

Specialised Services

NHS Foundation Trust

National Specialised Commissioning
Team



PROGRAMME

Mitochondrial Patients Day

Saturday 6th July 2013 1.30pm - 5pm

Lecture Theatre, 33 Queen Square, London WC1N 3BG

Organised by Catherine Parry, Clinical Nurse Specialist on behalf of Professor MG Hanna and the Specialist Mitochondrial Clinical Service

1.30pm **Registration**

2pm **Introduction**

Professor Mike Hanna, Professor in Neurology, NHNN

2.15pm **Exercise is Medicine: its role in Mitochondrial Disease**

Liz Dewar, Clinical Specialist Physiotherapist in Neuromuscular Diseases

2.45pm **Do you suffer from fatigue?**

Claire Wells, Specialist Occupational Therapist, NHNN

3pm **Financial Support**

David Moore-Crouch, Campaigns, Information and Advocacy Officer, Muscular Dystrophy Campaign UK

3.15PM – 4PM – Information Stands and Refreshments

4pm **Breaking down the barriers – a case study report**

Cath Parry, Clinical Nurse Specialist, Neuromuscular Diseases, NHNN

4.20pm **Update on the Mitochondrial Disease patient Cohort Study UK**

Dr Rob Pitceathly, Clinical Research Fellow, UCL

4.30pm **General Question and Answer Session**

Led by Professor Mike Hanna, Professor in Neurology, NHNN

5pm **Close**

INFORMATION STANDS

- **Cohort study** – Dr Rob Pitceathly and Mariola Skorupinska, Clinical Research Nurse, NHNN
- **Mitochondrial genetic testing** – Dr Mary Sweeney, Dr Cathy Woodward and Dr Ese Mudanohwo
- **Investigating muscle mitochondria in bio chemistry** – Dr Iain Hargreaves
- **Therapy Services** – Liz Dewar – Senior Neuromuscular Physiotherapist, NHNN and Claire Wells – Senior Occupational Therapist, NHNN
- **Service development and patient participation**
Trish Turner, Executive Administrator, MRC Centre, NHNN
Mariola Skorupinska, Clinical Research Nurse, NHNN
Catherine Parry, Clinical Nurse Specialist, NHNN
- **Muscular Dystrophy Campaign UK**
David Moore-Crouch, Campaigns, Information and Advocacy Officer, Muscular Dystrophy Campaign UK