

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.

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Techniques to prevent inherited mitochondrial disorders: “ethical issues”

- Mitochondrial donation should be allowed to prevent the suffering families like ourselves have been left to endure for a condition where there is no cure.
- I feel it is more unethical to allow this suffering to continue while there is now a found technique of preventing this happen for future generations.

1. In donating eggs with unaffected mitochondria, if the donor is aware it is purely the mitochondria being extracted from their donated eggs and not the whole egg being used, this in turn limiting the amount of genetic material passed on. The donor I feel has no relationship to the child as what is being donated is purely the unaffected mitochondria, not the whole cell so the characteristics of the child would never be identified to the donated egg , it is purely replacement of the mitochondria.

2. If a child was born using these techniques I see no harm in informing the child , surely it is the same principle of any parent wishing to tell their child they were born using IVF techniques, it would be a blessing to be able to tell the child that a genetic disorder has been prevented from affecting their lives which has impacted on the lives of their parents and grandparents and that they have a healthy life ahead of them , and will never have to go through the same scenarios as their parents and grandparents.

3. If this treatment was not available in the UK I may seek treatment abroad. This in itself proposes a number of further stresses placed on the situation, particularly as to which countries would be involved in the treatment. If they were non – English speaking countries this would make the situation even further stressful. It would be a seamless transition of care to be able to receive the treatment form the team at Newcastle who have been so involved in our families care, it is at times like this in pioneering techniques, and to have the teams influence and care throughout would make the situation far more achievable and less stressful. If the treatment was available only abroad it would feel like a further barrier had been placed in the way.