

## VICTORIAN INQUIRY INTO ACCESS BY DONOR-CONCEIVED PEOPLE TO INFORMATION ABOUT DONORS

My name is Romana Rossi and my husband and I have a 17-year-old son who was conceived using anonymous sperm donation. When our son was 6 years old he met his biological father or donor.

Thank-you for the opportunity to tell my story and to make this submission to your inquiry. Our son was born in 1993. Our journey to be a family with children started in 1991 when we accessed assisted reproductive technology in the form of donor insemination using anonymous donor sperm. In 2000 our son met his biological father and family and we continue to see them on a regular basis.

When our son was born, his rights were not recognised in law; he is a donor offspring conceived under an act of parliament that gave more rights to us and his biological father (donor) than to him. It would seem obvious to any reasonable person that every person should have the right to know his or her biological family. It is in fact ratified in the United Nations Charter on the Convention on the Rights of the Child that every person has the right to know their family.

Nevertheless, the medical profession, governments and our society conspire against the rights of Donor Conceived (DC) persons. Most parents who have donor offspring do not tell their children of their real identity and the few who do, most allow the donor to have only a shadowy existence of “some nice man/woman”. Others deny that their child will need to know their family. My husband and I thought like this too, at the beginning. Our awakening in this matter was gradual; **we thought at first that our only job with regards to donor conception was that we would tell our son about his donor origins and that would be enough.** And tell him we did, from the beginning in the form of stories and pictures and conversations.

At first we assumed that this meant nothing to our son. But inevitably at 2 years and 8 months of age, the first big question arrived at the dinner table when one ordinary evening our son turned to his dad and asked, "Are you my real father?" My husband answered in the affirmative but also informed him that he had 2 dads: the biological one who gave us the sperm to create him, and himself; the man who changed his nappies, plays games with him and looks after him.

Nearly another 2 years passed before the next big question (there were many little ones in between): "**Who is the donor, dada?**" our son asked one day while his dad was buttoning up his coat as we rushed out the door. But this time his dad had to answer in the negative: "I don't know mate- a man who wanted to help us to have children." "**Do you know him dada?**" our son further inquired. "No" was the only answer he had for him. Our son did not stop there, "**do you want to know him dada?**" His dad answered in the affirmative and added that he would like to meet him to say thank-you for donating. When his dad asked our son if he wanted to know the donor, he replied, "**Yes, I want to know what his teeth look like**". (We believe our son wanted to know why he looked the way he does).

My husband didn't forget that conversation because one evening he expressed the important suggestion that we should search for the donor. We felt that it was critical to our son's identity and to his self-esteem to know who the donor was. We were worried that identifying information might be lost or worse, that the donor could die before our son had the chance to meet him.

On May 13, 2000: the day before his 7th birthday, our son met his biological father. His biological father and his extended family are now part of our lives. We see his biological father and his family on a regular basis. We get together for all the important calendar events, birthday celebrations, weddings and

funerals. There is weekly contact in some form. In a real sense they are now part of our family.

We do not know what the future will hold, but my husband and I agree that we have a duty of care for our son that goes beyond nurturing and parental love. **Most people want to believe because our children are wanted and loved that this is enough. But duty of care is much broader than that.** My husband and I wanted to ensure that his true identity is openly accepted and embraced and that we do not make decisions that preclude any choice he may wish to make in the future. And make no mistake, when parents make the decision not to tell their children of their donor origins, and/or more importantly they deny their children their biological family from birth, they are precluding choices that their children would otherwise have. **We came to realise that fundamentally the donor conception process is flawed because it deprives people of their biological family. It is very difficult to form a parental/child relationship with someone you meet in adulthood.** The donor conception community likes to believe that biology does not matter; we really want to believe that it is the nurturing and love that counts but we do not love enough to include the biological family.

**This Inquiry is looking into DC people accessing information about their family. I cannot comment fully on all the terms of reference as I do not know all the answers but here are some recommendations and suggests.**

### **Terms of Reference:**

***A) The legal, practical and other issues that would arise if all donor conceived people were given access to identifying information about their donors and their donor-conceived siblings, regardless of the date that the donation was made:***

**Donor Conception today is in the same awful state as adoption was thirty years ago. The adoption experience has taught our community the horrors of unknown genetic origins, secrecy and depriving people of**

**their genetic family.** There is already in place in the Adoption Act 1984 (Victoria) a model for the legal and practical issues of giving retrospective rights to DC people to have identifying information about their family. The Adoption Act came about as a result of the work of people who were adopted and their supporters to informing legislators and society about their needs. DC people's needs are exactly the same. **Legislators do not have to reinvent the wheel to give retrospective rights to DC people.**

