



## BHF Workshop: UK Paediatric Services for Familial Hypercholesterolaemia

Wednesday 18 April 2018

Kings Fund, 11 Cavendish Square, London, W1G 0AN

### Programme

09:30 – 09:50	Registration
09:50 – 09:55	Welcome – BHF & Familial Hypercholesterolaemia
09.55 – 10.00	Welcome – <i>Professor Huon H Gray, National Clinical Director for Heart Disease, NHS England and Consultant Cardiologist, University Hospital of Southampton</i>
10:00 – 10:20	<b>Chair: Dr Anupam Chakrapani, Consultant in Paediatric Metabolic Medicine, Great Ormond Street Hospital, NHS Foundation Trust</b> <b>Genetics and natural history in childhood</b> <i>Steve Humphries, Emeritus Professor, Cardiovascular Genetics, Institute Cardiovascular Sciences, University College London</i>
10:20 – 11:00	<b>What should we be offering to children with FH: NICE guidance 2008-2017</b> <i>Mrs Lorraine Priestly-Barnham, Clinical Nurse Specialist in Familial Hypercholesterolaemia and Cascade Screening, Royal Brompton &amp; Harefield NHS Foundation Trust</i>
11:00 – 11:20	<b>How many children with FH are currently identified? UK Paediatric Register and PASS data</b> <i>Dr Uma Ramaswami, Consultant In Inherited Metabolic Disorders, Royal Free London NHS Foundation Trust</i>
11:20 – 11.50	Refreshments
11:50 – 12:10	<b>What services do we currently have? Have things improved since the National Audit 2010?</b> <i>Ms Kate Haralambos, Familial Hypercholesterolaemia Research Officer, Cardiff University</i>
12:10 – 12:30	<b>How many paediatric FH clinics will we need in 2020?</b> <i>Dr Melanie Watson, Consultant Genetic Counsellor, Wessex Clinical Genetics Service, University Hospital Southampton NHS Foundation Trust</i>
12:30 – 12:50	<b>How can children with FH best transition to adult services?</b> <i>Dr Bob Cramb, Medical Advisor to the West Midlands NHS FH Project</i>
12:50 – 13:50	Lunch
13.50– 14:30	<b>Parents' experience of having a child with FH</b>  <i>Mr Steve Boley, FH patient (15 minutes)</i>  <i>Ms Suzanne Sheppard, FH Parent (15 minutes)</i>  <i>Miss Jules Payne, Chief Executive, HEART UK and Mr Simon Williams, Head of Communications &amp; Policy, HEART UK - HEART UK Children's Information Leaflets (10 minutes)</i>

<p><b>14:30 – 15:30</b></p>	<p><b><u>Workshops</u></b></p> <p><b>1. How can we help to commission child FH services?</b>  <i>Workshop Chair: Steve Humphries, Emeritus Professor Cardiovascular Genetics, Institute Cardiovascular Sciences, University College London</i></p> <p><b>Round Table participants:</b></p> <p><i>Mr Robert Pears - Consultant in Public Health, Adults' Health and Care, Hampshire County Council, Winchester</i></p> <p><i>Dr Nadeem Qureshi, Clinical Professor of Primary Care, University of Nottingham</i></p> <p><i>Dr Melanie Watson – Consultant Genetic Counsellor, Wessex Clinical Genetics Service, University Hospital Southampton NHS Foundation Trust</i></p> <p><b>2. How can we improve current Paediatric Services?</b>  <i>Workshop Chair: Dr Uma Ramaswami, Consultant in Inherited Metabolic Disorders, Royal Free London NHS Foundation Trust</i></p> <p><b>Round Table Participants:</b></p> <p><i>Dr Saikat Santra, Consultant in Inherited Metabolic Disorders, Birmingham Childrens Hospital</i></p> <p><i>Ms Margaretha Vanmourik, Consultant Genetic Counsellor, West of Scotland Regional Clinical Genetics Service</i></p>
<p><b>15:30 – 16:00</b></p>	<p><b>Action Points and Summary of Workshops</b>  <i>Professor Steve Humphries and Dr Uma Ramaswami</i></p>
<p><b>16.00 – 16.10</b></p>	<p><b>Closing Remarks – Professor Steve Humphries and Jenny Hargrave</b></p>