

Harrogate International Centre, United Kingdom

Tuesday 29 September 2009

Rare Disorders Symposium

Organised by Professor Brian Neville

9.00 – 10.50	Presentations - each 15 minutes plus 5 minutes discussion <ul style="list-style-type: none">• Introduction – Brian Neville• Narcolepsy – Sonia Nevšimalová• Cerebellar hamartomas and hypothalamic hamartomas – Alexis Arzimanoglou• Landau-Kleffner Syndrome – Brian Neville• Sturge-Weber Syndrome – Sarah Aylett• Rasmussen's Syndrome – Helen Cross
10.50 – 11.20	Refreshments
11.20 – 12.50	Presentations – each 15 minutes plus 5 minutes discussion <ul style="list-style-type: none">• Aicardi-Goutieres Syndrome – Yanick Crow• Migrating partial seizures – Rachel Kneen• Encephalitis Lethargica – Cheryl Hemingway• The Bradford experience – how to diagnose and manage more than 150 rare disorders in a community – Peter Corry
12.50 – 1.50	Lunch
1.50 – 2.40	<ul style="list-style-type: none">• Experiences of the alternating hemiplegia in childhood study – Tsveta Schyns; Brian Neville; Francis Crawley• Do cognitive, behavioural, educational and need for support provide a common platform for services for rare disorders? – Christopher Gillberg ; EURORDIS; Sasha Henriques (Contact a Family)
2.40 -3.30	Breakout Discussion Groups and suggested facilitators <ul style="list-style-type: none">• What do parents want in terms of information, services and support? – Tsveta Schyns ; Philippa Russell; Contact a Family.• How important are cognitive, behavioural and educational issues and are they available to carers and professionals? – Christopher Gillberg; Brian Neville• What is the right research relationship for support groups with researchers, including basic science and translational? – Alexis Arzimanoglou; Francis Crawley; Anja Helm
3.30 – 4.00	Refreshments
4.00 – 5.00	<ul style="list-style-type: none">• Feedback from leaders and discussion• Carers perspective – Philippa Russell

This symposium is additional to the main European Paediatric Neurology Society 2009 Congress. The cost is £55 which includes lunch. Attendance can be booked through www.bpna.org.uk/epns2009. Places are limited to 150.

This meeting is partially funded by the European Union