In the past, the journey to legislative change which put the rights of adoptive people as paramount was not easy. Many people from the adoption triangle were upset; birth parents who did not want to be found, adoptive parents who wanted to be perceived as the real parents without interference from birth parents and occasionally even the adopted person who did not want to search for their family. The protests and the pain expressed were horrific. It was obvious that divulging the information to give adoptive people the right to their identity was going to cause hardship to some people. For example there were women who had never told their family about the relinquishing of a child. There were adoptive parents who had never told their children that they had been adopted and there were adopted people for whom the issue of adoption was something that they did not want to think about or deal with. In spite of the problems that giving identifying information could cause, brave legislators nevertheless passed legislation that gave adopted people their rights to know their family. The reason is that as a community we recognised that people needed to know where they had come from to know who they were. The right to know one's identity is in fact ratified in the United Nations Convention on the Rights of children to know their family.

Donor Conception is perceived as a medical procedure when in fact, like adoption, it should be heavily regulated by legislation and run by social workers who have been trained in this area. **Treating donor conception as an adoption would return some of the rights that DC persons are not given because of the nature of their conception.**

Currently the practice comes under the umbrella of a medical procedure to solve the medical problem of infertility. The enormous leap to acknowledging

that donor conception is similar to adoption is difficult for us who use it to create our children; first of all the child does not exist when one enters into treatment so how can that person have rights, and secondly there is no relinquishing of a fully viable human being like in adoption, just a few gametes. Furthermore usually one parent is related. **But, the end result to the people born from these procedures is emotionally the journey of adoption: someone has relinquished their genetic code to create that person, but does not parent.** The DC person is denied access to their biological family and as the long history of adoption informs us, the repercussions are profound. **I believe that if we are going to use a technology or process that creates a human being then at least, as a righteous community, we should give them the basic right to know their biological family no matter when and where they were born.**

At minimum, I would like all the members of the donor conception community to have the same benefits, rights and obligations as the adoption community; **that all DC people have the right to identifying information about their biological family and that this right be retrospective.** Donor conception legislation needs to change to give DC people the same rights as adopted people. There is always talk about 'the knock on the door' and how uncomfortable this is for the adults involved. But it is not the fault of the child relinquished for adoption or conceived through donated gametes that adults involved are uncomfortable or had been told that their donation was anonymous and that they would never be in a position to hear that knock on the door. At the time it was the practice to encourage secrecy and protection of privacy, but as a community we know more now about the long-term effects on DC people of not knowing their family.

Two other important points are: there are no closed adoptions in Australia because we recognise as a community that people need to know all of their family.

In Victoria, the Assisted Reproductive Technology Act 2008 (VIC), stated in section 5 that in Victoria, DC people have a “right to information about their genetic parents”. As of 1998 there should have been no anonymous donations allowed. DC people born after 1998 have access to identifying information about their family. The fact that this recognition and right does not exist for DC people born before 1998, discriminates between DC people depending on when the gametes from the donation were used to conceive them. It treats them like second-class citizens. If the best interest of the child is paramount which is what the Assisted Reproductive Technology Act 2008 purports to say, then this discrimination is wrong. We can no longer condone the practice of denying DC people the right to know their family just because they were conceived and born at a time when the medical practice of donor conception purported not to know any better. Given the knowledge we have now of the needs of DC people it seems amazing to me that so many in the medical fraternity especially and as well as some DC parents, will argue strongly and vehemently against retrospective legislation. Giving retrospectivity will help to correct some of the wrongs perpetrated against DC people in the past and give them rights that other DC people have as well as adopted people in Victoria.

In terms of other issues this inquiry might also consider the falsification of birth certificates of DC people. Victorian adoptees have truthful birth certificates that reflect their adoption. The fact that donor-conceived persons do not have this means that it is easier for parents to follow the advice of many medical professionals who tell them “If you want to, you can go home and forget about this” (the fact that they used donor gametes). Most parents do not tell their DC children about their origins. Truthful birth certificates would encourage parents to tell the truth to their DC children about their origins.

Current birth certificates of DC people are false and do not reflect the truth of their parentage/identity. As a person’s sole primary document of identity, birth certificates must be a truthful representation of a person’s identity and must list the identities of the genetic parents in addition to the recipient parent(s). For practical purposes the use of a birth extract which does not

contain the record of a donor conception if this information is considered sensitive, could be used. There needs to be a birth certificate that includes the legal parents and information added that could say 'by donation'. Again there is a precedent for a system that deals with this issue practically. A similar framework already exists for adoptions in Victoria.

Currently, the DC person's birth certificate is not a truthful one and prevents the DC person from finding their family and serves to further fracture the connection between the DC person and their parent/s. If the DC person goes on to reproduce, descendants will also not be able to have information on their grandparents.

