

Duchenne UK Parent Information Day DRAFT AGENDA

Saturday 1st October 2022

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, 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

Jatin Patni

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

Breakout sessions

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 – 4:20pm

Session 6: Open Forum

Panel of parents and experts

4:20pm – 4:30pm

Closing remarks

Drinks reception 4:30pm