



MitoNews UK



Oxford University Hospitals NHS Trust



Specialised Services

Issue 9 - 2013

Welcome

Welcome to the latest issue of MitoNews UK, our newsletter for patients with mitochondrial disease. We want to thank everyone who supported the Human Fertilisation and Embryology Authority (HFEA) public consultation at the end of last year. On the 20th March the HFEA publicised its findings which showed general public support for mitochondria replacement being made available to families at risk of passing on a serious mitochondrial disease. Read the full article in this edition!



The Lily Foundation have created a bespoke educational animation to explain how vital Mitochondria are to sustain life, and also what happens when they go wrong. Please visit The Lily Foundation website to watch the video: www.thelilyfoundation.org.uk.

If you have any feedback or suggestions for future issues of the newsletter, or if you would like an article to be included please email the team at: mitonews@ncl.ac.uk

Dates for your Diary...

The new Wellcome Trust Centre for Mitochondrial Research Website will be launched soon! We hope you will find the website informative!

Further details will be sent out soon!



Useful Contact Information

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Oxford

Julie Phipps, Clinical Genetics Research Nurse

Email: Julie.Phipps@ouh.nhs.uk

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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

Pioneering IVF technique supported by the public

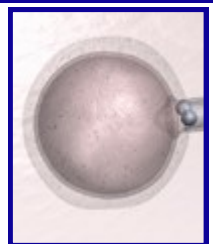
On the 20th March 2013, following a six-month public consultation, the Human Fertilisation and Embryology Authority (HFEA) announced its findings which showed general public support for mitochondria replacement being made available to families at risk of passing on a serious mitochondrial disease. The HFEA will now pass these recommendations to the Government.

A team of researchers at Newcastle University, leading on the development of the technique in humans, aims to prevent the transmission of maternally inherited mitochondrial disorders. Mitochondria are required to produce the energy that powers our cells, therefore vital for all the major organs of our body to function properly. Around one in 6,500 children are born with severe mitochondrial diseases, which include muscular weakness, blindness, fatal heart failure, liver failure, learning disability and diabetes that can lead to death in early infancy.

Parliament must now decide whether those who carry the risk of transmitting mitochondrial disease will be able to be treated in the UK. Reacting to the announcement by the HFEA, Professor Doug Turnbull, Professor of Neurology and Director of the Wellcome Trust Centre for Mitochondrial Research at Newcastle University said:

"Mitochondrial DNA disease runs in families and there is no cure. The techniques we are working on here in Newcastle, could help hundreds of women have healthy children. We are very grateful for the detailed public engagement exercise carried out by the HFEA and welcome the supportive views of most of the public. We understand that more research is required but believe it is crucial that the Government moves now to draft the regulations so that mitochondrial patients in the UK will have access to this treatment."

This article was published on the 20th March by the Newcastle University Press Office. To read the full press release please click on the following link: <http://www.ncl.ac.uk/press.office/press.release/item/pioneering-ivf-technique-supported-by-public>.



Changes to Disability Living Allowance

As many of you will know there are changes planned for **Disability Living Allowance** from April 2013. For working age claimants it will be replaced by **Personal Independence Payment (PIP)**. For those of you already getting DLA it will be a while before you are invited to claim for PIP.

From 8 April 2013 - An initial pilot of a few thousand new PIP claims in the North West and parts of the North East of England. No existing DLA claimants will be asked to claim PIP at this point.

From June 2013 - New claims to PIP will be taken in all remaining areas of Great Britain. The DWP will not accept new claims for DLA from anyone aged 16-64, unless they are making a renewal claim from a fixed term DLA award which is due to expire before the end of February 2014.

From October 2013 - The following DLA recipients will begin to be invited to claim PIP:

- Children turning 16 (unless the child is terminally ill)
- People reporting changes of circumstances which would affect their rate of payment (this does not include payability decisions as a result of going into a care home, hospital or prison or other changes of circumstances e.g. change of address). The rate of DLA will not be adjusted;
- Fixed-term DLA award recipients whose award expires from the end of February 2014 (reassessment activity starts approximately 20 weeks before existing DLA awards end); and
- Self-selectors (includes those with indefinite or fixed-term awards).

From October 2015 - All the remaining claimants in receipt of a DLA award will be invited to make a claim for PIP. DWP will randomly select those recipients of DLA in receipt of an indefinite award or a fixed term award, and notify them about what they need to do to claim PIP. DWP will invite claims as early as possible from recipients who have turned 65 after 8 April 2013, when PIP was first introduced.

How do you qualify?

In order to qualify for PIP you will have to score a certain number of points in relation to 12 activities.

There's lots of information on the web – please visit the following link for full information on the descriptors:

<http://www.disabilityrightsuk.org/f60.htm>

Meanwhile don't panic! Get advice when you get your application form and remember that it is always better to put in a letter of support from your consultant at the outset. Please contact **Rosemary Bell, Welfare Rights Advisor, for more information: 07702 665338.**

The MRC Mitochondrial Diseases Patient Cohort Study UK has now reached it's target of **1000 patients!** The MitoCohort has become a template for similar projects worldwide, which will ultimately lead to a better understanding of mitochondrial disease and develop strategies to treat the condition.

Please visit our **MitoCohort website** to find out more information about the cohort: <http://mitocohort.ncl.ac.uk>

West Highland Challenge!

On the 13th October 2012 Gayle Purdie and two of her friends, set off to walk the West Highland Way in Scotland. The challenge was to walk 96 miles over 7 days starting in Milngavie and finishing in Fort William.

Gayle wanted to complete the walk to raise money for mitochondrial myopathy. Gayle hopes that it will help to fund research that will one day find a cure for



Gayle Purdie
(pictured above)



Pictured from left: Dr Grainne Gorman, Susan Warnock, Professor Doug Turnbull, Gayle Purdie and Sr Catherine Feeny.

Gayle and Susan visited Newcastle University to present the cheque to Professor Doug Turnbull and the team. The team are incredibly grateful and the donation will be used to fund research and provide better care for patients who have mitochondrial disease.

this illness and help her inspirational friend Susan.

The walk was extremely challenging, however Gayle successfully completed it and raised £1182.63 for mitochondrial research.

Mito Adult Support - Facebook Group

Two of our patients, Susan Warnock and Laura Jakubowski, have set up a support group on Facebook for adults with mitochondrial disease.



Please search Mito Adult Support on Facebook: www.facebook.com and request to join the group.

Team Talk - Heather Moore, PhD Student

I studied Psychology at the University of York and then completed a Masters at Durham University in Cognitive Neuroscience, before starting my PhD at Newcastle University in the Wellcome Trust Centre for Mitochondrial Research.



I am looking at cognitive functioning (thinking processes, such as language and memory) in patients with mitochondrial disease. My study is an 18 month study comparing patients to matched control participants. Recruitment has gone well and I have all of the patient volunteers that I need. I am now recruiting volunteers without mitochondrial disease to act as controls in the study.