

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.

Beth Wilkes

I am a carrier of an affected mitochondrial mutation, which I did not know about until my son of 8 weeks was diagnosed with Leigh's disease. He died 5 weeks later.

I was fortunate in that all of my eggs that were tested in the PGD procedure came back with a low mutation of between 2-5%. Had they all been like my son, carriers of 98% mutation, then the pro nuclear transfer technique would be my only choice in conceiving a healthy baby. There is still no guarantee that my eggs in future will all be low, the nature of mitochondrial disorders is that it is completely random.

If I went down this route I would seek help from a friend. I wouldn't have any reservations in asking a friend because they wouldn't be giving me a baby with their characteristics or their genetic makeup, they would be giving me a baby with the energy to survive.

Would I tell my child? Of course! I think it's something to be very proud of, and my child would grow up thinking they were a miracle of science. I would not use such words as "you have three parents" because that is ridiculous. I will simply tell them that someone special gave them the energy that makes them function. They would have no reason to want to meet with the donor, because there would be no genetic link. The only reason they would want would be to say thank you.

I would prefer not to travel overseas, but I would because I would do anything to have a healthy child. I wouldn't have any reservation in accepting a donor from a different country. I would have to take into consideration the language barrier and operating standards in fertility clinics before going overseas. But if it was somewhere like Spain, I know they already have a good reputation.

So I am 100% in support of this procedure. Losing a child is the most devastating thing a parent can ever go through. You never get over it, but by having this procedure pass through law would enable so many devastated families move on in their life. It will never be the same, but it will help them move on without the apprehension of losing your child again.