



MitoNews UK



Oxford University Hospitals NHS Trust



Specialised Services

Issue 10 - 2013

Welcome

Welcome to the latest issue of MitoNews UK, our newsletter for patients with mitochondrial disease. In this edition we are delighted to announce the launch of our new website and will give you details on how to access this, we will tell you about the exciting announcement by the government which will radically impact the future care for patients with mitochondrial disease and also have details of our annual patient information day.



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. This video will be used nationally to help educate and raise awareness of Mitochondrial Disease. To watch the video please visit the website: www.thelilyfoundation.org.uk

If you no longer wish to receive MitoNews, or would prefer to receive it by email, please complete the enclosed slip and return it to Sister Catherine Feeney (Newcastle University)

Dates for your Diary...

Patient information Day
Friday 18th October 2013
3pm-7.00pm
Newcastle University
For information and to book a place please contact Professor Turnbull's secretaries Tel: 0191 2820340



Useful Contact Information

Newcastle upon Tyne

Specialist Nurse Tel: 0191 282 1740

Address: The Medical School,
Newcastle University, NE2 4HH

London

Specialist Nurse Tel: 0203 448 8009

Address: 8-11 Queens Square,
London, WC1N 3BG

Oxford

Julie Phipps, Clinical Genetics Research Nurse

Email: Julie.Phipps@ouh.nhs.uk

Address: Churchill Hospital, Headington,
Oxford, OX3 7LJ

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

Law change for pioneering IVF technique

On the 28th June this year, the Chief Medical Officer outlined support for a change in the law, which would allow an IVF technique to eliminate mitochondrial disease, to be used in patients. The techniques have been developed in human eggs by Professor Doug Turnbull and Professor Mary Herbert at Newcastle University.

Reacting to the announcement, Professor Turnbull, Director of the Wellcome Trust Centre for Mitochondrial Research at Newcastle University said: "I am delighted that the Government is moving forward with publishing draft regulations this year and a final version for debate in Parliament next year. This is excellent news for families with mitochondrial disease. This will give women who carry these diseased genes more reproductive choice and the opportunity to have children free of mitochondrial disease. I am very grateful to all those who have supported this work."



Alison Murdoch, Professor of Reproductive Medicine at Newcastle University, part of the team which has developed the technique added: "This is great news for UK science and gives hope to women who just want a healthy baby. The UK government has made a moral decision. "The death of a baby is a parent's worst nightmare. Our research is leading to a pioneering IVF technology to reduce that risk for mothers who have abnormal mitochondria. There is still more research to do, but this decision means that we could eventually be allowed to offer it as a treatment."

To receive more information in relation to egg donation: please visit the website: www.ncl.ac.uk/eggdonate

New website launches!

www.mitoresearch.org.uk



We are delighted to announce the launch of the new Wellcome Trust Centre for Mitochondrial Research website! We are very committed to keeping patients and families fully informed of new advances in mitochondrial research and explaining the complexities of mitochondrial disease. The website is part of our initiative in this area and we want to make sure that everyone finds coming to the website is helpful and informative. Over the next few years we will be developing new videos to explain mitochondrial disease and are constantly looking at new ways to explain mitochondrial disease. We are very keen to hear what you think about the website. Please email mitonews@ncl.ac.uk with your comments and let us know how we can improve.

The site is split into different areas:

Public/ Patient

- *Discover what mitochondria do and find out what mitochondrial disease is.*
- *Look out for interesting events that are coming up and how you can get involved.*

Science

- *Learn about the world class science that is taking place in the centre*
- *Learn about the latest scientific developments in mitochondrial research*

Research Teams

- *Meet the multidisciplinary team in the Wellcome Trust Centre for Mitochondrial Research*
- *Discover more about the research projects that the team are involved in.*

Services

- *Find out what happens in the NHS Mitochondrial Diagnostic Laboratory*
- *Information specifically for women is available and there are patient care guidelines which can be downloaded*

Fundraising - Dee's Story -

"Me and my husband Gareth have a 3 year old daughter Penny and we had a baby boy, Ted, in November 2012. He was perfect and brought us so much happiness, completing our little family. After a few months of newborn bliss we were devastated to find out that Ted had a mitochondrial disease. We all remained positive and spent our every moment with our wonderful baby boy when he was in and out of hospital but sadly we lost him when he was 5½ months. Our aim now is to focus on something positive by raising money for the Mitochondrial Research Fund



and help to raise awareness of mitochondrial disease. On July 20th we held a vintage bake sale, it was a fantastic day and we raised £1005! We were completely amazed at how well we did and feel so overwhelmed at the amazing turnout and generosity of everyone! We hope that

Newcastle University mitochondrial research fund is pleased with our fundraising. We are doing it in memory of our beautiful baby boy Ted and hope that we are making him proud!"

Team Talk - Susan Clark Speech and Language Therapist

I graduated in Speech Therapy from The Central School of Speech and Drama in London.

I worked for 2 years at The Glenrose Rehabilitation Hospital in Edmonton Alberta Canada before returning to the UK.

After working for a short time in London I moved to Newcastle General Hospital where I developed my interest in Neurology, helped by the inspiration gained from working under the then Dr John Walton.

I obtained my Masters in 1993 "Arterio- Venous Malformations and their affect on speech" under the supervision of Prof David Mendelow consultant Neurosurgeon. I continued to specialise in acute Neurology and was appointed as Speech and Language Therapist to the Mitochondrial Service in 2007.

