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.

Louise Blair

Preventing the transmission of inherited mitochondrial disorders.

Overview

- My daughter, Elisabeth Grace Blair – was born 17/6/10 and left this world on 27/5/11
- I am a 31 year old, happily married individual, who lost my first and only child – Elisabeth Grace, to an unknown mitochondrial disease.
- It was a normal pregnancy, she was delivered via c-section, one week overdue. At 3 days she was diagnosed as having a hearing impairment, this was confirmed as severe hearing loss at 2weeks. After her first vaccination at 6 weeks she was admitted to hospital with a viral flu. From here she struggled to put on weight. At 5 months she was diagnosed with a metabolic disorder, all tests came back normal, they still are. We were told that she wouldn't make it to her first birthday. She passed away peacefully in her sleep at home with me, at 11months and 1 week. Our journey to this diagnosis was not this straight forward.
- Our future family plans are limited. Still we have no answers, so PGD is not an option. At this stage our only option is to pursue a donor egg.

Even though I do not have a medical background to fully understand the scientific implications of this newly developing technique, I can say that from a social level if this technique was an option today, we would be going ahead with it. It is disheartening beyond words having to accept the idea that you, as a maternal woman, are not able to have a biological child. Not only do you have to go through the unbearable suffering and pain of losing your child, but also then face the prospect that what you had, you will never have again. There is absolutely no way, that we would risk passing this devastating disease on to any other innocent child. We would need assurance that it would definitely not happen again. Even if we were able to identify the defective gene, and we decided to embark on PGD, I would always think in my mind, what if they missed a gene? Whereas with this new technique, the concern would be completely removed.

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

No different to a person who would donate bone marrow to a cancer patient. There genetic make-up takes on part of the donors genetics, but it doesn't change who they are as a person. In my mind this person would be simply defined as a 'donor'. In comparison, when you talk of using a donor egg, the end result would be that this person would be the biological mother. Which is a lot more intrusive and hard to come to terms with. You would be forever thankful to this person for donating their mitochondria, just like you would to someone who donated any other organ. I would feel comfortable with my child having a relationship with this person, as they assisted me to have my 'own' child. I wouldn't feel threatened or uncomfortable by the child knowing the donor, because the child would biologically be a majority of our genetic make up.

Would you inform a child born using these techniques?

Yes, I would. As we are researching into going the path of a donor egg, a lot of information explains the importance of being open with your child. This is the aspect of donor egg donation that terrifies me, having to tell your child that you aren't biologically their mum. However, if this new technique was an option, because I would have a majority of my genes passed on, I would still consider myself to be the biological mother, with some minimal involvement of someone else. I would still be completely honest with the child, however it wouldn't be as bigger ordeal, in my opinion. In my mind there wouldn't be any real difference to explain to a child that we used IVF to conceive. A doctor and another lady helped us get pregnant with you.

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

Most definitely. When your whole life is affected so dramatically by medical development, if it can be achieved then you have to find a way of being involved. At this stage it would mean the difference between me having another of my own biological children or not.