

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.

Response Form
Nuffield Council on Bioethics
Emerging techniques to prevent inherited mitochondrial disorders: ethical issues

I have two sons with inherited mitochondrial disease who both began to experience serious symptoms when they reached the age of 42. One lives in Cumbria and the younger one in Australia, who is struggling to combat the Australian medical services as he has recently been seriously ill. It has been so difficult for both sons to find the appropriate care that they need.

As a mother to two sons directly affected with this terrible disease, I carry an enormous feeling of guilt. This feeling grows as the year's progress, and is something that does not abate. I feel as though I have condemned my sons to life sentences, of which I am also part of. Words cannot describe what it feels like having to witness the deterioration of the two most important people in my life, the cause of which I am responsible for. Just as there is limited support and understanding about this disease, there is also limited support and understanding for the sufferers and their families, particularly the mothers.

I completely support the research into replacing defective mitochondrial DNA in a human embryo. If I could have had the option of using these new techniques and treatment to prevent this disease I would have jumped at the chance. Whatever it would have taken to afford, and wherever in the world I would have had to travel, I would have done so. I would also have told my child about it.

I would be very happy to discuss any of these issues further if it would be useful.

The respondent's name:
 No

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Yes No