considered exactly the same as an adoption?

Mr ADAMS — Yes, because there are just so many similarities with the separation of kinship and with what adoptees experience with their emotions and how they deal with it. It is the same as what donor-conceived people deal with.

I would like to make a statement about the clinics and how they operate things at the moment with information access, because I think it is vital for the inquiry. Caroline Lorbach, from the Donor Conception Support Group, and I recently conducted a study for a paper we are writing which we have submitted for the upcoming special edition of the *Journal of Law and Medicine*, and we were analysing how clinics provide information for people and what they are able to provide. We found some things that were quite disconcerting; one was that there was a very low response rate, which is a similar response to what we hear from people when they contact clinics. Quite often they get what we call the ‘fob off’. There seems to be little regard for the information access process.

Some of the respondents completing the survey were the people you would contact at the clinics to obtain information, and one of the key problems we found was that those people were not always fully aware of the legislation and the regulations around the information they were supposed to provide. Some of them were unaware that areas had changed and that what people had access to or were allowed to have access to had changed over time. People are applying to these people for this information, but they are not fully aware of those people’s rights. How are people supposed to make sense of that? It is just going to create further levels of confusion. I admit that currently Victoria has a very good situation in which there are up-to-date central registers, but we need to ensure that that central repository is maintained, because clinics do not have a vested interest in the registers as it is not financially rewarding for them to look after this information. It needs to be kept separately from them.

I want to make a couple of statements now about Victoria because I think it is very important, even though it is an inquiry about Victoria. Victoria has been a world leader in this with legislation and how the practice is done around the world, and I think many other jurisdictions around the world recognise that Victoria has been very progressive. It is held up as a good model to follow because everybody else is pretty much in the dark ages. I think it is vital that Victoria still continues to provide these voluntary registers, because it is important to help those people who do not have records. You probably heard that there are some places that may have destroyed records or, as I have explained, keep extremely poor records. If you do not have records, what are you going to do? Even if we grant retrospective access, if there are no records, what is there? You can still provide these voluntary registers for people to go on.

Even with that, it can still fail to provide answers for some people, and I think one of the ways forward, and we are starting to see it increasing all the time, is the use of genetic genealogy — the DNA databases. So far, the evidence that we have been able to see in some of the databases that I am involved with is that people are able to create these matches. We know of some offspring who have been able to find their genetic fathers or even other close relationships. Not only that, the use of DNA also helps with genetic health testing, and while it only shows levels of increased risk factors, it would allow people to be able to take control of and be proactive about

their health. As you have already seen with Narelle Grech, if she had had information about this beforehand, she could have taken steps to safeguard her own health. Now she is having to deal with stage 4 cancer.

While Victoria is what I would class as a world leader in this, I think from the evidence you have seen the current model is still failing people, otherwise we would not be having this inquiry today. I feel Victoria is in a fantastic position to continue to provide exceptional leadership in this area and to make a statement that the rights of all children matter, not just those who are born through conventional relationships or those conceived through donor gametes after a certain arbitrary date. You have the ability to become the first jurisdiction to do so, and I can assure you that if Victoria takes the first step, other states will follow. But to make this happen, it is going to take people with vision and fortitude to take an ethical, moral stand on behalf of children and on behalf of the members of your community. I feel that in the wake of the federal Senate inquiry, both federally and at a state level everybody else is waiting for somebody else to do something about it. It is just sitting there, and it is only logical that Victoria be the state to take the first step.

This next statement, I think, is fairly humorous because I am a South Australian and we always have rivalry with Victoria. It pains me to say that I am envious of Victoria's track record in this and I wish I was conceived here, but I am yet to see an argument against retrospective release of information that cannot be successfully countered by legal, ethical, social and medical reasons. I am under no illusions as to the difficulty and complexity of such an undertaking; however, it has been done before, and without doubt in 20 to 30 years time this, too, will be seen as a success and as the correct thing to do, just as it was with adoption.

The CHAIR — Thank you very much, Damian.

Mr NORTHE — Well done, Damian. I am sure I can speak for all of us in saying that was very touching and came right from the heart. Well done. Just in terms of the mechanics of how a central register might work, how do you see that playing out when there may be medical clinics right across Melbourne and Victoria that may have their own records? Do you see a one-stop-shop, so to speak, having a register? Who would manage it?

Mr ADAMS — With the clinics you need to have duplication and you need to have some redundancy, because what happens if the clinic burns down? I hear of people trying to access this information all the time in the States when there have been floods and fire — and I do not know how clinics over there are getting insurance to be quite honest, because it happens that often. We do need to have redundancy for that. As I mentioned, a lot of us are cynical about the clinics, and it is hard for us to go back. Is that the right place to go? A non-biased, non-partisan place — as you said, a one-stop-shop — should be the primary place where records should be stored.

Mr NORTHE — VARTA has been proposed on many occasions.

Mr ADAMS — Yes, something like that.

