

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.

**Maria Hood**

**What is the relationship of the mitochondrial donor to a child born using these techniques?**

Donating healthy mitochondria, in my view, should be seen by the donor in the same light as donating an organ or giving blood. It should be made clear to the donors that they will not be given the name of the child and will not have any rights to the child as they are only giving the right to a healthy life and not any of the donor's characteristics. The child will have the characteristics of its parents like any other child, but will not have the mitochondrial disease.

I think there should be some record that the mitochondria have been donated – maybe on the birth certificate or other document – if later in life, the child has to be identified using cell samples, or when applying for insurance policies. My daughter, for instance, could not get her life insured when buying a house

**Would you inform a child born using these techniques?**

I think the child should be informed at an appropriate age, as you would inform a child who had been given a transplant.

**What would happen if this treatment was not available in the UK – would you travel abroad for treatment?**

I am a retired special needs teacher so I have seen the hardships and mental torment the parents go through and the difficulties, both physical and mental, a disabled child experiences.

I am also a mother of two girls, luckily not too badly affected by mitochondrial disease, but they have the potential to give birth to very disabled children. If this treatment were not available in this country, I would not have second thoughts about financing them to go elsewhere for treatment.

In some cases, Mitochondrial disease is a hidden disease. There are no outward signs that you are struggling with even the lightest of activities. Until you are diagnosed you question yourself and come to the conclusion that laziness or hypochondria is your problem. Everything you try to achieve is much more of a struggle than any able-bodied person. Mentally this can be harder than having an obvious disability because people judge you as being capable and expect so much more.

I wholeheartedly support further investigation into any techniques to prevent mitochondrial disorders.