

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.

Oliver Wilkes

‘Techniques to prevent inherited mitochondrial disorders: ethical issues’

- My son died of a mitochondrial illness
- We have a healthy daughter as a result of PGD treatment performed at the Newcastle centre for life, following diagnosis of my son’s illness.
- If Newcastle had been unable to find healthy eggs, the technique being discussed would have been our only hope for a child safely.
- If it was not possible to have a child safely, we may have tried unsafely – just hope it didn’t happen again.
- Once you become a parent, you change forever. If you lose your child, becoming a parent again becomes more important than ever
- The health and safety of the child, and the happiness of the parents, are the real, concrete, paramount considerations above all else.

Mitochondrial disease is doubly cruel. Not only does it rob a child of their life, and parents of their child, it also threatens the lives of any future children. The same thing that happened to your lost child could happen again.

Mitochondrial disease robs your child of its energy, slowly, remorselessly. Our son – and the children of other parents who suffered – got gradually weaker, more helpless, and there was nothing we could do about it. Once diagnosed with the illness, it is simply a matter of waiting and suffering. Losing your child, particularly after they had been healthy for the first few weeks, is an unspeakably painful experience. No one should suffer this experience if it can be avoided.

Once you become a parent, you change forever. Any parent will tell you how their world turns upside down, their priorities change. This does not reverse when you lose your child. You are still that parent, but with an unfillable hole in your life. The only way to recover from the loss is to become a parent again. I know people who have taken the dreadful risk, where they don’t have a diagnosis, because they simply could not wait for the diagnosis in order to be safe. Women might not feel they have too long to wait. Imagine going through 9 months of pregnancy, labour, and then waiting, looking for any sign, that your child is unwell. There can be no more terrifying torture than this. The parents, and child, even the state health service, is forced to gamble if this treatment is not available.

We would have done anything to be parents again. We were lucky, twice – we gained a diagnosis, and there were healthy embryos that could be used for PGD. If we didn’t have the diagnosis, we might have just gambled. If there were no healthy eggs – and this treatment were not available - we would have had no chance of being parents again. Our lives would never have recovered.

I would have no hesitation in using a mitochondrial donor – a friend, a stranger from the UK or overseas. They are saving 3 lives – the parents, and the child. They are giving a wonderful gift – but it is a one-way gift. Unlike an egg donor, where the characteristics of the donor may carry on to the child, and so a bond may remain, with a mitochondrial donor, there is no link, except the child is like the other 99.99% of the world. A child of a donated egg may want to meet the donor, to understand their genetic traits. A child of mitochondrial donor should only want to meet them, to say thankyou.

I believe there are fewer ethical dilemmas due to donated mitochondria, compared to donated eggs – for a donated egg, there are questions about the child’s biological parents. Half the child’s ‘nature’ comes from the donor. For mitochondria – someone helped them avoid a disease, beyond this, none of the mitochondria donor’s characteristics were transferred.

I would be happy to tell my child if they had donated mitochondria – and the donor. They would know they had been given the gift of safety, like a vaccine or like someone pulling them out of the way of

oncoming traffic – but as there is no genetic link beyond the mitochondria, I don't believe it would trigger any identity questions.

If we needed the treatment, I would go to the ends of the earth, pay any money, do whatever was needed to get it. It is impossible to overstate, once you have been a parent, how essential to your future happiness being a parent again is.