Amba Hotel Charing Cross, 6-7 March 2015

Agenda

	SPEAKER	TITLE	SUMMARY
08.30 - 08.45	**Caroline Harding** CEO Genetic Disorders UK **Nicole Boice** CEO Global Genes	Introduction	
08.45 – 09.15 Incl. Q+A	**Dr Clare Turnbull** Clinical Lead for Cancer Programme Genomics England	The 100,000 genomes project: opportunities and challenges	Dr Clare Turnbull will talk about the 100,000 genomes project, the structure and organisation of this programme and the opportunities it offers to transform the NHS to advance both clinical diagnostics and research into genetic disorders.
09.15 – 09.45 Incl. Q+A	**John Murray** Director Specialised Healthcare Alliance	Specialised commissioning: From here to where?	John Murray will review recent and prospective developments in specialised commissioning as they affect both small (under 500 affected individuals) and larger groups of genetic disorder patients.
09.45 – 10.15	**Julie Benson** Rett UK	Three UK charities will speak about their experiences of creating healthcare guidelines for patients	Julie Benson will talk about how Rett UK approached the creation of their National Best Practice Management and Care Guidelines developed in partnership with NHS professionals with special interest and expertise in Rett Syndrome.
	Claire Hennessey Max Appeal!		Claire Hennessey will talk about how Max Appeal! created a consensus document that provides a comprehensive and universally agreed lifelong care plan for people with 22q11DS within the framework of the NHS.
	William Davis A-T Society		William will talk about how the A-T Society plans to use their recently published clinical guidance to improve health care for children with A-T in the UK and abroad.
10.15 – 10.35	BREAK		
10.35 – 11.15 Incl. Q+A	**Angela Jackman** Partner Maxwell Gillott **Eleanor Wright** CEO SOS!SEN	Education, Health and Care Plans - A practitioner's review after the first six months	Angela Jackman and Eleanor Wright will discuss their experiences of the new regime after its first six months and the issues that those with children affected by rare genetic disorders may face in accessing the correct support for their child at school.
11.15 – 11.45 Incl. Q+A	**Robbie Spence** Benefits Adviser & Trainer Disability Rights UK	An overview of the benefits available to individuals and families affected by a genetic disorder	Robbie Spence from Disability Rights UK will talk about the latest changes to the range of benefits available for children and adults affected by a genetic disorder including Disability Living Allowance, Personal Independence Payment, universal credit and the bedroom tax.

11.45 – 12.30	**Zillah Bingley** CEO SPARKS	Four organisations with services to offer genetic disorder charities and support group will present their organisations.	Zillah will be talking about how Sparks can offer a research partner programme to other children's medical research charities.
	Dr Jelena Aleksic CEO GeneAdviser		Dr Jelena Aleksic is a geneticist working in the field of rare diseases. She will talk about her start-up GeneAdviser and how she is trying to speed up rare disease diagnostics using genetic testing.
	John Stamler Board Member Ben's Friends		John Stamler will speak about how Ben's Friends uses the power of the internet to create online support communities for people with rare genetic disorders.
	Dr Tim Guilliams **CEO Healx**		Out of 8,000 rare genetic disorders, only 200 have a cure today. Dr Tim Guilliams will talk about how his start-up, Healx, addresses this gap to identify novel therapeutic solutions for rare genetic disorders.
12.30 – 13.30	**LUNCH**		
13.30 – 14.00 Incl. Q+A	**Dr Caroline Wright** Senior Scientific Manager Wellcome Trust Sanger Institute	Finding new genetic diagnoses	Dr Caroline Wright will describe how new sequencing technologies are being used to find novel genetic diagnoses for UK families in the Deciphering Developmental Disorders (DDD) study.
14.00 – 14.30 Incl. Q+A	**Mark Larkin** Founder Vitaccess	What you need to know about patient registries	Mark Larkin will explain how data from registries can be gathered and used to further the quest for a cure, treatment or improve care of patients with genetic disorders. What important issues should charities or support groups be aware of when deciding to participate in or build their own registry?
	Paul Lenihan CEO Action Duchenne		Paul Lenihan will talk about how Action Duchenne has developed and used its highly respected patient registry in the search for a cure for Duchenne muscular dystrophy.
14.30 – 15.00 Incl. Q+A	**Dr William van't Hoff** Head of Clinical Research Facility, Great Ormond Street Hospital Joint Director of the NIHR Clinical Research Network: Children	Clinical Research: Helping you to help your families	Dr van't Hoff will discuss the importance of clinical research (including trials) in improving our knowledge of effective treatments and care for rare disorders, illustrating his talk with experience of how to overcome the common concerns and pitfalls.

15.00 – 15.20	**BREAK**		
15.20 – 15.50 Incl. Q+A	**Professor Bobby Gaspar** Consultant in paediatric immunology at Great Ormond Street Hospital Head of Molecular and Cellular Immunology at the UCL Institute of Child Health	The achievements of gene therapy to date and its potential for the future	Professor Gaspar will speak about the successes and challenges of gene therapy to date and the potential of gene therapy to treat and cure a range of genetic disorders in the future.
15.50 – 16.20	**Dr Nicolas Sireau** AKU Society	Three charities will speak about how their small charity has made a big difference	Dr Sireau will explain how he scaled up the work of the AKU Society in order to make a bigger impact for patients.
	Fiona Copeland Ciliopathy Alliance		Fiona Copeland will talk about the Ciliopathy Alliance and how the collaboration between patients, researchers and clinicians, for a variety of rare conditions caused by abnormal cilia, is improving the lives of those affected.
	Liz Curtis The Lily Foundation		Liz Curtis will talk about how she gained a voice in Westminster and played a major role in proposing new legislation to help families affected by mitochondrial disease.
16.20 – 16.50 Incl. Q+A	**Stuart Pritchard** Director of Development Genetic Alliance UK	The UK Rare Disease Strategy: What next?	The UK Rare Disease Strategy, published in 2013, identifies 51 commitments relating to healthcare and research relevant to patients and families with rare diseases in the UK. Stuart Pritchard will discuss how much progress have we seen and what should we expect to see happen next?
16.50 – 17.00	**Caroline Harding** CEO Genetic Disorders UK	Closing remarks	
	CONFERENCE ENDS		