SUBMISSION TO THE
SENATE INQUIRY INTO DONOR CONCEPTION PRACTICES PAST AND PRESENTATION 2010

FROM

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Two clinics hold identifying information about our children's donors. Our experiences with clinics have not always been happy, as you will read in our submission, and because of this we struggled long and hard over whether we should make our submission open or confidential.

We told our children the truth about their conception from a very early age so that they would never remember a time when they did not know this integral part of their identity. We have tried to raise them in an atmosphere of openness and honesty so our final decision was that our submission would be open for all to read.

We will start by telling you about ourselves so that you can understand how important the issues surrounding donor conception are to our family.

We found out in 1987 that Patrice had a zero sperm count. We were too old to adopt within Australia so our only option to have children was to use donor insemination. We went on to have 3 children by donor conception, our first son was born in 1989 (Andrew now 21), our second son in 1992 (Callum now 17) and our daughter in 1995 (Elizabeth now 14).

Our three children have three different donors and the eldest was conceived at a different clinic to the younger two.

We believe that we, like many other parents of donor conceived children, are truly "experts" in the long term effects of donor conception. We may not have degrees in medicine or psychology but we are living every day with the repercussions of the practice of donor conception as it has been carried out.

We have long held the belief that donor conception is only in very small part a “medical practice”. Medical professionals are the “technicians” who are able to perform the medical screening of potential recipients and donors, the freezing of semen and carrying out of the inseminations. The other areas of donor insemination such as the selection of donors, the preparation of recipients, informed consent, record keeping and access to those records has long been controlled by medical professionals, but these things are basically social and psychological in nature. They can have long term effects on families and medical professionals are not trained in these areas and should not have a controlling interest in them.

Legislation in the area of ART must not be placed under a health department Act. It must have its own legislation which demonstrates its unique nature.

We feel that we were not adequately informed about all the ramifications of having children by donor conception. When we started our family there was never anything in the media, about how parenting donor conceived children would be any different than a “normal” family.

The question must be asked why has it taken so long for families to speak out and suggest that change in the area of donor conception is long overdue. It is a very hard question to answer so we will explain things from our point of view.

Firstly it was even hard for us to ask the clinics which we attended for information on our children’s donors. We wanted to do this so that we had information on the donors for when our children started asking questions. We also knew that there was very little preventing doctors from destroying donor records. There was at the time only a 10 year limit for the retention of records in NSW. We felt that it was our duty as parents to do what we could to safeguard our own children’s records.

Even with our responsibility to our children in mind we approached the clinics with some trepidation. Because the clinics had never told us that we could ask for information we weren’t even sure that they would give us any. The clinics never gave us any guidelines for what we could and couldn’t get or expect from them. When we started to realise as our children grew that things needed to change in the area of donor conception and we discussed this in the media we met with a certain coldness from clinic staff, they did not seem to like the fact we were saying that the way they had been doing things for so long could do with changing. In some cases clinic staff were almost openly hostile, and did not seem to want to understand how it was for our family. So it takes a great deal of courage for anyone to speak out against a powerful group of medical professionals who just seem to want to do things the way they have done them for decades. It is no wonder that more people have not spoken out.

Late in 1996 when our oldest child was 7 we wrote to the two clinics to ask for whatever information they could provide on the three donors. The first clinic didn't even know that we had a child as they did no follow ups after you became pregnant. In those days that appeared to be common practice and still is today.

The clinics sent us a letter with all the information which they said was available on the donors.

We wrote to the two clinics after this to ask if they would forward a letter to each of the donors. The letters were open so that the clinic could read them. In these letters we thanked the donor and gave him some information about the child that he helped to create. Both clinics did not seem to be able to decide easily what to do about this, they obviously had no policies or protocols in place for an event like this. We were the first people to ask these two clinics to contact donors. Neither clinic asked us to come in and speak to them so that they could understand why we thought it was important to send these letters.

The clinic where we conceived our two younger children decided that they would write to the two donors and ask them if they would like to receive the letters from us. Elizabeth's donor replied and said yes and this letter was sent to him. We were told that the second letter to Callum's donor was returned with "no longer at this address" written on it. We were told over the phone by the clinic counsellor that the clinic would do no further searching as the donor's name was too "common". We were not told what the donors name was.

In early 1997 we did some media for the Donor Conception Support Group speaking about openness in donor conception families and the need for legislation. In the article we spoke about what sort of non-identifying information we had on Elizabeth's donor and used some of it to illustrate our point. The following week we had a phone call from the clinic counsellor to tell us that the clinic staff had had a meeting about us. They wanted to strongly remind us that we had signed a consent form saying that we would not seek out, directly or indirectly, the identity of the donor. This had never been our intention and the information we had used on Elizabeth's donor was virtually identical to that of Andrew's donor – right down to both of them having careers in banking. Of course this clinic wouldn't have known that because Andrew had been conceived at another clinic.

We were devastated at being told off by them as though we had done something terribly wrong but we were too afraid to assert ourselves because the clinic is the only connection we and our children have to our donors.

