

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 6

- To my understanding using the mitochondrial DNA of the donor will not have any genetic influence on the appearance or the character of the child. I think of the procedure as a necessary medical treatment which allows the treated children to live a healthy life.
- Yes, I would probably inform my child about the used technique.
- Yes, I would probably travel abroad to get the treatment.

I am a 32 year old woman with a 2 year old daughter. She was born in 2009. About the inherited MELAS-Syndrom my family found out in 2011 after my mother had a stroke like symptom and died shortly afterwards. I was tested positively for MELAS later on.

My husband and I always wanted to have at least 2 or 3 children but now that we know that all of our children are going to have this genetic disorder we are not so sure what to do. One of the horrible things about this disorder is that there is no chance that your child is not going to have it through a natural conception. There is just the question of how badly it will be affected. Luckily our daughter is developing well so far, but we are always a little anxious about when and what kind of symptoms she will develop in the future. We are really sad to know that she will never be able to exploit her full potential and in case she has children will pass this disease on to her children.

Concerning another child we are thinking about egg donation at the moment because this would be the only way to have a healthy child. But obviously genetically it would not be my child!

One thing is for sure: If there would already be the possibility to get the treatment we would definitely go for it. I personally see the treatment more like a medical treatment than a real genetical change to the foetus. I cannot see that the child would be a child of three parents like you have it after an egg donation. The foetus would only get a new and healthy cytoplasm with healthy mitochondria and not a new DNA.

It is already allowed to have egg donations. The main techniques are already established. I can't really see why the mitochondrial treatment would be ethically different from that.

Even if the treatment will not be soon enough available for myself, it is good to know that at least our daughter will hopefully have the possibility to have healthy children.