

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 12

1. I was diagnosed with Mitochondrial Encephalopathy in 2003, I knew from a early age that I seemed different to other children in the way of lack of energy , both academically and physically. I understand more now as time passes the different types of disabling & daily enduring pain it brings so many in this field. I have a sister & brother also diagnosed with the same condition.

2. My sister has two daughters who by nature will want to be mothers themselves. They are both in their early 20s and diagnosed with MERRF. I like any family member wish for their children and any future generation be mitochondrial healthy & free of this disorder.

3. It is my belief, with the success of proposed IVF techniques that mitochondria disorders should be eradicated. I feel that any Mother suffering from a mitochondrial disease has the right to have a child free of mitochondria disorder.

4. I feel that any child born with IVF intervention should have a right to know full details about their conception.

5. I feel strongly that this treatment should be available in the UK. Both my nieces have in the past discussed having children with Professor Turnbull, but at that time this potential research was not on the cards. The research needs to start immediately so that future parents are not facing the dilemma of having children who would develop this degenerative disease or to be childless.