Not long after this we had another call from the clinic; they had received a letter from Elizabeth's donor and would send it on to us.

We received a lovely handwritten letter saying that he had been meaning to write a reply to our letter but had been busy. He had seen the article we had done in the newspaper and was pleased that he could now show a picture of Elizabeth to his own two daughters. He also told more about himself.

The clinic where our oldest son was conceived took nearly a year to finally make up their minds about what they would do with our letter. In one phone call with the clinic we were told that they would not send the letter, then we were told that they would do it for us but not for anyone else. During one of these calls the counsellor gave us some more information about the donor - we were never told why this information was not given to us when we requested information before - it also made us wonder what other information was also recorded which we had not been given. Finally when nearly a year had gone by we were told that a scientist at the clinic knew the donor and would ask him if he would like to receive our letter . We never received any explanations from the clinic as to how any of these decisions had been arrived at. We then received a call from the counsellor to say that the scientist could not contact the donor as he had moved but that he would keep our request on file as he might "run into" the donor.

In November 2000 after viewing a current affairs show about a young girl in Adelaide meeting her donor our two sons were talking about their own donors. We asked them if they would like us to write again to the clinics requesting that they do some more searching to try and find their donors.

When we contacted the clinics to ask them we also told them that the Royal Hospital for Women in Sydney had recently set up a voluntary register and that if necessary would search electoral rolls to find donors. We also told them that we knew of one case where the Royal Womens had sent out 30 registered letters in order to find the donor of a 10 year old girl.

Both clinics said they would try again.

In May 2001 we had a letter from one of the clinics saying that one of their scientists had managed to track down Callum’s donor by phone – he had agreed to receive our letter. They then told us that they had a call back from him a week or so later saying that he wanted no further contact.

Not long after that we had a call from the counsellor of Andrew’s clinic. We met with her and she gave us a 2 page document full of information about Andrew’s donor. The counsellor informed us that she had called the donor at the phone number that was on the donor’s file. It turned out that the donor had never moved nor changed phone numbers. We had clearly been lied to by the scientist who said that he could not find the donor. When the counsellor had spoken to the donor he had said that he did not want contact with us and the counsellor had asked him if he would be willing to give her more information about himself to share with any children.

This shows how important it is that the right people are involved with contacting donors and information sharing; we wonder if it had been a counsellor who had been the first person to try to find Andrew’s donor whether we would have had information years ago. And in the case of Callum’s donor whether we would have more information than the 3 lines of very, very basic information that we do have.

The reason we feel that you need to know of our experiences is to show how much in need of guidance infertility clinics are when it comes to anything outside the medical area. Yes, clinics do have counsellors but it is very obvious that in most clinics the decisions in these very sensitive non-medical areas are still made by doctors. Clinics are owned by Doctors and business people they are not the right people to be making decisions about issues in donor conception that will affect people for their whole life and for generations to come.

The challenges of raising donor conceived children are many:

- working out how to tell our children the truth about their conception
- trying to get information in order to answer their questions
- explaining to them why each of them has such a different amount of information about their donor.
- helping them as teenagers explore the issues of when to tell a girlfriend/boyfriend that they were donor conceived in case their friend was too.

And the list goes on. Our family started the process of telling our children at a time when there was no support group. After the Donor Conception Support Group of Australia (DCSG) was formed in 1993 we helped others by sharing our experiences and still do to this day. The DCSG became a big part of our lives; it allowed our children to grow up knowing other children who where conceived the same way; a hugely important thing to our family. We also worked with the DCSG to help improve understanding of donor conception in the wider community.

We would now like to cover a few issues that we consider important in donor conception.

Consent

It is only relatively recently that counselling has become commonplace for all couples entering a donor programme. We never had any counselling when we embarked on our journey to have children. Looking back it would have been good to have had to sit down with a counsellor and discussed some of the possible consequences of parenting a d.i. child. It would have been good to have another person bring up many of the issues that we did not think of at the time and now face. When we signed consent forms to have our children by donor insemination there was absolutely no way that we were giving a properly informed consent. Most people first visit a clinic with no or very little information about donor conception and for most of them the only information they will received comes from the clinic which is running a business to make money. Given this is it ever possible to have true consent unless an independent authority is also giving information to prospective parents?

Counselling.

Counselling must become an integral part of informed consent. Counselling is mandatory for couples wanting to adopt, it should be the same for donor conception. Of course some people will always be resistant to counselling feeling that it says something about their “ability to cope”. Probably the way around this is that instead of calling it counselling we call it information sharing and discussion. If counselling becomes a compulsory part of going onto a donor programme then people will accept it. Those who do not like the idea of counselling may still hear something in a session which will make them think and consider what they are doing.

Counselling should be mandatory for all participants in donor programmes and that includes all donors and donor partners, who will also have to live with the long term consequences of gamete donation.

