

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.

## **Anonymous 1**

### New techniques should be permitted

I believe that the new techniques to prevent transmission of mitochondrial disease using donated mitochondria should be permitted and hence reduce the number of children who suffer or die from these disorders.

As a parent who has lost a child to an inherited auto-recessive mitochondrial disorder it is vital that couples should be offered solutions to raising their own children whom can be born free of life limiting illness.

I am 'lucky' in that I can benefit from existing PGD treatment practices. Women who carry a maternally inherited disorder should also be able to benefit from IVF treatment which enables the child to carry their DNA.

### No relationship to donor

The majority of genetic information transferred to the child would predominantly be from the mothers egg with only a small amount (mtDNA) inherited from the donor egg. To this extent the child would carry the genetic characteristics of both its parents. I believe that this is more beneficial to a child than using a donor egg or adoption as there will be physical and personality trait similarities. I do not see any relationship between the mito donor and the child. In essence the donor egg, without the determining nuclei DNA resembles a 'host'. If a person receives a donated organ there is no perceived relationship between the donor and recipient and I don't see this as any different.

### Communicating with children

If I were to find myself in this situation and a child wished to know more about say why they are healthy and a sibling is poorly, or has passed, then I would explain that they were conceived using IVF so that they could be healthy. I would explain that a donor egg had to be used to carry Mummy's DNA but that who they are has come from both Mummy and Daddy's DNA, just like their friends and cousins etc.

### I would travel

If I was in this situation and treatment was not available in the UK then I would travel abroad to receive it. However, I would prefer to receive the treatment in the UK where the HFEA ensure tight controls and regulation over IVF clinics and procedures.

### 'There is always adoption'

I get fed up of hearing about how 'there is always adoption'. The importance of having one's own child should never be underplayed and adoption in the UK remains a difficult and lengthy process and can never replace having one's own child. If science can enable this then it gets my vote.

### Risks of not permitting

- More children born with life limiting illnesses, potentially suffering and dying young.
- Psychological impact on women of not conceiving ones own child.
- Women may travel abroad for treatment and the UK has no jurisdiction over overseas IVF practices.