

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 23

My view on mitochondrial donation is based upon personal experience.

My husband and I found out that I had MERRF in 2007 after a family member passed away from the mitochondrial disease. I myself am unaffected but it also emerged that my brother who died at the age of four and a half in 1981, when my mother was six months pregnant with me, had also died from the disease. We found out this sad news in the first few months of our marriage, exactly around the same time we were planning on starting a family. Subsequently it meant any child I had would also have MERRF and possibly be affected.

As any mother and father would we went to talk through possible techniques to reduce our chances of having a baby that may be affected by the disorder. Professor Turnbull at Newcastle University gave us lots of information and was incredibly helpful. After a lot of consideration Pre Genetic Diagnosis was what we hoped for, although we were saddened to learn it was unavailable in the UK. We however traveled to Paris and met Dr Julie Steffan and after many tests and discussions we were able to have PGD in Paris.

In 2009 my husband and I had successful PGD and due to this incredible process we gave birth to an amazing, healthy, beautiful, little boy in 2010 and I cannot ever explain how grateful we are to everyone who was involved and what an amazing technology we believe it is. It has given us a child of our own that we thought was never going to be a real possibility and because of it we feel like we are walking on air.

I know the technique of mitochondrial donation is different to the technique my husband and I used, because we used my egg and my husbands sperm, however during the PGD process I produced eighteen eggs and I was shocked to learn only two embryos were viable to transfer due to high levels in the remaining embryos. It hit home how close we were to not having a child of our own and I know had we not been successful we would most certainly have considered mitochondrial donation as our next option.

With regards the questions raised by the Working Group, I believe a mitochondrial donor is no different to a donor of an organ. They are selfless to give another family assistance in giving or continuing life but they are not the mother and genetics surely prove that.

I personally would inform a child born using these techniques, to avoid any confusion, the same way we will inform our son and explain to him that he is as loved as a child conceived naturally, particularly because of the lengths we went to to conceive him.

Most certainly we would travel abroad as we already have done.

I am a Christian mother and I do not in any way consider this technique to be unethical and I do not believe it should be unlawful to help stop families suffering from mitochondrial disorders and assisting them to conceive healthy children.