

This response was submitted to the call for evidence by the Nuffield Council on Bioethics on *Emerging techniques to prevent inherited mitochondrial disorders: ethical issues* between January 2012 and February 2012. The views expressed are solely those of the respondent(s) and not those of the Council.

Anonymous 13

Summary:

- Personal view.
- What is the relationship of the mitochondrial donor to a child born using the techniques?
- Would I travel abroad?
- Informing a child using this technique?

1. Personal View

I am 52 years old and I am a female member of a family with a Mitochondrial Disease called MELAS. My main symptom is fatigue.

What does a mitochondrial disease mean to me on a personal basis?

- A Physical Devastating disease.
- A Physical Destructive disease.
- A Physical Debilitating disease.
- An Emotional disease.
- And GUILT.

Why? I have MELAS a mitochondrial disease myself; however this is mild compared to my siblings. I am the youngest of the siblings with an age gap of 19, 7 and 3 years. Since being a small child I have watched the suffering and deterioration of my sister and brother. Also sadly, I've watched my mother and my middle sister die of the disease that has no cure. The rest of the family, nephews and a niece, the time bomb may just be around the corner for them.

My own son has the mitochondrial disease. I can't turn the clock back but what I know now, my life would have been mapped out for me very differently. However, the punishment of life long guilt of passing it on, of watching, of waiting, of asking why, still goes on each day. Mitochondrial disease not only affects the person but also affects partners as care needs to be given twenty four hours a day. This rare mitochondrial disease to some people is misunderstood and because symptoms are not always visible and physical, some people tend to be ignorant towards it.

2. What is the relationship of the mitochondrial donor to a child born using the techniques?

Science has progressed so that it has helped many people from suffering over the centuries. Antibiotics, blood transfusions, test tube babies, surrogate mothering, IVF, organ transplants are all part of this progress.

The advancement and acceptance of this new technique can rid generation after generation of all types of devastating mitochondrial diseases that has no cure. The replacement of unhealthy mitochondria will be no different to the procedures used when a blood transfusion or an organ transplant is needed to stop suffering. Science must be allowed to progress to allow cures to be developed; otherwise suffering will always be allowed to continue.

3. Would I travel abroad?

This new technique is too late to help me, however if the treatment was available anywhere in the world I would have travelled to receive this procedure only if my finances would have allowed it, knowing it would get rid of the heartache that has affected my family and can affect it, for generations to come.

4. Informing a child using the technique?

When the child is old enough to understand I would explain to them about the procedure of the technique. It would also be important to inform them about the mitochondrial disease that affected the family for generations and could have affected them also.

Patient