



MitoNews UK



MRC Centre for Neuro-muscular Diseases



Oxford University Hospitals NHS Trust



Specialised Services

Issue 4- Winter 2011

Welcome.....

Welcome to the fourth issue of MitoNews UK, our newsletter for patients with mitochondrial disease. We hope that you had a peaceful Christmas and New Year.

In this edition find out more about our international meeting in Washington DC. There is information about how you can get involved in a new exercise study and read about our researchers who set up an exhibition called 'Meet the Scientist' at the International Centre for Life in Newcastle.

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

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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

Dates for your Diary...

- The Lily Foundation Annual Ball - Saturday 25th March 2012 - visit the Lily Foundation website for further details.
- Mitochondrial Research Open day at Newcastle University - April 2012. Further details will follow.



Meet the Scientist!

During October half term, 10 researchers from the Mitochondrial Research Group took part in 'Meet the Scientist' at the Centre for Life. They were invited to do this following on from the success of a number of researchers in another activity – 'I'm a Scientist – Get me out of here!' One of the researchers won this activity and the prize from this competition, funded by the Medical Research Council, allowed this exhibition to take place.

They set up an exhibition which took visitors on a journey from the brain to brain cells, then into the cells to look at mitochondria and mitochondrial DNA. Visitors to the exhibition were led on their journey by 'Mitoman' and his side kick, 'ATP'. They could find out what their brains feel like, look at some brain cells under the microscope, delve through the DNA of a cell to find the elusive mitochondrial DNA and even have a go at one of the techniques we use to look at mitochondrial DNA in the lab.

The exhibition was a great success and there was a constant stream of visitors of all ages. All the scientists thoroughly enjoyed the opportunity to talk to members of the public about their work and explain to some of the younger generations why our brains and mitochondria are so fascinating. We have been invited back again next year and hope that it will be as much of a success as it was this year!



Pictured above from left to right: Mr Paul Keane, Dr Amy Reeve, Dr Beth Stoll and centre: Mr Oliver Russell.

Are you ready to Exercise?

The Mitochondrial Research Group is excited to announce a new exercise study for 2012. If you have a mitochondrial disease, the Research Team would like to find out more about your barriers to exercise and how they can help optimise the benefits of exercise for you.



Are you:-

- Over 18 years old
 - Able to walk with or without a walking aid
 - Able to commit to a 16 week exercise programme?
- If your answer to these questions is 'Yes' and you would like to find out more please telephone Katherine Jones (ACSM Exercise Specialist pictured) on **0191 222 3009**.

Fundraising News

On Monday 5th December Mr and Mrs Hogg visited Prof Doug Turnbull and his team in Newcastle to present a number of cheques totalling £1000. This kind donation to Mitochondrial Research was in memory of their son Philip, who sadly passed away from mitochondrial disease earlier in the year.

The very generous donation will be used both to fund research and to provide better care for patients with mitochondrial disease.

MRC Centre for Translational Research in Neuromuscular Disease

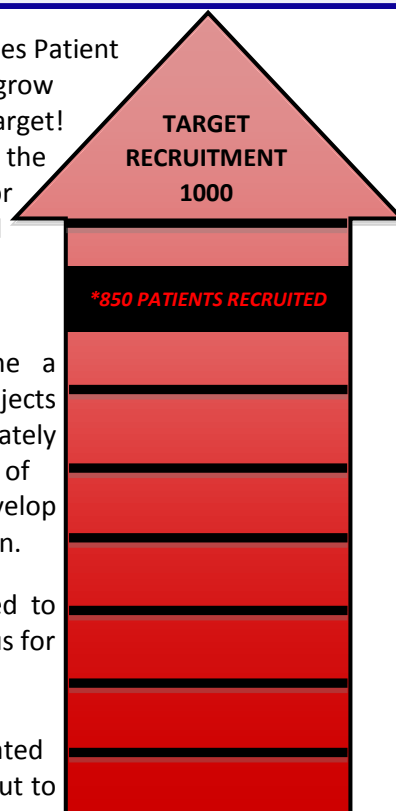
Mitochondrial Disease Patient Cohort

The MRC Mitochondrial Diseases Patient Cohort Study UK continues to grow and we are close to reaching target! We have been praised by the Medical Research Council for our efforts, and are so grateful to those of you who have registered.

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.

If you have not yet registered to this database, please contact us for further details.

We now have a website dedicated to the MitoCohort - check it out to find out more about the cohort and how it is being used to improve the management of patients with mitochondrial disease: <http://mitocohort.ncl.ac.uk>



International Meeting in Washington DC

Thanks to the kind support of the J. Willard and Alice S. Marriott Foundation, Prof Turnbull and his team were able to organise an international two day meeting in Washington DC on the 20th & 21st October this year. The meeting, jointly hosted by Professors Turnbull, Di Mauro and Hirano (both from New York) and Dr Stephen Hersh from Washington, brought together mitochondrial disease experts from around the world, with the specific aim of developing better standards of care for patients with mitochondrial disease.

Lots of issues relevant to patients were discussed at the meeting including clinical trials, guidelines for best care in mitochondrial disease, an international patient database, genetic counseling and identifying potential treatments. The meeting was very successful, with agreement reached in all of these areas and plans to form smaller working groups of experts to drive forward progress over the next 18 months. The Newcastle team returned jet-lagged, but very pleased to have been leading this successful initiative for patients!

Team Talk - Dr Roger Whittaker, Consultant Clinical Neurophysiologist



I am a Consultant Clinical Neurophysiologist at the RVI. Neurophysiology means the study of how the nervous system and the muscles are working. We have several different types of test that we use to measure the function of different parts of the nervous system. Many of you will have been for brain wave recordings (EEG) or tests of the peripheral nerves and muscles (nerve conduction studies and electromyography or EMG).

My own research interest is how problems with mitochondria can affect the working of the nervous system. Nerves and muscles need a lot of energy, and so are commonly affected in mitochondrial diseases. I am involved in a number of research projects to try to understand how this happens, particularly why patients with mitochondrial disease experience so much fatigue, and also in trying to predict who might be at risk of developing epilepsy.

We want to hear your news! If you have a story you would like to share or if you have any feedback about our fourth issue please email: mitonews@ncl.ac.uk