Submission to the Legal and Constitutional Affairs References Committee of the Australian Senate – Inquiry into the past and present practices of donor conception in Australia .

## **Our family**

We are an ordinary working class family. Mum, Dad, two children, a mortgage and a dog. I worked for 20 years prior to becoming a stay at home Mum. I will return to work once my youngest child starts school. My husband is a welder and has been working for 27 years.

We will never have a brand new car or overseas holiday. Instead we chose to have a family. We endured 7 years of IVF and fertility treatment costing us over \$20,000 in out of pocket expenses prior to the conception of our first child Joshua. Our second child Emily cost us \$3,000. A small price for such a delight.

Years of IVF treatment meant terrible emotional and financial suffering and a terrible sense of loss that will never be forgotten. We nearly gave up on having a family as it was so hard and so expensive.

Joshua and Emily were both conceived with frozen donor sperm. We were not able to have a child with normal IVF or ICSI. We tried to have a child created by both of us for years without success. Donor conception was our last chance at having a family. I am thankful to the sperm donor and Melbourne IVF for making us a family. We are happy, complete and life would not have the same without my children.

I am thankful that donor sperm is an option available to infertile couples and I believe it should continue to be available in Australia. Donor sperm is helping bring children who will be loved and cherished into the world.

# **Medicare Rebates and Safety Net**

Changes to IVF Medicare practices and introduction of safety net and IVF rebates during out IVF treatment made it possible for us to fight our infertility battle. Ordinary working couples need Medicare rebates as IVF treatment to so costly and it is not right for couples to miss out on having a family because of cost.

Since our children were born IVF costs have increased and it concerns us that some couples will go childless because it is just getting too expensive to have a child.

I am thankful for Medicare rebates and the Safety Net, as without them we would not have a family.

We did spend years on IVF but I do not feel guilty. Infertility is a medical condition. It should be treated just like any other condition. We have worked and payed taxes all our lives. It is not unreasonable to want a family. Drunks and smokers get hospital treatment. So too should infertile couples.

## **Donor Regulations and Legislation**

Joshua was born in 2003 and we entered his details on the "voluntary register". At the time we were given the choice of two donors. A two page document listing personal appearance and hobbies of the donor was all the information provided to us. We were advised that Joshua could attempt to contact the donor when he turned 18.

Emily was born in 2007 and we were advised she would be listed on a "register" and that this register was now a legal requirement.

Joshua and Emily were born from the same sperm donor.

In 2010 we advised the IVF clinic we wished to donate our remaining IVF embryos to another couple. We have attended two counseling sessions to proceed with this option. We wish to give our embryos a chance of life. Clinic has advised there are legal issues with donating embryos created with donor sperm. Waiting to hear from the Clinic as to whether or not we will be able to do this.

We were advised that our children could contact the donor when they turn 18. We believe this is too late. We would like our family to meet the donor earlier. We want to know more about him.

As a parent I would like more information on the sperm donor and wish that I too had a right to contact them. I would like to ensure that the sperm donor is a decent person before embracing him with our children.

I understand that recently laws changed and that from 2010 police checks occur on all IVF patients and donors. I wish I also had the ability to obtain this information on our donor to ensure our children are safe with this person unknown to us.

#### Conduct of clinic and medical services

I will always be grateful to Melbourne IVF for making it possible for us to have a family. The doctors, nurses and lab technicians are professionals. We would not have a family without them.

## **Concern about embryo donation process**

Recently we started the donor embryo donation process. In counseling sessions held by clinic I felt pressured to donate our embryos to gay and lesbian couples and single women. I specified that we wished to donate to a normal heterosexual family and was made to feel unreasonable at specifying this requirement. I have no personal issue with gay, lesbian or single women. I just want to be able to have a say in the environment my genetic child is brought up in.

The process of donating needs to be simplified and improved. We wished to donate our embryos and we did not feel we needed a second counseling session. We wished to sign the required paperwork to progress our donation but were 'required' to sit through counseling for the sake of counseling.

