

Novel techniques for the prevention of mitochondrial DNA disorders: an ethical review

Inherited genetic disorders caused by mutations in mitochondrial DNA can cause a wide range of severely debilitating and disabling health problems including heart and other major organ failure, stroke, dementia, blindness or deafness. These progressive disorders can onset at any age from birth and can cause premature death. There is currently no cure for these conditions.

Research into techniques that could prevent the transmission of inherited mitochondrial DNA disorders is advancing, spearheaded by UK scientists. Using variations of IVF procedures, techniques such as pronuclear transfer (PNT) and maternal spindle transfer (MST) (see diagram overleaf), could make it possible for a woman carrying mitochondrial DNA mutations to have a healthy child that is genetically related to her. Both techniques rely on the use of healthy mitochondria from a donor's egg as replacements for the damaged mitochondrial DNA that would otherwise be passed on from the mother.

In June 2012, the Nuffield Council on Bioethics published a report exploring the ethical issues relevant to affected families, potential donors, researchers, medical professionals and policy makers confronted with questions about the possibility of using these techniques in treatment. It concluded that:

- Provided that the techniques are shown to be sufficiently safe and effective, and an appropriate level of information and support is offered, it would be ethical for families to use these techniques as treatment.
- Donors of mitochondrial material should not have the same status in regulation as egg or embryo donors for reproduction. For example they should not be required to be identifiable to the adults born from their donation.

Under the proposed regulations, any use of the technique would remain subject to licensing approval by the Human Fertilisation and Embryology Authority (HFEA). Before a licence can be granted, the HFEA is required to give careful consideration to the safety and effectiveness of the techniques in the proposed context of use.

If the techniques are to be approved as treatments, the Council makes a number of further recommendations concerning the circumstances in which they should be used. These include that:

- Information and counselling about the implications of these novel treatments must be provided to prospective parents by specialists with appropriate training and up to date information.
- Follow up and evaluation will be crucial to further knowledge about the outcome of these treatments. This could be supported by a centrally funded register of procedures performed in the UK that is available to researchers over several decades.

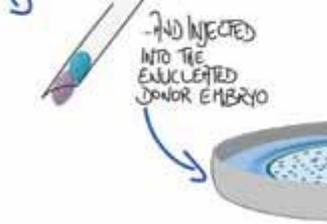
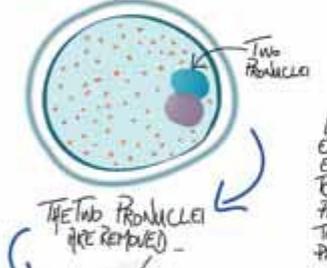
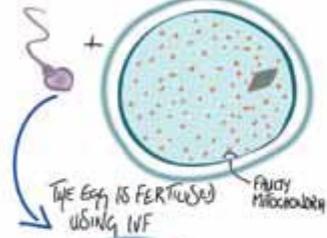
The proposed regulation would see the authorisation of these techniques for the specific purpose of preventing the transmission of inherited mitochondrial disorders. This would not extend to techniques that might seek to alter any genes contained within the nuclear DNA - any such future technique would need to be considered separately.

Copies of the report are available from:

<http://nuffieldbioethics.org/project/mitochondrial-dna-disorders/>

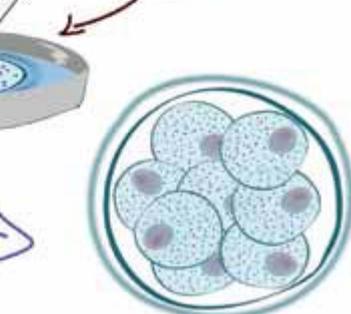
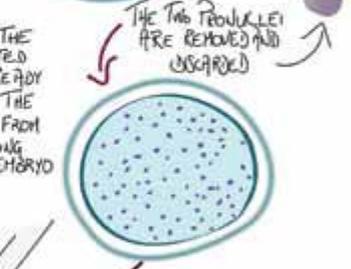
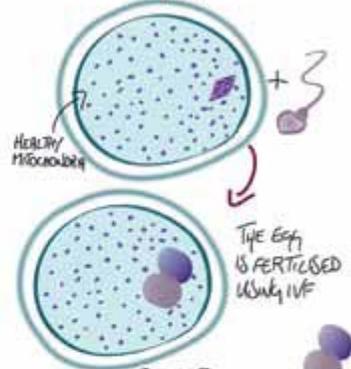
Pronuclear Transfer

Sperm and Egg from the Intending Parents



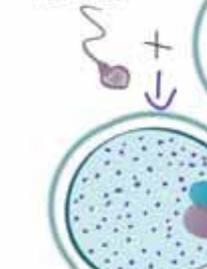
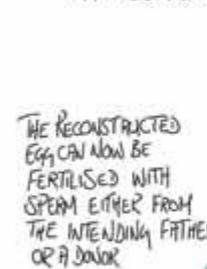
THE RECONSTRUCTED EMBRYO CAN GO ON TO DEVELOP UNAFFECTED BY MITOCHONDRIAL DISEASE

DONOR EGG AND SPERM FROM THE INTENDING FATHER



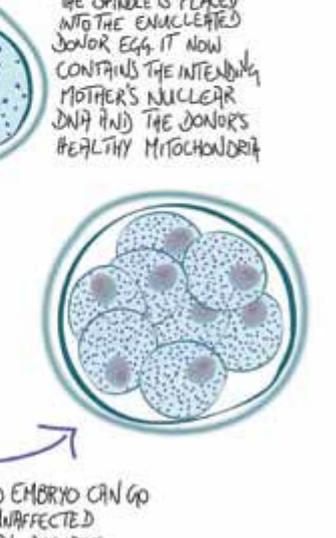
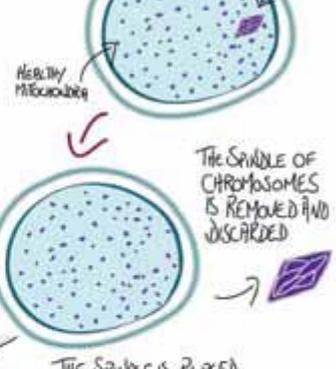
MATERNAL SPINDLE TRANSFER

INTENDING MOTHER'S EGG



THE RECONSTRUCTED EMBRYO CAN GO ON TO DEVELOP UNAFFECTED BY MITOCHONDRIAL DISEASE

DONOR EGG



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