

# Living with a Rare Disease

## Programme

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

Thursday 5th March 2014, 13.30—1700pm

### SUBJECT TO CHANGE

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|-----------------|--|
| 13.30 - 14.00pm | Registration & refreshments  |
| 14.00pm         | Welcome by the BPSU Chair<br>Dr Richard Reading, <i>Norfolk &amp; Norwich University Hospitals</i>   |
| 14.10pm         | Working together to tackle rare diseases<br>Earl Howe, <i>Parliamentary Under Secretary of State for Quality, Department of Health</i>                 |
| 14.25pm         | Rare and severe - how one might help<br>Prof Timothy Cox, <i>Cambridge University</i> & Daniel Lewi, <i>Cure &amp; Action for Tay-Sachs Foundation</i> |
| 14.40pm         | Parent perspective of living with a rare disease<br>Dr Nicolas Sireau, <i>Findacure</i>  |
| 14.50pm         | NIHR Translational Research Collaboration for Rare Diseases<br>Prof Timothy Barrett, <i>Rare Disease Centre, University of Birmingham</i>              |
| 15.05pm         | Young persons perspective<br>Thines Ganeshamoorthy, <i>RCPCH Youth Advisory Panel</i>  |
| 15.20pm         | Question and Answer session  |
| 15.30pm         | Afternoon tea, sandwiches and assorted extras  |
| 16.00pm         | Public health and rare disease<br>Prof John Newton, <i>Chief Knowledge Officer, Public Health England</i>  |
| 16.10pm         | Award of the Sir Peter Tizard Research Bursary<br>Dr Elizabeth Starkey, <i>Derby Hospitals NHS Foundation Trust</i>                                    |
| 16.20—1700pm    | Networking   |



RARE DISEASE | UK

