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 21

I write in connection with your call for evidence on the above subject. As a father of three children I discovered when they were aged 20, 25 & 26 that one of my sons carried a mitochondrial disorder which is hereditary. I only discovered this after my middle child Richard, then aged 25, suffered a series of three strokes which left him totally blind, and was diagnosed with MELAS syndrome, which is degenerative. Richard appeared to be a perfectly healthy child who loved to play sports and the only sign that there was anything wrong was that he suffered occasionally from epileptic seizures, which we didn't know at the time was connected to anything else, however it turned out that they were a symptom of MELAS syndrome. That happened on May 12th 2005 and Richard degenerated over nearly seven years with the condition also slowly taking away his hearing and weakening his heart. He was unable to be left on his own and over the last three years suffered multiple organ problems and was wheelchair-bound. Over the last eighteen months or so he suffered hallucinations, one of which was he believed constantly that there was a snake in his bedroom. He is now out of his misery as he passed away last month on January 15th, spending his final days in total distress and leaving behind a devastated wife and two young sons aged 13 and 7. We were totally distraught when we were told of Richards illness and no other family should have to suffer the way that we have over the last seven years when it may be possible through genetic research that something could be done to eradicate it for future generations. We now have to live in the knowledge that our remaining son and daughter could be struck down with this horrible disease and that any children that my daughter might have would have this mutated gene passed on to them, fortunately she has no children at the moment.