

Mitochondrial technique is ethical

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(Medical Xpress) -- An influential independent body has found that a pioneering mitochondrial transfer technique is ethical. Developed by a team at Newcastle University, the technique aims to prevent the transmission of maternally inherited mitochondrial disorders.

Today the Nuffield Council on Bioethics has announced in a report that the technique would be an ethical [treatment option](#) for affected families, so long as research shows that treatment is likely to be safe and effective, and families are offered full information and support.

Mitochondria are essential to produce the energy that powers cells. These small structures are located outside the cell nucleus and have a small number of their own genes which affect mitochondrial function, but are not thought to carry information on any other personal characteristics. Faulty genes in mitochondria can, however, lead to serious disorders involving heart malfunction, kidney disease, liver disease, stroke, dementia, blindness or deafness and premature death. These symptoms can begin from any age and there are currently no cures for mitochondrial disorders. It is thought that around 6,000 adults in the UK are affected, either through mutated mitochondrial DNA or mutated nuclear DNA affecting the mitochondria. One in 6,500 children - around 2,000 children in the UK - is thought to develop a more serious form of mitochondrial DNA disorder.

Newcastle University scientists have pioneered research into variations of IVF procedures (pronuclear transfer and maternal spindle transfer) that could prevent the transmission of the genetic mutations that cause

these disorders. These techniques use part of an egg donated by a healthy individual to replace the faulty mitochondria of the affected mother. The intention is to give affected families a chance to have healthy children that are genetically related to them, but born free of mitochondrial disorders. Such techniques are not currently permitted for treatment in the UK, but under existing legislation Parliament could vote to allow them.

Dr Geoff Watts, Chair of the Council's inquiry into the ethics of these potential treatments, said: "If further research shows these techniques to be sufficiently safe and effective, we think it would be ethical for families to use them if they wished to, provided they receive an appropriate level of information and support.

"They could offer significant health and social benefits to individuals and families, who could potentially live their lives free from what can be very severe and debilitating disorders. We would recommend that families commit to allowing long term follow-up of the resulting children, supported by a centrally funded register of such procedures performed in the UK, which would be accessible to researchers over several decades."

Alison Murdoch, Professor of Reproductive Medicine at Newcastle University, part of the team which has developed the technique, said: "We welcome the findings of the Nuffield Council report, it is very reassuring that they support our aims and we hope the Government will also give support.

"We understand the challenging ethical issues that are associated with our research and welcome this comprehensive expert review. The Report places the ethical issues within the context of our aim to prevent suffering due to MID (Mitochondrial Inherited Disease). Whilst the ethical issues will still be debated, it encourages the patients who are

wishing us success with our research and hoping that parliament will permit MT-IVF (Mitochondrial Transplant IVF) treatment in the UK.

"IVF started with pioneers in the UK and now millions of babies have been born worldwide from this treatment. Here in the UK, we have the opportunity to be pioneers again. We want to take the knowledge and skills gained from helping infertile couples to give hope now to those suffering from other medical problems.

"Research that is ethically challenging is difficult for scientists and regulatory decisions are not easy for politicians who are distant from the problem. But these problems are insignificant in comparison to those faced by couples who carry a risk of passing illness to their children.

"We are delighted with the response that we have had from women in the North East who have volunteered to donate eggs for our research. As a result we are making good progress to understand the potential success rate and safety of the proposed treatments. As the Report recommends, this is essential prior to offering MT-IVF (Mitochondrial Transplant IVF) treatment."

The Council concludes that the proposed treatments would be a form of germline therapy, as changes resulting from the replacement of mitochondrial DNA would be passed on not only to the resulting children, but also to the descendants of any girls born from the techniques, via their eggs.

"We understand that some people concerned about the idea of germline therapies may fear that if such treatments for mitochondrial gene disorders were approved, a 'slippery slope' would be created towards comparable alterations to the nuclear genome. However, we are only talking about the use of these techniques in the clearly-defined situation of otherwise incurable mitochondrial disorders, under strict regulation"

said Dr Watts.

"Other germline therapies, including different techniques which would act on the nuclear genome, would involve further ethical considerations and would need to be considered separately. Future policy debates would benefit from a fuller discussion of the ethics of prospective and theoretical germline therapies than was possible within the remit of this particular report."

The Council's report finds that no strong social or cultural emphasis is generally placed on mitochondrial inheritance as a specific element of personal identity. Many of the social and biological aspects which typically imply a 'parent', and may be relevant in egg donation for reproduction, do not apply to mitochondrial donation. The Council therefore suggests that if the treatments were made available, mitochondrial donors should not have the same status in regulation as reproductive egg donors. This would mean, for example, that it should not be legally required for mitochondrial donors to be identifiable to the people born from their donation.

Clinical geneticist and member of the Working Group Professor Frances Flinter said: "Whilst these children would have a genetic connection to three people, only 0.1% of their DNA would come from the donor and 99.9% of their DNA from their parents. As far as we know, mitochondrial genes alone create no unique identifiable genetic link between the child and donor. The child's recognisable likeness to family members would come from their parents' nuclear DNA. Given these, and other reasons, we think it is both legally and biologically inaccurate to refer to a mitochondrial donor as a 'second mother' or 'third parent' to the child."

Provided by Newcastle University

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