

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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I am the mother of two severely physically disabled adults who have a mitochondrial disorder. They are both unable to walk; they struggle to talk and are fed via a PEG tube. Living with the fact that I, albeit unknowingly, caused their difficulties, is very hard and I would certainly welcome any chance of eradicating these disorders for future families.

I would like to make the following points:

- We are told that prevention is better than cure for many illnesses and diseases. Why should this only apply after conception?
- Transplants are morally and ethically acceptable to the extent that some authorities want a change to the opt in/out law. It could be argued that replacing faulty mitochondria is a form of transplant. Again, why not at conception.
- A life is a life, whether at conception or throughout childhood and adulthood. We should do our very best at each stage.
- IVF is acceptable for a woman who cannot conceive naturally. Should a woman who knows that she has faulty mitochondria not be given the same rights to have a child?

We are not talking about niceties – gender, appearance etc. We are talking serious, debilitating conditions that could condemn a person to a life of suffering and pain. To eradicate these conditions, would that not be the greatest gift that a mother could give her child?