The reason that counselling is so vitally important especially for people considering using donated gametes as a parenting option is that when people find out that they cannot have a child and that donor gametes are the only option then they are not always in the best position to look into the future and see all the possible ramifications of having a family this way.

We are a good example of this. We found out that we could not have a child together when Patrice’s sperm count results came back with a zero count. The specialist told us that we could try adoption or donor insemination and gave us details of a clinic we could go to. We didn’t take much time to make up our minds and it wasn’t long before we were on a donor program. We had no counselling and the only decision we had made in relation to a possible child was that we would tell him or her about how he or she was conceived. When we raised this with the doctor his only comment was that no one needed to know, not even the child. We had no encouragement from any clinic staff to look further than that.

At the time all we wanted was a child and that was about as far as we could see. It is vital that there is a more objective person (counsellor) to talk to people about all the issues which they have not thought of.

Limitation of the number of offspring from one donor.

We very strongly believe that there has to be a legislated limit to the number of offspring from any one donor.

We feel that the absolute limit should be 5 families including the donor's own family. We would prefer thought that one donor was allocated to one family because then with doors being identifiable all half siblings would know of each other.

Apart from the possibility of our children entering into consanguineous relationships, and the devastating emotional consequences that would have on them, we cannot but feel uncomfortable with the thought that our children could have upwards of 20 or 30 half-siblings in the Sydney area. We have been told by Andrew's clinic that he has 18 half siblings. We have to add here that we are not at all sure that this is the full number. We mentioned earlier that the clinic did not know that we had given birth till Andrew was seven and we contacted them for information. So how many other women had conceived and never told them? How many families did our donor donate to? Does the donor know how many children he has helped to create? After being lied to by the clinic about contacting the donor we do not have a lot of trust in them.

For some offspring their curiosity may be satisfied by the briefest of physical descriptions, for others it may be that they need to know the identity of the donor and perhaps even meet him. It is not for us to determine the limit of our children's curiosity.

Medical Histories

We have been for years confused about the conflicting opinions coming from the medical profession about medical history. When we visit a general practitioner often the first question we are asked is if we have a family history of certain conditions. If we get referred to a specialist they will often ask the same question and go into our family medical history in even more detail. When we visited the two clinics at which we conceived our children we were also asked questions about our family medical history.

But when it comes to children conceived by donor gametes suddenly it is not considered by medical professionals that these children need to be given a full medical history of their donors.

What will happen if one of my children needs to have as many details of their family medical history as possible? Who will give them the information they need? The clinic may tell us that at the time of donation the donor told them that he had nothing of significance in his medical history. But, what if he became aware of things later and did not inform the clinic? Clinics do not keep in contact with donors and do not get updated information from them. Indeed as we have already said the two clinics which we attended have lost contact with two of our children's donors. What happens if one of our children desperately needs medical information or perhaps in the worst possible case needs something like a bone marrow donation? They will be cut off from someone who could possibly save their life. We certainly did not think of things like that when we wanted to have children.

Central Register.

We strongly believe that a central register must be set up in this country for the storage of donor conception records. To us it seems quite logical that records relating to our children's donors should be safeguarded by a government authority not in the hands of private individuals. After all we don't let our family doctor keep a private register of our children's births. Currently because of the sale of the clinic our eldest son's records are now apparently in storage at a large pharmaceutical company. All donor conceived people mo matter what state they were born in and no matter when they were born should have access to all donor information that is stored on the register. If the Senate decides not to recommend the retrospective right of access to identifying donor information be given to all donor conceived people then they need to justify why donor conceived people deserve lesser rights than adoptees and other members of society

Birth Certificates.

The government sees it as important for all births to be recorded as accurately as possible with the Registrar of Births, Deaths and Marriages, so why not donor conception records?

At the present time the Federal government is sanctioning inaccurate records when it comes to donor conception. Birth certificates are intended to be a record of biological and not social parentage. Birth certificates should have an addendum which lists the donor.

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Recommendations

We believe that in the area of donor conception we must keep the needs of the offspring first and foremost in our minds. If we believe that, then we must also believe that changes in the present system are absolutely necessary and must have the full backing of federal legislation.
What is needed is:

- Federal legislation so that all donor conceived people throughout Australia have the same rights.
- Legislation should be enacted that deals specifically with the long term affects of donor conception – therefore legislation must not reside in the sphere of health.
- A federal register to store all donor conception records
- That all records on this register be kept permanently
- That the federal government collects 'old' donor conception records that may be kept by retired doctors etc.
- That all donor conceived people should have access to whatever information is stored about their donor no matter when they were born.
- Donor conceived people should have access to information about their half siblings both from donor conception and from the donor's own family.
- That there be an addendum to the birth certificates of donor conceived people so that they can know how they were conceived.
- Counselling must be a mandatory part of donor conception programmes as it is in adoption.
- A limit most be placed on the number of families that can use the gametes of one donor – this must be absolutely no more than 5 including the donor's own family.
- No gametes or embryos should be imported into Australia – the problem of donor conceived people accessing donor information from overseas is too problematic.