

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.

## **Preventing the transmission of inherited mitochondrial disorders**

*Submission by: Kemal Altug*

### **Foreword:**

As a father of a 4 year old girl with a suspect mitochondrial disease (Cytochrome C Oxidase deficiency), I am too aware of the devastating and profound impact such inherited metabolic disorders have on the child, but also to the family members.

Unlike more 'common' childhood disorders, such as cystic fibrosis (devastating as they are), mitochondrial disorders have too long been ignored in terms of research for prevention, cures, and treatment.

I am fully in favour of the research being carried out in relation to mitochondrial donation. Specifically, the process appears to be safe, and ethically less burdened due to nature and role of mitochondrial DNA, as opposed to Nuclear DNA

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

The questions of inheritance and of human characteristics are almost entirely irrelevant in mtDNA donation; as these do not carry the codes for physiology, and therefore make many of the tough questions usually associated with egg donation rather mute. In my opinion, as less than 1% of genetic code belongs to the donor, the relationship is extremely slim.

The donor effectively gave battery to energise the cells – and not much more. No eye colouring, facial features, height, or any other human characteristic have been transferred.

If I can use an analogy, a Halfords battery is powering a Jeep. What is the relationship of Halfords and the Jeeps design, the Jeeps colour, the number of seats, the size of tyres? Apart from providing power, there is nothing else at all. The relationship, has no bearing on the physicality - It's still a Jeep, and If I had used a different battery – it would still remain a Jeep.

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

Yes – but I would make it clear that human characteristics and physiology have not been inherited by the donor

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

Yes. Having seen first hand the devastating effects of mitochondrial disease, once such treatments have been established abroad, I would not hesitate. Avoidance altogether of such diseases is paramount not just for the child, but for the siblings and parents.

### **Conclusion**

I consider the research both brave and logical. It is less fraught with the ethical questions of other egg donations, and is a sensible and safe approach.

Kemal Altug