

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.

Joanne Cullen

1. What is the relationship of the mitochondrial donor to the child born using these techniques?

The relationship should be what ever the families & donor wish it to be, it can be an anonymous donor or if the donor wished a known donor. I think that when women donate their eggs for this procedure, once they have had the relevant counselling it should be included in their consent form whether they wish their identity to be made known to the person receiving the donated egg & the child in the future.

I think that there is no reason why that from a young age the child should understand how special and lucky they are to have had someone help them to be mitochondrial disease free, and then if the child wished to have contact with the donor they can. It may be worth creating a charity to help all the parties involved communicate with each other (a little like NORCAP for adopted children and birth parents to find each other).

2. Would you inform a child born using the techniques?

I have really answered this in question 1, I am in no doubt that all children should be aware of how lucky they are and that they have had this procedure. I cannot see any reason why they would not be told.

3. What would happen if this treatment was not available in the UK?

Parents who have been through this with their children and know how painful and difficult it is for them, their child and all their other family members, would, I can only assume be desperate not to lose another child through this.

We all want to have healthy happy pain free children to love and nurture throughout their lives. Everybody I can imagine who has been through this would do EVERYTHING in their power to not put anyone through it again and I believe would travel to the end of the earth to achieve this, no matter the cost.