

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.

### **Melissa Rippon**

- Our son died 5 months ago from mitochondrial disease, Leighs disease
- There is no family history
- He was 2yr and 4 mths old
- He had very little quality of life and was very ill and suffered greatly, as did the entire family
- These last couple of years have been devastating beyond belief for all of us
- We have one healthy daughter who is nearly 5
- We would love more children to make our family completebut cannot take the risk this could happen again, so until our gene is found, we are pursuing donor egg options
- We have travelled abroad to seek donor egg treatment
- If this new treatment was available to us , we would definitely use it.
- We would 100% inform any child born of the techniques used, and feel strongly that the child would be grateful to have a genetic link to myself (mother) rather than no genetic link at all (with the donor eggs we are currently using). I believe the impact on the child would be minimal. It only takes me telling them the story of how our son died to make them realise why we would have pursued this technique to ensure another child didn't suffer this way.
- We would 100% travel abroad for this technique, we are already going to Spain for our donor eggs
- I believe the donor would be just that – the donor. A kind and generous person that has given a wonderful gift to a mother who has been unlucky enough to have mitochondrial disease destroy her life and her family. The donor would be an amazing person to give such hope and chance to a broken family. I believe I would be the mother as I would have carried the child and given birth to it and raised it, and it would also have my genes. The donor would be the secret fairy godmother that enabled it to be a healthy child without a mitochondrial shadow hanging over them.