

## **Duchenne UK Parent Information Day DRAFT AGENDA**

Saturday 4<sup>th</sup> March 2023

Holiday Inn Bloomsbury, Booker & Turner Suite, Coram Street, London, WC1N 1HT

9:00am – 4:30pm

Welcome tea and coffee: 9:00am

Meeting starts at 9:35am

**9:15am – 9:30am**

**[An introduction to newly diagnosed and first-time parents](#)**

Alex Johnson & Emily Reuben, Duchenne UK Founders

**9:35am – 9:50am**

**Session 1: Introduction and updates from Duchenne UK**

Alex Johnson & Emily Reuben

**9:50am – 10:00am**

**Session 2.1: Why we set up DMD Care UK and the aims of the project**

Alex Johnson & Cathy Turner, DMD Care UK Project Manager and TACT Coordinator

**10:00am – 10:20am**

**Session 2.2: DMD Care UK - Endocrine**

Dr Jarod Wong, Consultant Paediatric Endocrinologist, The Royal Hospital for Sick Children Glasgow

**10:20am – 10:30am**

**Session 2.3: DMD Care UK - Emergency**

Dr Vasantha Gowda, Consultant Paediatric Neurologist, Evelina London Children's Hospital

**10:30am – 10:40am**

**Questions**

**10:40am – 10:55am**

**Session 2.4: DMD Care UK - Respiratory**

Dr Anne-Marie Childs, Consultant Paediatric Neurologist, Leeds Teaching Hospitals

**10:55am – 11:10am**

**Session 2.5: DMD Care UK - Cardiac**

Dr John Bourke, Consultant Cardiologist & Senior Clinical Lecturer, John Walton Muscular Dystrophy Research Centre, Newcastle University

**11:10am – 11:20am**

**Questions**

**11:20am – 11:50am**

**Tea & coffee break**

**11:50am – 12:10pm****Session 2.6: DMD Care UK - Psychosocial Project**

Dr Dorothea Bindman, Consultant Psychiatrist, National Hospital for Neurology & Neurosurgery, University College London Hospitals NHS Trust

Dr Jatin Patni, Clinical Neuropsychologist, Centre for Neuromuscular Disease and Neuromuscular Complex Care Centre, Queen Square

Sheli Rodney, Duchenne Research Fund

Rory Conn

**12:10pm – 12:30pm****Session 2.7: DMD Care UK: Physiotherapy**

Dr Anna Mayhew, Consultant Research Physiotherapist, The John Walton Muscular Dystrophy Research Centre Newcastle University

**12:30pm – 12:45pm****Discussion & questions****12:45pm – 2:00pm****Lunch****1:15pm 1:55pm Breakout session****Education: Inflexible behaviour and communication, home & school**

Nick Catlin, Decipha

**2:00pm – 2:30pm****Session 3: Research updates & Gene therapy**

Dr Alessandra Gaeta, Duchenne UK Director of Research

**2:30pm – 3:00pm****Session 4: Steroids and Vamorolone with Q&A**

Dr Michela Guglieri, Senior Lecturer, Honorary Consultant in Human Genetics

The John Walton Muscular Dystrophy Research Centre Newcastle University

**3:00pm – 3:20pm****Session 5: Italfarmaco data**

Dr Michela Guglieri

**3:20pm – 3:50pm****Tea & coffee break****3:50pm – 4:10pm****Session 6: Open Forum**

Panel of parents and experts

**4:10pm – 4:20pm****Events & fundraising****4:20pm – 4:30pm****Closing remarks****Drinks reception at Callaghan's bar 4:30pm**