

Specialised Services

NHS Foundation Trust

National Specialised Commissioning
Team

MRC | Centre for
Neuromuscular Diseases

PROGRAMME

Mitochondrial Patients Day

Saturday 20th June 1.30pm - 5pm

Lecture Theatre, 33 Queen Square, London WC1N 3BG

Organised by Natalie James, 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 **The Neuromuscular Complex Care Centre (NMCCC) and Transition**

Dr Ros Quinlivan, Consultant in Neuromuscular Disorders

2.40pm **Exercise and service development ideas**

Sarah Holmes, Specialist Neuromuscular Physiotherapist, NHNN

Natalie James, Clinical Nurse Specialist, Neuromuscular Diseases, NHNN

3PM – 4PM – Information Stands and Refreshments

4pm **Patient involvement, sensory support in mitochondrial disease**

Natalie James, Clinical Nurse Specialist, Neuromuscular Diseases, NHNN

Sarah Holmes, Specialist Neuromuscular Physiotherapist, NHNN

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

Dr Enrico Bugadini, 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 Enrico Bugadini and Mariola Skorupinska, Clinical Research Nurse, NHNN
- **Mitochondrial genetic testing** – Dr Ese Mudanohwo
- **Investigating muscle mitochondria in bio chemistry** – Dr Iain Hargreaves
- **Service development and patient participation**
Sarah Holmes, Specialist Neuromuscular Physiotherapist, NHNN
Natalie James, Clinical Nurse Specialist, NHNN
Sally-Ann DeSouza, Senior NCG Secretary
- **Muscular Dystrophy UK**
Maddy Rees and Shivani Handa, Campaigns, Information and Advocacy Officers, Muscular Dystrophy UK