Clinic needs to understand how difficult it can be to attend 'required' counseling sessions. We had to drop Joshua off at school, arrange a sitter to look after Emily and my husband needed to organise time of work to be able to attend the appointment. We then had a 100 km round trip to drive into the city for counseling we did not feel we needed. We wanted to donate our embryos. We did not wish to receive anything. The process should be easier for us.

I am unsure of the process endured by sperm donors however it needs to be easy and simple so that more donors are recruited and more donations made. Sperm donors would also have to make arrangements to 'donate' so clinic needs to be more accommodating to encourage donations.

## **Payment for donors**

There are not enough sperm donors available. When we did donor sperm we had a choice of two donors. We wanted to have a child and accepted the donor closest in description to my husband. It wasn't very hard to pick one donor out of a choice of two. We were at the end of our IVF journey and desperate to have a child.

Payment of donors may be a way of addressing this issue however IVF costs are already too high for couples and clinics would need to pass this cost on. Additional costs will exclude some couples from having a child. It would be unfair if only the rich can afford to have children.

Perhaps it would be better if clinics received "rebates" based on the number of new donors created. A financial incentive to advertise more widely and recruit donors.

## **Management of Data**

At commencement of the donor sperm cycle in 2002 we were given a two page document with a numerical code identifying our sperm donor. The form gave us basic features such as hair and eye colour, height, and hobbies. It also specified any known medical conditions.

I have kept this document in a safe place and I intend to use it soon to find out more information about the sperm donor and if there are any other siblings in existence. At the time we first received the "donation" the counselor advised us that there were other children already born from the same donor.

On the birth of each of our children we were required to complete paperwork for the clinic advising the date and sex of our newborn baby. It is my understanding that this information is held by Melbourne IVF and would have been passed on to the sperm donor.

We have never received any correspondence from the sperm donor and do not know if they wish to have contact with our children.

It was our understanding that a body called the ITA held all donor records however this body no longer exists and we have since been advised that we need to contact Births, Deaths and Marriages.

I do want more information and to be honest it would have been easier to go to the ITA. It seems so impersonal to go through Births, Deaths and Marriages. In fact it scares me that a party so impersonal will be proving us with such personal information.

## **Counseling and support**

Early on in our IVF treatment counseling provided was very beneficial. In fact it was a counselor who first asked us if we had considered our donor options.

However now with two children we have very busy lives. It is difficult between work and school responsibilities and pressures to travel into the city for counseling. If we can we will work any problems that arise out between ourselves.

I am aware that Melbourne IVF has counseling available and that we can access it at any time.

I am also aware of the Donor Conception Support Group of Australia and intend to join them in the future so our children can meet others from donor origins.

#### Information needed

We are aware of a number of books available to assist us to tell our children about their donor conception. These include "My Story" and "Where did I really come from?"

We intend to use these along with donor information to tell our children how they were created.

If our children do not accept our explanation or have difficulty accepting the situation we will seek out counseling.

## Number of offspring born

We are unaware of the number of offspring born from the same donor at this time. I do however intend to investigate this information very soon.

I have checked the Births Deaths and Marriages Victoria website for information and application forms to find out more about our sperm donor and any other siblings born. The application forms are complex (similar to Centrelink) and there is a \$61.50 cost to access the central register. The impersonal nature of the website and forms are discouraging to me and I disagree that we should be charged to access important information needed by our children.

## **Rights of donor individuals**

We believe our children have a right to know just how special they are. At age 7 and 2 we have so far told them that we needed help from IVF doctors to make them. In the next year of so we will tell them that they were both born with help from a sperm donor.

I would like more information about our donor and a photo to help us tell our children about how they were created.

We would like to meet the sperm donor as a family but probably not for a couple more years. Our children are not yet mature enough to understand.

We are Joshua and Emily's Mum and Dad. We just needed help from a sperm donor to make them. My husband will always be their Dad. Michael has changed their nappies, read stories, played with them and helped look after them when they were sick.

The donor helped with their conception and for that we are grateful. We know that he must be a kind and generous person to give us the gift of a family.

