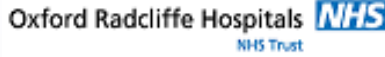
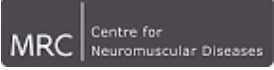




MitoNews UK



Specialised Services



Issue 3 - Autumn 2011

Welcome.....

Welcome to the third issue of MitoNews UK, our newsletter for patients with mitochondrial disease. Find out more about how mitochondrial disease affects the heart and how you can get involved in a research study.

The Patient Information Day in Oxford was a success and it was great to meet those who attended. We hope that you found the event useful.

This Autumn we are advising that all patients clinically affected by mitochondrial disease have the seasonal 'flu' vaccine, which should be offered by your GP.

If you have any feedback or suggestions for future issues of the newsletter, or an article to be included in future issues please email the team at:

mitonews@ncl.ac.uk

Useful Contact Information

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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

Dates for your Diary...

• The Lily Foundation Annual Ball -
Saturday 25th March 2012 - visit
the Lily Foundation website for
further details.

• Mitochondrial Open day at
Newcastle University - Spring 2012



Running for Research



As reported in the last edition of MitoNews, the Ryan Stanford Appeal www.ryanstanfordappeal.org.uk is a charity established by David and Anne Stanford, Ryan's parents, to raise funds for research into understanding the causes of Alpers' syndrome, a neurodegenerative mitochondrial disease affecting children.

The picture on the left shows David Stanford (left), together with friend Jaclyn Redman (middle) and Prof Rob Taylor from the Newcastle Mitochondrial laboratory (right) before completing the Great North Run in Newcastle recently, through which they collectively raised over £2,500 towards the continuing research being carried out in Newcastle.

Having completed the run, David and Anne – pictured with Ryan – came into the Medical School to meet the Newcastle team and present them with a cheque towards the funding of the "Fight Alpers" research project. We are very grateful for their continuing support, and that of all patients and their families whose donations fund ongoing research projects into understanding the causes of mitochondrial disease and developing treatments.



Pictured left to right: Dr Robert McFarland, Professor Doug Turnbull, Mrs Anne Stanford, Ryan Stanford, Mr Dave Stanford, Miss Helen Bogle (PhD student) and Professor Rob Taylor.

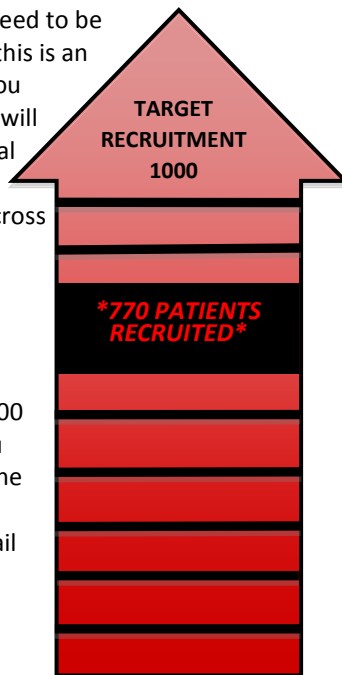
MRC Centre for Translational Research in Neuromuscular Disease

Mitochondrial Disease Patient Cohort (MitoCohort UK)

A big thank you to those who have agreed to be part of the MitoCohort. As you know this is an anonymised computer record about you and your mitochondrial disease which will help us learn more about mitochondrial disease progression, and to develop best standards of care for patients across the country. It is also a means of readily identifying patients who may be suitable for clinical trials in the future.

We are even closer to our target of 1000 patients, with **770** now enrolled. If you have not yet consented to be part of the MitoCohort, but would like to do so, please contact us in Newcastle or email mitonews@ncl.ac.uk and we will arrange for information and consent forms to be sent to you.

<http://mitocohort.ncl.ac.uk>



Fundraising News



Pictured above from left to right: Mrs Jane Brown, Mrs Bernadette Caygill, Mrs Margaret Short, Specialist Nurse Catherine Feeney and Mrs Sue Callender.

Mrs Margaret Short, mother of Kevin Short, who has sadly passed away, kindly donated a cheque for £250 towards mitochondrial research. Kevin Short sadly lost his battle with the disease earlier this year. Mrs Short visited the Newcastle University Research Labs and met members of the team.

Professor Turnbull and the team are very grateful for the generous donation and will continue to work very hard to try and improve the lives of patients with mitochondrial disease.

Heart of the matter

Mitochondrial disease can affect many different organs of the body, including the heart which has a high demand for energy. Different aspects of the heart, including its rhythm or its pumping function, can be affected but we know little about how or why this occurs.

We are currently running a study that looks very closely at the structure and function of the heart in patients with two common mitochondrial DNA (mtDNA) mutations— those that most frequently cause MELAS (3243) and MERRF (8344). We are using magnetic resonance imaging (MRI) to study both the movement of the heart and the energy levels within it. We hope to be able to identify early evidence of heart involvement so that we can start treatment for heart disease at the earliest opportunity.

Another aspect of the study looks at how the heart responds to the endurance exercise that is often recommended to people with mitochondrial disease. So far we have scanned 19 people but we need a few more people to complete the study. If you're interested, please feel free to contact me on 0191 222 3007 or send an email to: matthew.bates@ncl.ac.uk



The exercise bike in action.

Pictured from left to right: Djordje Jakovljevic, Christian Thoma and Sarah Moore who are part of the MoveLab team.

Team Talk

Jane Newman, Physiotherapist, Newcastle



I qualified as a physiotherapist in 1987 and have worked within the field of Neurology for nearly 20 years. I first became involved with patients with mitochondrial disease whilst working on the Regional Neurology ward at the Royal Victoria Infirmary. At this time I was involved in an exercise trial with some colleagues in the Institute for Exercise and Environmental Medicine in Dallas. This triggered my interest in this group of patients and the possibilities of being involved in research. I am currently working on two trials looking at the effect of exercise in mitochondrial disease and I am also involved in devising clinical guidelines for the physiotherapy management of patients with mitochondrial disease.

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