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.

Jolene Sharp

Dear Sir/Madam,

I would like to take the opportunity to respond to the call for evidence on mitochondrial disorders. I appreciate that this may not be the normal form of response as it is not a detailed analysis on process or a social report, however, I felt that it was important to try and put in some context in terms of the type of condition that the techniques to prevent mitochondrial orders may help prevent.

I have kept my submission brief as in all honesty there is no way of expressing how totally devastating this kind of condition is, nor the reality of living with for those who have this type of condition and their families.

The reason that I have decided to respond is that my younger brother Richard passed away in January 2012, after many years of suffering. He was diagnosed in 2005, after suffering a series of strokes, with MELAS syndrome (Mitochondrial Encephalopathy, Lactic Acidosis and Stroke-like episodes).

The impact on Richard was severe from the outset. Having already been diagnosed as epileptic he then lost his sight and part of his hearing, and in the years that followed he lost his mobility, suffered with his stomach and muscles, having problems with his heart and bowel. He also suffered from fatigue, nausea, had headaches and also a form of dementia which often left him confused. Any of these would have been bad enough in isolation but Richard suffered from them on a daily basis. He had frequent visits to doctors and specialists to try and maintain a quality of life. The condition also impacted on our family and in particular his wife and young sons who took care of him.

I am sure that there are many people who suffer to this extent and given that there is no cure for this type of condition I feel that looking towards prevention of such disorders is a positive step.

I appreciate that any form of advancement that alters the genetic makeup is controversial and raises complex issues. However, I remember how grateful I was on realising that Richard's condition would not be passed on to his two young sons, or should my other brother have children that it will not directly affect them. As a female relative of someone who has been diagnosed with the genetic form of MELAS I realise that this is not a position that everyone with MELAS is in. It is a cruel illness which usually develops in childhood, and whilst I myself do not have children, I have an immense amount of sympathy with families having to watch their love ones suffer so badly from this type of condition, particularly if they are too young to understand what is happening.

I would have liked to have given some consideration to the wider issues that surround the area but circumstances at the moment make that quite difficult. However, I would like to add that personally I would give consideration to using emerging techniques in the future in the hope of avoiding passing on such a devastating condition.

Yours sincerely,

Jolene Sharp