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.

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- The procedure to replace defective mitochondria should not be regarded as unethical or controversial once it is fully understood.
- Comments being made in favour of banning the proposed therapy are akin to opposition to previous medical advances which were originally thought to be interfering with nature.
- The existing techniques of preimplantation genetic diagnosis and prenatal diagnosis do not prevent the transmission of mitochondrial disorders and as a carer my view is that this new research is essential. Studies have suggested it could totally prevent transmission of inherited mitochondrial diseases.
- Records of egg donation should be kept and managed by the appropriate authorities.

1. The ethical questions arising from emerging techniques such as PNT and MST require careful consideration, however some of the concerns such as " three parent families" are unfounded. The call for evidence document advises that after the use of these techniques, children would inherit nuclear DNA (around 25,000 genes) from their parents, and mtDNA (13 genes) from the donor of the egg. This small percentage is like replacing a battery and therefore has no impact on the DNA that determines all other factors. As such my view is that any donor of mtDNA would not be a parent of a resultant child or entitled to a relationship with that child. I see this as being similar to the relationships between those involved in organ or tissue transplantation or a donation of other bodily material.

2. If there is a risk of transmitting any adverse side effects of the techniques to future generations I think it would be reasonable to permit prospective parents using these technologies to also use pre-implantation sex selection (choosing male embryos). However if the research shows that the risk is insignificant the question of sex selection should not be an issue.

3. If mitochondrial donation were not to be approved from research into medical treatment in the UK, this would be unethical because we would be allowing children to continue to be born with mitochondrial diseases which can be extremely difficult to treat and with no cure. If treatment was not available in the UK I would advocate travelling abroad for treatment because of the devastation which can arise from carrying this defect.

4. These emerging techniques should be treated no differently from a legal or ethical perspective than egg and sperm donation using IVF. How can it be lawful for a female to donate one of her eggs in its entirety but not lawful for a female to donate a part of her egg? There should be a consistent approach here.

5. It would be desirable for records of donations to be maintained by the appropriate authorities. This would include the names and addresses of the parents, the donor and the date of birth of the resulting child. The information in this database should only be made available on request to the parents, or the donor, or the resulting child and any successors of the resulting child.