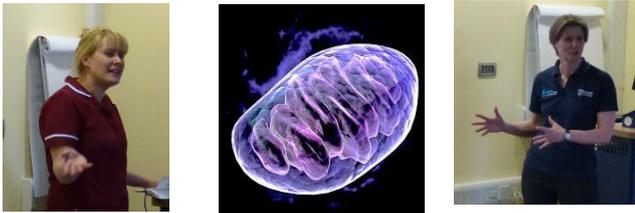


# MITOCHONDRIAL RESEARCH MATTERS EVENT

Wednesday 16<sup>th</sup> March 2016



Patients and their relatives / carers from the **North East Region** were invited to celebrate their involvement in mitochondrial research.

We showcased some of the most recent clinical research conducted by our team, *to give feedback on past studies.*



For any queries please contact:

**Senior Research Nurse**

**Alex Bright**

Wellcome Trust Centre for  
Mitochondrial Research  
Mitochondrial Research Group

Medical School

Newcastle University

NE2 4HH

Tel:

**0191 208 3008**

Email:

[Alexandra.Bright@newcastle.ac.uk](mailto:Alexandra.Bright@newcastle.ac.uk)

**It was a great opportunity...**

- To meet other patients
- To meet the wider research team
- To have questions answered
- For patients to feel valued for their contribution to research
- To raise awareness of mitochondrial research

# Studies We Presented

## **Incidence of complications of pregnancy in patients with Mitochondrial Disease**

The main aim of the study was to capture information on the risk of complications in pregnancy in women with mitochondrial disease. To do this, Catherine looked at women with a mitochondrial diagnosis and women without.

### **Results**

Women with mitochondrial disease are at greater risk of complications in pregnancy such as:

- \* Gestational diabetes
- \* Premature delivery <37 weeks
- \* Increased likelihood of surgical delivery
- \* Low birth weight babies- SCBU

### **How we plan to improve care in the future as a result of this study?**

- \* Pre pregnancy counselling
- \* Active pregnancy management
- \* Delivery plan
- \* Post-natal care



*'Catherine would like to thank everyone who took part in her study'*

## **Memory in Mitochondrial Disease**

The main aim of the study was to assess cognitive ability in patients with mitochondrial disease and those without. To do this, Heather and Alex together, conducted memory tests and questionnaires with people who took part.

### **Results**

This research showed that some patients had memory problems but their memory was fine when using a memory cue or prompt. The memory ability of patients were the same as volunteers who were of the same age and had similar abilities in childhood.



### **How we can improve our practice as a result of this study?**

- \* Share information with you differently
- \* Memory Monitoring

### **How you can help yourself?**

- \* use memory aids to make it easier to remember
- \* help your children in future by giving them support in their education and development now

*'Many thanks from Heather. Your time was much appreciated'*

## **The effect of aerobic exercise on cardiac function and movement in people with Mitochondrial Disease**

The main aim of the study was to confirm that exercise was safe in patients with mitochondrial disease, especially with regards to heart function. To do this, Jane recruited patients with mitochondrial disease and people without.



### **Results**

- \* Reduced exercise capacity is linked to muscle function and is improved with exercise.
- \* Patients with mitochondrial disease achieved similar proportional benefits in exercise ability.
- \* There was no increase in fatigue with the exercise programme
- \* Walking in patients with mitochondrial disease has discrete differences to the control group

### **How we can improve our practice as a result of this study?**

- \* We can now fully endorse exercise as part of the management of mitochondrial disease.
- \* Work to improve how we assess exercise

*'Thank you for your time and effort'*

## Julia Maddison informed us that our Mitocohort helps:

\* Achieve rapid identification and recruitment of eligible patients to research studies

\* Understand how mitochondrial diseases progress over time



To date **1300** patients throughout the UK have consented to take part.  
Because of your participation...

A large number of published journals on all aspects of mitochondrial disease and care of patients

Evidence to support policy change:  
**Mitochondrial Donation**

Changes to UK clinical guidelines for the treatment of mitochondrial disease.

Recommendations for clinical care of mitochondrial patients worldwide

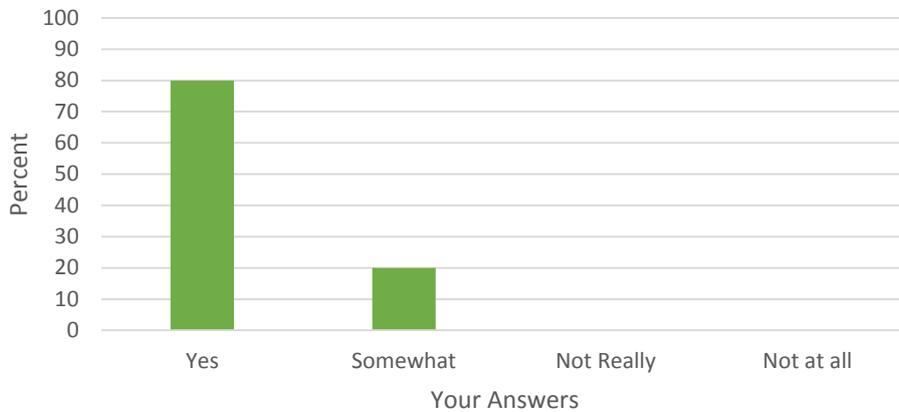
New research questions generated by results



**A Big Thank You to Everyone Who Joined Us**

# What you thought of the day...

## Has This Event Increased Your Awareness Of The Research Process?



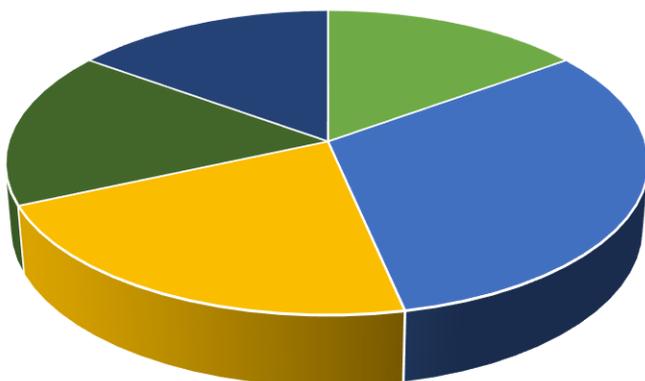
**'Definitely would attend future events'**

**'The presentations were excellent – they gave a lot of information in a short period of time'**

**'It is important for me to be kept informed'**



## What Did You Enjoy Most About The Day?



- Meeting other patients / networking
- A raised awareness of our research
- Feeling valued for my contribution to research
- Meeting the wider research team
- All of the above

**'I am a family member who was not too informed about this, but now it is much clearer'**