

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.

Anonymous 11

1. I am writing in support of the research to prevent passing mitochondrial disease to the next generation
2. My family were not diagnosed with this disease until 2012. This made us realise how disabling this disease has been when we look back at previous generations of our family.
3. There are five current sufferers of the MERRF mutation in my family. My two brothers are now registered disabled due to the Mutation. My symptoms are progressing rapidly and I am struggling with everyday tasks. I have two daughters who are in their early twenties, who are both showing early symptoms of this degenerative disease.
4. Both daughters wish to have children but face the dilemma, is this fair to their potential offspring who will carry the mutation.
5. The possibility of stopping the disease for the next generation if this research was allowed to go ahead would be incredible. The end of mitochondrial disease and the suffering it causes is a must.
6. I understand the ethical argument against the research, using a donor egg, the mother's egg and IVF treatment but by not going ahead with this in order to prevent future sufferers of MERRF would be a travesty. Potential mothers are not asking for 'designer babies' just healthy ones who can lead their lives free of mitochondrial disease and put an end to it for future generations.