

Community Affairs References Committee
Submission: Science of mitochondrial donation and related matters

To the Community Affairs References Committee

Science of mitochondrial donation and related matters

I am responding to the following terms of reference:

- The impact of mitochondrial disease on Australian families and the healthcare sector;
- The safety, efficacy and ethical implications of these techniques;
- Consideration of legal changes and safeguards that would be required to allow mitochondrial donation in Australia; and
- The value and impact of introducing mitochondrial donation in Australia.

My name is [REDACTED], I am a 29-year-old woman with mitochondrial disease from Victoria.

I was diagnosed with mitochondrial myopathy through a muscle biopsy by my neurologist in 2016. As I write this submission, I'm currently waiting for my genetic test results. They could be inconclusive (hopefully not), show a defect in my nucleic DNA, or show a defect in my mitochondrial DNA. At this stage, there's no knowing which result I could have.

As you read this submission, I'd like each member to consider the impact they could have on my life, my husband's life, and my family's lives through considering mitochondrial donation.

I'm considered to have a "mild" form of mitochondrial disease. Many other people with mitochondrial disease have more extreme forms of the illness, as it can target any organ and begin at any age. It currently causes extreme fatigue and pain in all my muscles. I have all my organs checked annually, visit my neurologist and an array of other health professionals regularly. I can't work full time anymore, can't exercise anymore and need a lot of sleep (10-12 hours a few times a week). Despite this, my husband and I would like to have a family. We think with the right help, we would be caring parents with a lot of love to give.

My husband [REDACTED] and I have been married just over three years. With my diagnosis being at this time in the lives, in some ways we're lucky. We can make sure we have all the genetic facts before trying to start a family. We have decided we won't try to have biological children at this time if the gene defected is in my mitochondrial DNA. We've made this decision because if you have a defect in your mitochondrial DNA, you're essentially making a gamble. There's no way of knowing if you'll pass on a little bit of the defected mitochondria or all of your defected mitochondria. Meaning the child could have a mild to extreme form of the illness. Mild like me or extreme and be terminal. And we're just not the gambling types.

However, the introduction mitochondrial donation IVF, literally removes the risk of throwing the dice and gambling with a future child's health. By another woman donating her healthy mitochondria, which is more like an organ transplant than egg donation, the child has less than 0.01% of the third woman's DNA and no longer risks having mitochondrial disease. The donation doesn't even pass on ANY traits from the third person, apart from the ability for the body to process energy production correctly.

It's truly incredible that science has progressed as far as it has and now it's time for Australian legislation to progress too.

Support mitochondrial donation and you are giving me and my husband the opportunity to have a healthy baby and grow our family.

*Community Affairs References Committee
Submission: Science of mitochondrial donation and related matters*

When thinking about the ethical implications I believe it is important to consider the human rights aspects of mitochondrial donation. Article 24 of the *Convention on the Rights of the Child* states that "...Parties recognise the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health...". Mitochondrial donation removes a major health risk and provides an opportunity for children to be given every chance at having a future with good health.

The science has the capacity to support women like me, who want to start a family but won't risk the life and extreme illness and early life expectancy it could cause future biological children. Therefore, safety of the process is critical.

The United Kingdom has provided a precedent and guide for implementing legislation and regulation for mitochondrial donation. One suggestion however, could be for the Australian Mitochondrial Disease Foundation to be funded to monitor the registering process for patients wanting to use this form of IVF.

Finally, please think about the message you're sending with your report. Do you support Australian women having healthy babies? Do you want children to have every chance to have a healthy future?

Recommending the amendment of current Federal legislation to allow Australian families to access mitochondrial donation will save lives.

In summary, these are my conclusions:

- The impact of mitochondrial disease on Australian families and the healthcare sector
Mitochondrial disease can be debilitating, but its impact on a family's ability to have children adds an extra, unnecessary burden. Mitochondrial donation will help families have healthy children and reduce burden to the healthcare system.
- The safety, efficacy and ethical implications of these techniques
The techniques work in the UK, and can work in Australia. The ethical implications are important, but can clearly be resolved in the case of mitochondrial donation.
- Consideration of legal changes and safeguards that would be required to allow mitochondrial donation in Australia
The UK provides a model, and all involved with mitochondrial disease in Australia will work towards a solution that suits Australia.
- The value and impact of introducing mitochondrial donation in Australia.
Families just like mine depend on mitochondrial donation for the chance of growing their family and having healthy children.

Thank you for considering my submission.

Kind regards