Mrs PETROVICH — Thank you, Damian. That was a very heartfelt and very well-thought-out submission. I have a couple of questions. You made reference to the Senate inquiry. Should we be looking towards this committee making a finding — maybe not a recommendation but a finding — that we should be looking at some consistency through federal legislation around donor-conceived people?

Mr ADAMS — It is a good question. I think the problem is that, as you know, health is controlled by the states. The federal Parliament does not have the constitutional powers to do so. I know Sonia Allan has written a paper on how this can be addressed, and I think that should be taken into account. In an ideal world it should be done federally, because donors travel interstate and even sperm and embryos pass interstate. Rights vary from state to state, and we need to have a nationally consistent model. In an ideal world that would be done federally, but doing that may be difficult in the current situation. I know SCAG has been discussing this, but I also know they have been sitting on their bum for the last couple of years because I was one of the people who first started them talking about it. But it has not been mentioned in any of the discussion papers since that date.

We need to get nationally consistent legislation, ideally at the federal level, but I am having trouble seeing how they are going to be able to co-opt the constitutional rights to be able to do that. They have managed to do something similar with some of the cloning legislation. Maybe they might be able to achieve it that way, but I do not hold out too much hope of them being able to find a way to do that. The way forward — and as I

mentioned, Victoria has been the most progressive — that I would like to see in an ideal world is retrospective access, and then perhaps through a process such as SCAG we would see the other states start to implement the exact same thing as what has happened in Victoria.

Mrs PETROVICH — In another vein, because your submission raises a whole range of thoughts and questions — —

Mr ADAMS — It is never simple.

Mrs PETROVICH — You spoke about a preliminary overview of DNA databases, which is something we have heard a little bit about before. I personally have some concerns around that. I wondered if you had put any thought into protection from identity fraud, security around DNA databases and controls around making sure we do not have any poor record-keeping or mix-ups, because we may compound the issue.

Mr ADAMS — I am a scientist. I do molecular biology. I deal with DNA every day. That is my job.

Mrs PETROVICH — We are in the right place then!

Mr ADAMS — That is right. I think there are a lot of misplaced views about DNA and people being able to steal things through DNA. Some of the concerns are about, as I mentioned before, the fact that people are able to do genetic health testing, which helps to show where they have an increased risk — but all it shows is an increased risk — and whether insurance companies would then use that information against people. I think currently there is legislation that does not allow insurance companies to do that, so you can always protect that information.

There are databases currently running. People do them on a voluntary basis. I am on some. We voluntarily send off our information, and we get whatever tests we want done. Matches are made by the company — there are numerous different companies that do it — and we can then also submit some of that information to non-company databases, just online ones, where you can also do matches that way. But we do it on a voluntary basis — we submit what information we want. With a match to you that I receive — say that we match up — you may select to be not contactable, so nobody can contact you about that information. They cannot find out your name. It is only through mutual agreement to contact that we can then find out names and other information. I do not have actual access to your result. It might tell me that I have a certain number of matches and that these parts of our DNA match, but I cannot access your information and make any changes. There are lots of security measures that are done through IT that protect that.

As I said, there are a lot of misplaced fears. Perhaps there are reasonable fears that this could happen, but in lots of ways it is working well at the moment. DNA databases are very good. We are doing it now.

Mr NORTHE — On the DNA aspect, one of the things that has worried me as we have been going through this inquiry has been hearing about some of the shoddy record keeping. If you are going to have a match — even if we are on the voluntary register and have a match — how do you actually verify that? Should you possibly have DNA to make sure that you have that foolproof aspect to it?

Mr ADAMS — I think that is vital, because we have seen evidence through other things before where people have had a match and it has then been proven later on that the match was incorrect.

Mr NORTHE — I shudder at the thought of going through this whole scenario and then — —

Mr ADAMS — Yes, they had formed a relationship with each other, and then all of a sudden they were told they were not a match. That is devastating. It is similar to originally finding out that you were donor-conceived. You have to reconstruct your familial relationships again. In an ideal situation DNA testing would be done to make sure that these things are absolutely correct and that they have not done shoddy workmanship with the records or destroyed things or changed things. Back in the day we used to write things on tubes with texta. Things would get rubbed off, and you would say, 'What have I got now?'. We know there are people who thought their husband's sperm was being used to inseminate their eggs and later on found out it was not their husband's sperm that was used. That is a tragedy. It is a tragedy for all parties. I think it is vital.

A lot of people argue, 'How are we going to run these registers and do this DNA analysis?'. That all costs money; I realise that. Perhaps the way to help achieve that is — although I understand that currently getting

infertility treatment is a financial burden, and it costs many thousands of dollars — if we just co-opt or add on a small percentage of that. Another \$50 out of \$5000 is not really too much for a person to bear when you consider the positive outcomes in the future.

The CHAIR — Thank you very much. That was very helpful.

Witness withdrew.