

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.

## **Pat Chisholm**

Question 1: What is the relationship of the mitochondrial donor to the child

The mitochondrial donor, though hugely important, is a means to enable a couple to achieve a healthy baby and the relationship would be less than that of a sperm or egg donor. Even though this will affect the DNA of future generations, which organ donation wouldn't, it is such a small part of the genetic make-up and wouldn't have any effect on the characteristics inherited from both parents.

Question 2: Would you inform a child born using these techniques

Yes, I feel it is important to always be open and honest, and the child should be told as soon as it starts to ask questions and maybe explained again, in more detail, when the child is old enough to understand. Many people now have full and active lives as a result of organ donation, new medicines and scientific research, and using healthy mitochondria from a donor is another way of ensuring a healthy life.

As a mother of two adopted children, I think a child growing up in a secure and loving family will be able to accept this information and be glad to have been born healthy as a result of this marvellous research.

Question 3: What would happen if treatment was not available in the UK

If any of my family were in this position I would certainly help them financially to travel abroad to receive treatment not available to them in the UK, however, many other countries are not regulated as well as the UK and so a lot of investigation would have to be done before.

My own granddaughter had a mitochondrial disorder and died aged 4. She needed 24 hour care, was often in pain and my daughter and her husband were emotionally and physically exhausted. Anyone who has any knowledge of loving and looking after a child with mitochondrial disorder would do anything to make sure that if it could be prevented by using healthy mitochondria from a donor then it should be allowed. This research is so important to stop the suffering of children born with this disorder.

Pat Chisholm ( Mrs )