

Joining Together For Better Care

Programme

Royal College of Paediatrics and Child Health,
5-11 Theobalds Road, London, WC1X 8HS

Thursday 20th March 2014, 14.30—1700

14.30 - 14.45pm	Registration & refreshments
14.50pm	Welcome by the RCPCH President <i>Dr Hilary Cass, President Royal College of Paediatrics and Child Health</i>
15.00pm	Implementing the UK strategy for rare disease <i>Alastair Kent OBE, Chair, Rare Disease UK</i>
15.10pm	Undertaking rare disease research and surveillance <i>Dr Chris Verity, Consultant Paediatric Neurologist</i>
15.20pm	Patient Involvement in rare disease research <i>Miriam Evans, Niemann-Pick Disease Group</i>
15.30pm	Question and Answer session
15.40pm	Afternoon tea, sandwiches and assorted extras
16.00pm	Living with a rare disease Podcast <i>Introduced by Earl Howe, Parliamentary Under Secretary of State for Quality, Department of Health</i>
16.20pm	Closing Remarks <i>Thines Ganeshamoorthy, RCPCH Youth Advisory Panel</i>
16.20—1700pm	Networking

