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.

Brian J Somerville

Techniques to prevent inherited mitochondrial disorders:ethical issues

My summary points are as follows:
(1). I fully support the introduction of this technique.
(2). I strongly disagree with the title "Triparenting".
(3). In my opinion the donor of the mitochondrial DNA (mtDNA) is not a parent of the mtDNA recipient.
(4). I believe the decision to tell an individual that they were conceived using a donor's mitochondrial DNA is entirely down to the
parents.
(5). If I wanted to have children free from mtDNA disorders I would travel abroad for treatment if this technique was not available in the UK.

My thoughts on each of the above points are explained/developed further in the numbered paragraphs bellows, referencing each numbered bullet point in turn.

(1). I fully support the introduction of this technique if it is safe and can be performed without risk to the child. I appreciate that very few things in life are completely safe and not without risk but if this technique can be demonstrated to be practicably safe then it should definitely be allowed to take place. It should be supported whole heartedly as it can cure the disease from "conception" and save suffering from the individuals and families who live with this genetic disorder. It will, if successful, not just cure the disease in individuals conceived in this way but also eradicate this disease from families blighted with it for future generations.

(2) + (3). I strongly disagree with the title "Triparenting" for this technique as this implies that the donor (egg) contributes towards the genetic information which defines the individual's characteristics. This is not the case and donation of the mtDNA from the donor egg should be seen as no more than a person donating, for example, a kidney or a heart. In both of these examples the donor is not a parent of the recipient despite donating something that provides or sustains life and I think that the donor of the mtDNA should also not be seen as a parent. This was not an easy conclusion for me to arrive at because the mtDNA is found in every cell in an individual and is so crucially important to life itself but I had to stop myself from getting hung up on *our* DNA/gene obsession and see that the mtDNA has a completely different role from the nuclear DNA: that is, the mtDNA primarily produces energy for the cell through protein production etc etc whereas critically the nuclear DNA is what defines us as individuals. And, at the end of the day, that is what is important and should not to be lost from sight in deciding who the parents are. This headline title smacks somewhat of being a way of getting the public's attention in the media but crucially is not helpful in letting the reader form an unbiased opinion of what is involved in this technique and only serves to build up barriers to this kind of life saving work from being carried out. The sole reason for performing this technique is to save lives and prevent disease, suffering and misery in those afflicted with it and again that must not be lost from sight. It is not an attempt to bring about the creation of a new mixed genetic person or confuse the person born from this technique as to who its parents are. It is simply a way to cure a life threatening disease which causes pain, suffering and heart ache in all those who come into contact with it.

(4). This is entirely the parents decision and that should be respected.

(5). I suffer from the disease, as do or have 10 other members of my family (to-date) who all have MELAS A3243G strain of the disease. I am 40 years old and have personally lived with the disease since I was 28 years old. In that time my quality of life has changed markedly as I now have diabetes (insulin controlled), moderate deafness (60dcB threshold at present but still deteriorating as the years go by and wear hearing aids to compensate for my hearing loss), hypothyroidism (leavothyroxin treated), fatigue issues (ubiquinone treated at present), potential heart issues (still under investigation and to be resolved/treated), vertigo (causing mobility issues in everyday life, particularly after dark) and chronic constipation as a result of weak bowel muscle (treated with a mild laxative taken every

day); these are all things which cannot be cured with current medical procedures/treatments and I only dread to think what else lies in front of me. The other members of my family also suffer to different degrees from these conditions and some have been very ill during their middles ages as a direct result of the disease. It is completely horrible and down heartening each time another member of my family is diagnosed as carrying the A3243G mutation which happened as recently as two weeks ago in my family's case and also opens the door for each of her three children, one of which is a girl, to potentially develop the disease as they get older and also potentially pass on the mutated gene to her children and start the cycle again. This technique offers healthy life, free from all of those conditions and diseases this *God forsaken* disease causes and should be allowed to be developed to the full. I also believe (ignorance is bliss!) that the mitochondrial disorder we have in our family is at the lesser end of the spectrum of what mitochondrial disorders can cause and have read that other mutations and deletions can cause much more immediately life threatening conditions. To me, it therefore only makes sense to seek this cure where ever it was available and if that meant going elsewhere than the UK to find it then that is what I would do. This, however, is not ideal for someone living in the UK and would only add to the considerable stress, both emotional and perhaps also financial, that making this kind of decision brings. Personally, I would feel disappointed if I knew this treatment were available elsewhere in the world and not in the UK and think it should be made available in the UK for UK citizens if they want it.

Brian J. Somerville

24th February, 2012.