

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.

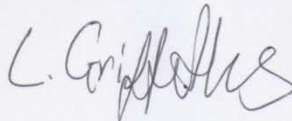
Lauren Griffiths

Dear Madam,

Re: Preventing transmission of inherited mitochondrial disorders.

1. I am writing in support of the research to prevent passing mitochondrial disease to the next generation.
2. I am twenty one and was diagnosed with MERRF disease in 2002. I want to have children in the future but worry about the percentage of the mutation I would pass on. My affected family members have mutation loads of around 70% and suffer from a variety of devastating symptoms which effect their everyday life and independence.
3. I understand the ethical issues associated with the research. The fact that children would have in effect three parents, but surely this is no more startling than patients who have received donor organs who could be said to have four parents. The three parent IVF treatment may be seen by some as interfering with nature but advances in medicine mean that this is happening every day. The initial uses of antibiotics, chemotherapy etc., I am sure were seen to un- natural at first but are now seen as lifesavers.
4. The cost of the research and potential IVF treatment should not be seen as prohibitive because the savings made by not treating the symptoms of mitochondrial disease must outweigh this.
5. It is every female's right to have children. There must be many women faced with the same dilemma as myself, whether to have children or not. If an end to mitochondrial disease for future is a possibility then research into this should not be prevented. Women of child bearing age with these diseases are not asking for designer babies just children who will be able to grow up without devastating mitochondrial disease.
6. The possibility of stopping the disease for the next generation, if this research was allowed to go ahead would be phenomenal. The end of mitochondrial disease and the suffering it causes is a must for future children.

Yours sincerely



Lauren Griffiths