Furthermore, all recipient parents who use a donor outside of the clinical system should be obliged to provide the donor's identity when registering the birth of a child with the Registry of Births Deaths and Marriages. Unless the disclosure of the donor's identity is made obligatory it is most likely the DC person will be unable to trace their genetic parent(s) if they wish to do so in the future.

Once it is recognised that donor conception is an adoption of a kind it is easy to legislate along the lines of adoption legislation to make certain that DC people's rights are paramount. Legislators do not have to re-invent the wheel. It can use current adoption legislation in Victoria as a model.

***B. The relevance of a donor's consent or otherwise to the release of identifying information and the National Health and Medical Research Council's ethical guidelines on the use of assisted reproductive technology in clinical practice and research.***

I do not have authority or experience with regards to the legal matters on the donor's consent but I would strongly recommend that any rights that are given to the donor because of this consent should be made void. The rights of DC people must be made paramount and the only way to do this is by giving them identifying information about their family. In the past when the consent was signed there was a culture of secrecy and a defensive and unnecessary protection of privacy but as a society we now understand that this as well as

the contract between the donor and clinic is no longer valid.

Disclosure of identifying information will also benefit the family of donors who want to know where these children are. It should also be taken into account that the donor's family is not part of the consent process and I have seen the emotions that our son's grandparents and extended family have encountered. No one asked them what they thought about the donation before it happened. It should be noted that they did not have a say about the donation and they have a strong need to know our son (and his siblings) and have him in their lives. When we met our son's biological father's extended family they were overjoyed to meet our son and upset that they had missed out on the first 6 years of his life. They immediately included us into the fabric of their lives. They did not care how our son got here and consent forms and legal issues meant nothing to them. **Our son is rightfully their grandchild, nephew, cousin and friend.**

***(C) Any practical difficulties in releasing information about donors who provided their gametes before 1 July 1988, because in many cases records are not available either because the procedure was carried out privately or records were not stored centrally;***

The Voluntary Register held at the ITA gives DC people and their families the opportunity to come forward. Funding could be allocated to educate people about the Voluntary Register and to encourage past donors to come forward. Campaigns in the media could be launched about the Voluntary Register. In the past the ITA has offered counseling to the DC community in regards to reunions. The ITA used to have its own counseling service with a qualified counselor trained in the adoption field. This service was excellent and should be re-instated.

VANISH an organization that can assist with searches should also be given funding to assist DC people and their family to search. VANISH has an excellent record at assisting reunions by finding family members and then providing support to assist people to deal with the emotions associated with this reunion.

Furthermore, a campaign could also be launched to request that health care professionals come forward with names and faces of donors that they can remember especially before these health professionals die. These could be nurses who dealt with donors, social workers, receptionists and the medical practitioners who provided the medical procedure and/or donated. Medical professionals could be requested to disclose places where they recruited donors and those areas targeted as well. People in the general public who know of donors could also come forward with names.

***B) The options for implementing any changes to the current arrangements, including non-legislative options;***

Quick resolution is needed. My concern is that to give retrospectivity to DC people through legislation will take too long to implement and be too difficult to pass through parliament. If possible changes could be made at a regulatory level or as a policy change and/or as an amendment to the ACT. For many the wait to obtain identifying information about their family is preventing them from enjoying their life; it is depriving them of an integral part of who they are and this is very painful.

***C) The impact that any such changes may have on the donor, the donor-conceived person and future donor programs;***

Giving retrospectivity to DC people and allowing them the opportunity to meet their family will be positive and life affirming for the DC person in ways that only they will be able to tell us. Knowing and having our son's biological father and family involved in our life has been wonderful. I believe that we are better able to parent our DC child because we know his family. For example my husband and I are the ultimate couch potatoes and it took others to point out to us that our son needed to attend gym classes, that he needed to be out every day; running, jumping and riding his bike. He remains very athletic. Our son's family is very athletic. His biological father was involved for many years in playing football and coaching. He loves to camp and commune with the great outdoors. Our son is the same. Little did we know when we used donor sperm to conceive that my husband would be getting out of bed at 4:30 am every morning to take our son swimming! Our life joyfully revolves around sports! Every weekend is taken up with sports. His biological father, until he became ill, would drive two hours from rural Victoria every weekend

to see our son play football and then cricket and then to swim. We know why our son looks the way he does. Knowing our son's family helped us to know and understand him better and has made us a happier family. First of all everyone knows that we used donor sperm to create our son. Everyone has met his biological father. There are no secrets and to be open about our son's donor origins allowed us to seek help and support from our friends, family and people in the adoption community and in turn we are sometimes able to help others. (One of the problems with keeping a secret about one's child's donor conception is that parents and donors cannot get support from others and this creates an enormous pressure on marriages and families. Often parents cannot even talk to each other. I know this because in my capacity as a contact support person in the donor conception community, I have fielded the phone calls from many parents needing support who are not coping with the life long issues of donor conception.)