All donor children have should have a right to know about the origins of their conception. Donor children should be able to meet their donors if they wish to. Donor children should also be able to meet other siblings and have full details of their medical history available to them.

## Challenges of parenting a donor conceived child

Our children are a gift and we hope they will understand our reasons for using a sperm donor to create them.

We do fear their reaction and the reaction of family and friends when we tell them. Immediate family know the origins of our children but it is not something you tend to discuss at a birthday party or family function.

Our children are just like any other kids. They play, fight, talk too much, enjoy movies, love animals, love reading stories. They also love their Mum and Dad.

Joshua will receive sex education classes in two years time in grade three. It will be at this time we intend to explain how he and Emily were created.

I am not sure how teachers and students will react to this news. Knowing Joshua it will become his "show and tell" talk at school. Once the cat is let out of the bag there will be no going back. There will be no secrets.

## What changes need to be made to help us and other donor families?

- All donor conceived children should have a right to learn about their donor.
- All donor parent recipients should also have a right to know more about their donor.
- A photo should be made available to donor family to assist with explanations later if possible.
- Police checks should be completed on all past and present donors and this information provided to donor families where there is a sex crime involved.
- Donors and their families should have a legal right to meet at an earlier age if desired. Perhaps 10.
- A letter should be sent to all donors and donor families advising them exactly where their donor information is held and relevant contact details.
- A letter should be sent to all donor families advising how many donor siblings exist.
- A letter should be sent to donors requesting an update on any significant medical conditions in the family which could be relevant to a donor child. This information should be communicated to the donor family.
- Donor recipients and their children should not be charged to access information relating
  to their origins by Births Deaths and Marriages Victoria. Currently there is a \$61.50 fee
  to access information held on the Central Register. The Voluntary Register is free.
  Parties should be encouraged to seek out their origins and the impersonal complex
  nature of the application forms, and the cost is discouraging.
- If a donor requests contact prior to 18 they should be able to contact the parents of the child to make this request. The parents should have the final say about the right age as they will know at what stage of development their child is at and the best time to tell.
- All donor children in all Australian States should have the same rights.
- Use of frozen sperm should continue. Both our children were created by frozen sperm.
   Sperm does not need to be fresh and it is impractical to get sperm donor to attend clinic on multiple occasions. We used frozen sperm 4 times to achieve 2 children.
- Do not pay sperm donors as this will be passed on to couples trying for a family.
   Additional costs will make IVF too expensive and only an option for the rich. I am happy to donate my embryos and I do not expect payment for them. Donors should not be paid this is creating an industry focused more on money making than creating children.
- Continue to limit the number of children a donor can create. For a donor child to meet their genetic family it needs to be manageable numbers.
- Unknown donors should be prohibited. A child has a right to know their genetic origins.
- All donor sperm used in Australian IVF Clinics should be from donors who reside within Australia. It is too hard for donor conceived children to meet their donors if they live overseas.
- Birth certificates should not identify any one else except the legal parents of the child. A
  birth certificate is used for banking, kindergarten, school and may other ID uses. It is not
  necessary to label a donor child or humiliate them when producing their birth certificate
  for such purposes.

#### In conclusion

I hope my submission is helpful to the Legal and constitutional affairs committee of the Australian senate . I hope my experiences of donor conception are of value to the inquiry into donor conception practices past and present.

I have spoken as a normal working class family. A typical heterosexual mother and father with two children. We are no different to other families within Australia. We just needed medical assistance to become a family.

Donor families often don't speak out for privacy reasons and because of how the media portray donor families. The practice of sperm donation needs to continue to be available as an option to couples with infertility problems.

I would be happy to attend committee hearings held within Melbourne to answer any questions. I would be unable to speak at interstate hearings due to financial restraints and family responsibilities.

Thank you for listening.

Tonia, Michael, Joshua and Emily

#### To our Sperm Donor

I do not know who you are but I would like to thank you for your precious gift. You changed our lives. You gave us children.

I wanted a baby more than anything else in this world. Without Joshua and Emily our lives would not be complete. You gave us love and you gave us joy and laughter.

Thank you for changing our lives. Thanks for making us a Mum and Dad.