

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.

A. Maguire

- **What is the relationship of the mitochondrial donor to a child born using these techniques**

I would not consider there to be any blood relationship between the mDNA donor and the receiving embryo.

I would see the link more like that of receiving an organ donation. This would be in the sense of a medical intervention that involved donation of organelles that would improve the chance of survival of the recipient. Nothing more than that.

Whilst I appreciate there are differences between organ donation and these techniques (as the donated mDNA will be passed down through subsequent generations), I consider that to be a positive aspect of the technique, as within a specific family, the disease could be eradicated and not passed down through subsequent generations.

(I assume much longer term, theoretically, this type of inherited disease could be eradicated using this technique.)

Because of the tiny % of donor DNA compared to the nuclear genome from the parents, combined with the fact that all physical characteristics contained within the nuclear DNA will be all from the mother and father (like eye colour, hair colour, intelligence etc.) I would not consider the donor and the child to be related.

- **Would you inform a child born using these techniques**

I would definitely inform the child.

The specifics of what information I gave the child would obviously depend on the age that I told the child, but from my experience of being adopted I really believe if you are honest with a child from a young age, and that the information is age appropriate then children are very good at just accepting things they are told, and then this forms a basic foundation for building on as they get older.

I am assuming that if a family was using this technique they would already have had an affected child (who probably died or would be very sick) that the current child would know about.

I would probably tell my child about the age of 5 as I think they are old enough to remember info that they are told but at this age they accept things easily and once the underlying facts are there they will be easier to expand on when the child gets more inquisitive.

I would say that do you remember mummy told you that your sister was very sick when she was born and that she was in hospital lots..... The doctor's couldn't fix her and so she died and we all miss her very much. Well so as you could be born healthy, you were given some special cells in hospital to make sure you were not sick like your sister.

As the child grew older and understood about reproduction I would expand on the idea that they were still 50% mum and dad but that the special cells were actually batteries to make their own cells work properly, and that they were called mitochondria. These healthy batteries made sure that they didn't get sick like their sibling. Kind of like a medicine that stayed in their body all their lives to protect them. You could follow on to explain that it would also protect their children and their children's children.

- **What would happen if this treatment was not available in the UK – would you travel abroad for treatment?**

Yes I would travel abroad for treatment although it would obviously add tremendous additional stress to an already difficult process, not to mention the risk of un-reputable practices offering unregulated techniques, which may lure less wealthy families in their desperation to have a healthy baby.

I watched this disease slowly disable and kill my daughter over 4 years. There was no effective treatment for her painful symptoms and no hope of cure for her condition. If there was a way to prevent children being born with conditions that cannot be effectively treated or cured then it should be agreed without any doubt.

I think you need to have been close to a family with this condition to fully appreciate the devastating impact these conditions can have on a family.

I would not be worried about any side effects of the treatment as no side effects could be worse than watching your child suffer and die with the condition itself.