

Programme



10.30 **Registration and Tea / Coffee**

10.45 Welcome
Wendy Edwards, Chair of the Board of Trustees, Headlines

Session 1

11.00 The “multi-faceted” role of a Craniofacial Nurse Specialist
Colette Turnock and Jane England, Craniofacial Nurse Specialists
Alder Hey Children’s Hospital, Liverpool

11.20 Coping with everyday challenges . . . and how clinical psychologists
can help
Helen Care, Clinical Psychologist
John Radcliffe Hospital, Oxford

11.40 Through the eyes of a father
John Connett, parent of child with Apert syndrome

Question Time

12.10 The role of speech and language therapy in craniofacial care
Susanna Carter and Zoe Healey, Specialist Speech and Language Therapists
Birmingham Children’s Hospital

12.30 Sing and Say: Web-based language stimulation app for children with
craniosynostosis – an update
Sarah Kilcoyne, Principal Specialist Speech and Language Therapist
John Radcliffe Hospital, Oxford

12.40 Biomechanics of craniosynostosis
Mehran Moazen, Lecturer in Biomedical Engineering
University College London

Question Time

13.00 **Lunch**

Session 2

14.00 Management of children with sagittal craniosynostosis in the designated UK craniofacial centres

Martin Evans, Consultant Maxillofacial and Craniofacial Surgeon
Birmingham Children's Hospital, University Hospital Birmingham

14.20 Intracranial pressure in craniosynostosis

Chris Parks, Consultant Paediatric Neurosurgeon
Alder Hey Children's Hospital, Liverpool

Question Time

14.50 Living with an appearance-altering condition: What can we learn from psychological research?

Nicola Stock, Research Psychology Fellow
Centre for Appearance Research, University of the West of England, Bristol

15.20 Mathematical development in children with Apert syndrome

Caroline Hilton, Lecturer in Primary Education (Mathematics)
University College London

Question Time

15.40 **Tea / Coffee**

Session 3

16.00 Genetic testing is evolving - a guide to what your geneticist is talking about

Emma McCann, Consultant Clinical Geneticist
Liverpool Women's Hospital FT and Liverpool Craniofacial Team

16.20 Public and patient involvement in information and research

Discussion group sessions:

1. Patient information leaflets
Emma McCann, Wendy Edwards and Justine Tweedie
2. Encouraging patient involvement in research
Wendy Edwards and Nicola Stock

Question Time

16.50 Summary and thank you

Diane Amey, Trustee of Headlines

17.00 **End of Conference**