

MITOCHONDRIAL RESEARCH MATTERS EVENT

Wednesday 16th 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:

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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

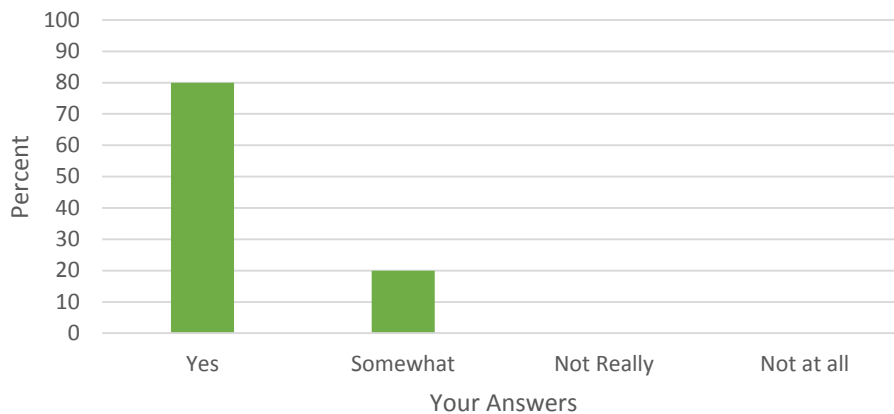
New research
questions
generated by
results



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?



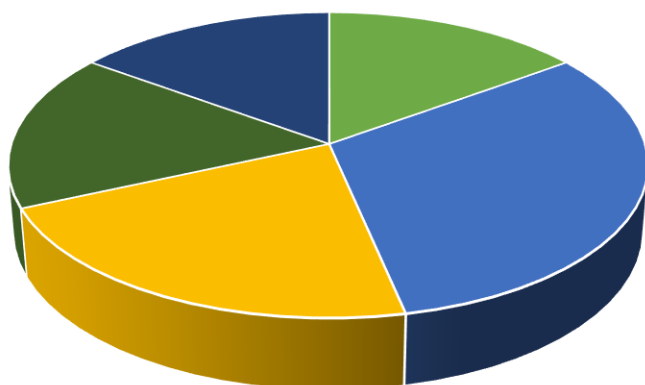
**'Definitely
would attend
future events'**

**'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'**