At first the search for the biological father terrified us but when we started the search I made contact with members of VANISH or the adoption community who were experienced at helping us deal with the situation. We did not know what to expect and were worried that our son's biological father might have values that were completely different to ours or that he might be a criminal but we decided that no matter who this man was, he was our son's biological father and we would have to accept him. We were also very afraid to meet him because we did not know what the impact on our family and would be; for example my husband was worried that his son would be stolen from him, but I have to say that in our first meeting he looked so much like our son that it was easy to like him and accept him. He was family from the beginning. Fortunately our fears were unfounded. I believe making contact with our son's biological family early has prevented some potential problems for our son. My husband and I are extremely glad that our son's family is involved. We wanted our son to feel that his true identity is openly accepted and embraced and we wanted him to form a strong relationship with his biological father early instead of meeting him as an adult. I could not imagine meeting my mother or father as an adult.

My husband and I wanted to address the problem we had created for our son by using anonymous donation. We welcomed the new Victorian legislation that gives DC people the right to know their family, but in all fairness it is best if all DC people have access to identifying information. This is an important step forward in correcting the wrongs of donor conception practices. But we

know that there is a lot more to be done as the shame of infertility and the horrors of secrecy about our children's donor origins still prevail.

***D) The impacts of the transfer of the donor registers currently held by the Infertility Treatment Authority to the registrar of births, deaths and marriages;***

I know from the experience of DC people who used the service that the ITA had an excellent counselor who had experience in donor conception issues, infertility and adoption; a rare combination. Because of their experience with the reunions of DC people with their families, the knowledge of the practices of donor treatment procedures and understanding of the ACT, I believe that it would have been good to have kept the Registers and counseling with the ITA. I would be deeply concerned if the task of assisting reunions was given to infertility counselors and their clinics who have no experience in post-adoption issues. When we wanted to meet our son's biological father, the social worker said to us, "we have never done this before... ". My husband and I are very grateful that she facilitated our first meeting with the biological father despite a complete lack of protocols for this process. Fortunately we were able to turn to the adoption community for support and answers to our many questions.

***(E) The possible implications under the Charter of Human Rights and Responsibilities Act 2006.***

I believe that Assisted Reproductive Treatment Act 2008 contradicts the Charter of Human Rights and Responsibilities Act 2006 because it discriminates between DC people depending on when the gametes from the donation were used to conceive them.

## **Conclusion:**

**Donor conception is a process that intentionally creates a class of people whose rights to be loved and raised by their biological family are denied. Donor Conception intentionally removes people from their families.** Any changes in legislation that can give DC people the right to know their family would be an enormous step in diminishing the pain felt by DC people because of their hidden donor origins.

I understand now the complexities of Donor Conception in ways that were not understood or explained to me at the time we created our son. **We will always put his best interests and rights before our own; and it is why his social father (my husband) and I have made available to him, as early as possible in his life, his biological father and paternal relatives.** Most DC persons are denied this option, and even our son has still been denied information and access to his half-siblings (we believe there are 5 siblings). However, Donor Conception is still a difficult journey for a young man and one that presents many challenges throughout our lifetimes. We have each needed support along the way; and have not been too proud to accept help as required. As a society we need to change our practice of denying the rights of people who had no choice in the manner of their conception.

When I see the difficulties that our son negotiates to make sense of his donor origins, and when he returned home as a 7 year old from 'Show and Tell' at school where he had announced that he is a donor boy and appealed to me with, "Mama I just want to be an ordinary boy" I know that I have burdened him. Given the time again I would not inflict this on anyone never mind someone I love more than myself.

I have expressed views which have been formed by firstly being a parent of a DC person, a founding member of Tangled Webs: an organisation which challenges donor conception, a past Coordinator of the Donor Conception Support Group-Victorian Branch for many years and a member of Vanish, I have also participated in research in this field. This experience has brought me into contact with hundreds of people from the donor conception community. I have listened and heard the stories of many of these people and

this has helped me to form these opinions. **Mostly though I have listened to courageous DC people who tell us that being denied knowledge of and access to their biological family, hurts them.**

In changing legislation or amending it, it is paramount to put the needs of DC people before us, their parents and the business of the infertility industry.

**Ms. Romana Rossi**

**August 6, 2010**

**I AM HAPPY FOR THE SUBMISSION TO BE PUBLICLY AVAILABLE.**

**I WOULD LIKE TO BE PART OF ANY PUBLIC HEARINGS THAT OCCUR**