

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 14**

I am responding personally as someone who has been diagnosed with a mitochondrial disorder as has my son.

1. The devastation of carrying and passing on mitochondrial DNA mutation 8344A to all of your children is in itself cruel and destructive. I have one son and two daughters. My son is a victim of MERRF syndrome. His life was completely changed when at the age of 23 he was tested and received the devastating news. He is now in a wheelchair and suffers from severe ataxia. He lost his eyesight in October 2010 but this has now returned. As a family we have prayed every night and I have tried everything a mother would for her son who could see no reason to carry on living. At the moment there is no known cure. I am a Christian; I believe in God; I am a teacher; I believe in justice for all: and I believe in life.

2. How can a mother live with the fact that she could be passing on a death sentence to all her family through her faulty mDNA? It's easy to just say No to this research – but doctors and researchers need us to advocate this and see past the potential “ethics” issues and look into the miracle of reproduction and the help we can give to people with this condition.

3. Why do we give food and water to starving children? Why do we give antibiotics to fight off nature's illnesses? Why do we give transplants to replace faulty organs? If we didn't, knowing we have the knowledge, knowing we have the healing powers, would that make us inhumane? That child we are saying “No” to because it is unable to speak for itself should have people like me on its side!

4. Yes to the research. No to those who don't really understand what it's like to have a child living with MERRF – it's like every day having the “sword of Damocles” living with you. When you are given some hope with well thought out research ideas – you have to welcome it with open arms – like a mother loving her child - and give hope not despair.