

# Provisional Conference Programme

(these details are correct at time of going to press, but may be subject to change)

## Friday 17 May Evening

6.00pm

**Evening Meal**

7.30pm

**followed by  
Annual General Meeting chaired by  
Professor Darren Monckton  
(Registration will be open for those attending the AGM)**

## Saturday 18 May Morning

8.30am

**Registration and refreshments on arrival**

9.30am

**Welcome by Michael Walker Chair of the Board of Trustees**

**Chair for the Day Professor Darren Monckton**

9.40am

**Welcome to Newcastle**

9.50am

**The Peter Harper Memorial Lecture: Dr Chris Turner  
"Hope for people with myotonic dystrophy"**

10.25am

**Research: Professor Darren Monckton and Glasgow Team**

11.00am

**Registry Update: Ms Helen Walker, Curator**

11.15am

**Refreshments** (during which the auditorium will be partitioned for workshops)

11.45am

**Workshops Session One**

12.30pm

**12.30 for 12.45pm Lunch**

## Saturday 18 May Afternoon

2.00pm

**Workshops Session Two**

3.00pm

**Workshops Session Three**

3.45pm

**Short Break** (during which the partitions in auditorium will be removed)

4.15pm

**"Why it is important to come to your annual neurology appointment"  
Dr Chiara Marini-Bettolo**

5.00pm

**Goodbye's**

**Workshops:** There will be three workshop sessions,  
one before lunch and two after.

The following workshops are being planned;  
Myotonic Dystrophy and the Brain—**Dr Mark Hamilton**  
Speech and Swallowing—**Jodi Allen**

DNA and Bananas—**Dr Sarah Cumming and Team**

Daytime Sleepiness—**Dr Chiara Marini-Bettolo**

Help with PIP forms—**Laura Hayward and Adrian Davey**

Exercise and Management—**Jassi Michell-Sodhi and Dr Valeria Di Leo**

Issues with the Heart—**Dr Chris Turner**

Questions and Answers—**Dr Richard Petty**

### **Speakers:**

**Professor Darren Monckton;** Research Professor of Human Genetics,  
(Molecular Biosciences) University of Glasgow

**Dr Chris Turner;** Consultant Neurologist, and Clinical Director, National Hospital,  
Queen Square, London

**Dr Richard Petty;** Retired Neurologist, Scotland

**Jodi Allen;** Clinical Specialist, Speech and Language Therapist, National Hospi-  
tal, Queen Square, London

**Dr Mark Hamilton;** Consultant Clinical Geneticist, University of Glasgow

**Dr Sarah Cumming;** Research Associate, Molecular Biosciences, University of  
Glasgow

**Dr Chiara Marini-Bettolo;** Consultant Neurologist and Principal Investigator for  
UK Myotonic Dystrophy Patient Registry, University of Newcastle

**Jassi Michell-Sodhi;** Neuromuscular Research Physiotherapist, University of  
Newcastle

**Dr Valeria Di Leo;** Research Associate, University of Newcastle

**Helen Walker;** Curator UK Myotonic Dystrophy Patient Registry

**Laura Hayward (MDSG Member) and Adrian Davey;** Digital Support Workers, at  
the charity, Connection Support, Oxford