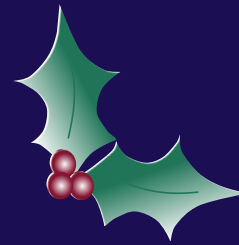


# MITO NEWS



## Lily Family weekend

Patients with mitochondrial disease, along with their families, came together at the Lily family weekend for a weekend of family fun and interactive seminars. We were very pleased to be part of this fantastic weekend. For more information about the Lily foundation please see their website: [thelilyfoundation.org.uk](http://thelilyfoundation.org.uk)



## Engaging with future researchers and members of the medical community



We have been raising awareness of Mitochondrial disease to doctors of the future by running a session at Newcastle University's mini med school. Prof. Chrzanowska-Lightowlers, and Drs Amy Reeve, Lyndsey Craven-Butterworth and Julie Murphy gave talks on mitochondrial biology and Medicine. We have been raising awareness of Mitochondrial disease to the future medical community by speaking to over 600 postgraduate students at the North east post graduate conference (NEPG). This conference is the UK's largest annual postgraduate conference for medical biosciences. Young researchers Christie Waddington, Nicole Mai, and Pavandeep Rai from our Centre helped to make sure mitochondria and mitochondrial disease was a major focus of the day.

## International collaborations

Clinicians and Scientists from the Centre at Newcastle have recently returned from a trip to Hong Kong, funded and supported by a Newcastle University Strategic Internationalisation award and the Joshua Hellmann Foundation, where they delivered a series of lectures and talks to over 150 clinicians and scientists (right top).

Professor Yasutoshi Koga (President of the Japanese Society of Mitochondrial Research) together with Dr Tatsuya Fujii (paediatric neurologist and the president of Shiga Medical Center for Children, Japan) visited our Centre earlier this month to learn about research going on within the centre and to develop collaborations with the research team (right bottom).





## Patient perspective



"Hello, I'm David Freeman aged 30 and I live in Edinburgh. I have a mitochondrial disease - MERRF. Up until the age of 18 I was doing everything a normal boy would do - dating, clubbing, driving, working and going on holiday with my mates. Then things began to change - it started with myoclonic jerks, losing my balance, my muscles started to feel weak and I felt tired. Even so, I managed to achieve Higher National Diploma in Construction Management in 2006. I also lost my eyesight - very depressing - but through the love and support of family, friends and specialists it gradually returned, which is amazing. Good things can happen if you don't give up. I enjoy going to the gym on a regular basis and have made good friends with the coaches." David has kindly come up with the following hash tag for us to use on Twitter over the Christmas period:

**#Whatsamitowithme**

## Researchers perspective

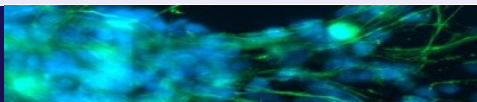
I'm Alex Bright and I'm the Research Nurse for the Newcastle Mitochondrial Research Group. I've worked in Neurology for nearly 20 years, the last 3 of these in the Mitochondrial Research Group. My job is really varied, I'm able to see patients in our clinics and I also travel the country, visiting families for the Lily Foundation Exome Sequencing Study. It's great to meet everybody in clinic and have the opportunity to discuss our current and upcoming studies, made possible by our patients' participation in the Mitochondrial Cohort.

***I'd like to thank all of our patients and their families for their support and interest in Mitochondrial Research..... you're amazing!***

***Best Wishes for Christmas and 2016, Alex.***



## MITOART



***Corinne Lewis-Ward is a local artist who is looking to meet and chat with patients, friends and family members who are affected by Mitochondrial Disease. Sessions are about sharing experiences, and possibly making some art!! All art activities are accessible to a wide range of abilities and require no training or qualifications in order to get beautiful results. If you live within the Newcastle area and would like to come in for the sessions or are simply curious to find out what is going on, please contact us at the Newcastle email/postal address at the bottom of this page. Alternatively if you cannot make the sessions/don't live in the Newcastle area but would like to display some of your own art work in a new area of our website please send a copy of your work to us to display along with a few lines about yourself or your work that can be published online. All ages, abilities or types of work welcome.***

**Please remember to have your flu jab if you haven't already!**

### Useful contacts

#### Newcastle upon Tyne

Specialist Nurse Tel: 0191 2821740

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

#### London

Specialist Nurse Tel: 0203 4488009

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

### Websites

The Rare Mitochondrial Disease Service for Adults and Children: <http://www.newcastle-mitochondria.com>

Muscular Dystrophy Campaign [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)

Treat NMD [www.treatnmd.eu](http://www.treatnmd.eu)

CLIMB [www.climb.org.uk](http://www.climb.org.uk)

We Move [www.wemove.org](http://www.wemove.org)

The Lily Foundation [www.thelilyfoundation.org.uk](http://www.thelilyfoundation.org.uk)

The Ryan Stanford Appeal [www.ryanstanfordappeal.org.uk](http://www.ryanstanfordappeal.org.uk)

For updates, please like and follow us on Facebook or Twitter by searching for Mitoresearch.

Alternatively please get in touch with us at: [mrg.socialmedia@newcastle.ac.uk](mailto:mrg.socialmedia@newcastle.ac.uk)