

Living with a Rare Disease

Programme

Council Chamber
Royal College of Paediatrics and Child Health,
5-11 Theobalds Road, London, WC1X 8HS
Thursday 30th March 2017, 13.30—17.00pm

13.30 - 14.00pm Registration & refreshments

14.00pm Welcome by the RCPCH Vice President for Science & Research
Prof Anne Greenough, *Royal College of Paediatrics and Child Health*

14.15pm Working together to tackle rare diseases
Dr Larissa Kerecuk, Rare Disease Lead, Birmingham Children's Hospital

14.25pm 100,000 Genome project—a major contribution to rare disease research
Dr Helen Brittain, Genomics England

14.40pm Developing a rare disease clinical research strategy for the 21st Century
Dr Kiki Syrad, Great Ormond Street Hospital Children's Charity

14.50pm Students for Rare Disease
Dr Lucy McKay

15.00pm Afternoon tea, sandwiches and assorted extras

15.35pm Rare Revolution & Rare Together—Launch of a Children's and young people rare disease online supplement
Rebecca Stewart, Rare Revolution Magazine & Richard Lynn, BPSU

15.50pm **Key note speaker**
Prof Gina Radford, Deputy Chief Medical Officer for England

16.05pm Award of the Sir Peter Tizard Research Bursary
Dr Bob Basu, Sheffield Children's Hospital

16.05 - 17.00pm Networking