

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 24

I set out below my submission regarding preventing the transmission of inherited mitochondrial disorders (and have attached the required response form):

In our family mitochondrial disease (MERRF) has caused many serious problems. I very tragically lost a son, aged four & three quarter years in 1981. He suffered a great deal throughout his short life and so did we as his family. Four years ago my great nephew died from MERRF and it is possible that other deaths in the family were due to this. Mitochondrial disease also affects surviving members of the family and, of course, causes great anguish in the female line.

My daughter gave birth to a wonderful healthy son, a much longed for child, in March 2010 after a course of PGD in Paris. We are eternally grateful to all concerned for this procedure, as it gave the opportunity of conceiving a child with a reduced risk of this terrible disease.

As a result of our experience I take the view that mitochondrial donation would have huge benefits for families such as ours. As a Christian, I believe that that this method of IVF would be justified for the following reasons:

1. I understand that only a very small proportion of genes is donated. I therefore take the view that the relationship between the donor and the child would be more comparable to someone receiving an organ donation, and we all know how grateful families are for donated organs which save the lives of their loved ones. In the same way there would be heartfelt gratitude to those wonderful women who would be prepared to donate their eggs for this procedure, to ensure a healthy child is born.

2. Embryos created and not used would be no more of an issue here than with other IVF techniques (including as above with my daughter's PGD).

3. For families such as ours, mitochondrial donation could potentially overcome terrible suffering and anguish while, in my opinion, the ethical arguments against appear to be no stronger than for example, when abortions are carried out, sometimes for social reasons.

If this technique were not available in the UK, but available abroad, we would definitely travel for treatment (as already done for PGD in Paris).

We would inform any child of these techniques having been used. The parents of our much-loved grandson will, of course, tell him details of the PGD used for his conception, when he is old enough to understand.