



MitoNews UK



Oxford University Hospitals NHS Trust



Specialised Services

Issue 7 - Special Edition

Welcome.....

Welcome to this special edition of mitonews. The advances in mitochondrial research have recently been publicised on the television, radio and in newspapers. Please use the following link to read an article featured in the Guardian Newspaper <http://tinyurl.com/6vfp89g>



Professor Doug Turnbull

Scientists at Newcastle University 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.

In this issue we will explain more about the recent publicity and provide information about what happens next as we move forward with our research to prevent the transmission of mitochondrial disorders.

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Websites

The Rare Mitochondrial Disease Service for Adults and Children:

www.mitochondrialncg.nhs.uk

Muscular Dystrophy Campaign

www.muscular-dystrophy.org

Treat NMD

www.treatnmd.eu

CLIMB

www.climb.org.uk

We Move

www.wemove.org

The Lily Foundation

www.thelilyfoundation.org.uk

The Ryan Stanford Appeal www.ryanstanfordappeal.org.uk

Mitochondrial Technique is Ethical

On the 19th January 2012 the **Nuffield Council on Bioethics** launched a call for evidence on the ethical issues raised by techniques to prevent the transmission of inherited mitochondrial disorders. At present, there are no known cures for these disorders, which can cause severe symptoms such as heart failure, liver failure and blindness, and may cause death in babies, children and young people.

Research is currently at an experimental stage on these techniques, which use healthy mitochondria from a donor to replace the mother's unhealthy mitochondria at the point of reproduction. We wrote to you earlier in the year as the working party wanted to hear from affected families, medical professionals and anyone who has an interest in this area. Professor Turnbull and the team would like to extend their thanks to everyone who contributed their views.

The responses were considered by a working group and a report was published on the 12th June 2012. The Nuffield Council on Bioethics announced in the report that the technique would be an ethical treatment option for affected families, provided research shows that treatment is likely to be safe and effective, and families are offered full information and support. **Extract from the Nuffield Council on Bioethics Press Release 12.6.12.**

If you would like to read the full report from the Nuffield Council on Bioethics please use the following link:

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

Press Coverage

There has been both positive and opposing views following the report by the Nuffield Council on Bioethics.

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."



Professor Alison Murdoch

Sir Mark Walport, Director of the Wellcome Trust said: "I am delighted to see that its report has found use of the techniques ethical. We urge the government to outline a timetable for considering amendments to legislation to permit use of the techniques in the clinic if, as we hope, the Human Fertility and Embryology Authority's consultation in autumn shows public support for this important technology."

Extract from the BBC News Website 12.6.12

One of the opposing views was from Dr David King, director of Human Genetics Alert, who said: 'the proposed techniques are both unnecessary, and highly dangerous in the medium term, since they set a precedent for allowing the creation of genetically modified designer babies.'" **Extract from the BBC News Website 12.6.12**

The Next Steps

The **Human Fertilisation and Embryology Authority (HFEA)** is the UK's independent regulator of treatment and research involving human embryos. The **HFEA** want to involve the public through an open and independent consultation to understand the full range of views about new techniques to avoid mitochondrial disease. The public consultation will launch in **September 2012**, as part of a wider programme of engagement. The calendar of events is detailed below.

Date	Event
June 2012	The HFEA will be carrying out a survey to measure public attitudes about the issues involved.
July 2012	The HFEA will hold a series of dialogue events where members of the public will be invited to share their views. This will take place across the UK and will give members of the public the opportunity to discuss the issues in more depth.
September 2012	The HFEA will launch a website containing information, videos and background reading on the issues around mitochondrial disease and emerging techniques designed to prevent the disease. People will be invited to feed in their views via a survey on the HFEA website.
October 2012	The HFEA will hold a series of discussion events with the public. This will be a chance for people to come together to explore the issues and share their views.
2013	The HFEA plan to publish their findings in 2013. You can register now, or at any time before then, to receive updates about the engagement programme by emailing: mitochondria@hfea.gov.uk .

Get involved

If you'd like to find out more or to get involved in the consultation process, please email mitochondria@hfea.gov.uk, with 'subscribe' in the subject line. Please also visit the HFEA website for more information: <http://www.hfea.gov.uk/>