



**Family & Professional Conference
Saturday 17th November 2012
Agenda**

- 9.00 Welcome & Housekeeping
Marie Baker - Chairperson, Dravet Syndrome UK
- 9.10 Personal Overview of Dravet Syndrome and Seizure Types
Dr Charlotte Dravet, Epileptologist, Necker Hospital, Paris.
- 9.40 Early Intervention & Medication Options
Dr Elaine Hughes - Consultant Paediatric Neurologist, Kings College Hospital, London & Evelina Children's Hospital, London
- 10.10 Research into Dravet Syndrome - UK & Globally
Dr Sameer Zuberi - Consultant Paediatric Neurologist, Royal Hospital for Sick Children, Glasgow
- 10.40 Break
- 10.55 Parental Experience of Dravet Syndrome
Kate Watts - Parent to Laura
- 11.25 Round Table Option 1
- 11.40 Round Table Option 2
- 11.55 Research Update - Genetic heterogeneity of Dravet syndrome: the pathological roles of SCN2A, SCN1B and GABRG2 in Dravet syndrome patients negative for SCN1A mutations
Dr Seo-Kyung Chung -Epilepsy Research UK, Research Fellow, WERN
Dr Rhys Thomas - WCAT Clinical Lecturer in Neurology, WERN
- 12.25 Q & A
- 12.40 Lunch



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- 1.40 Dravet Syndrome in Adults
Professor Sanjay Sisodiya - Professor of Neurology, UCL Institute of Neurology
- 2.10 Co-morbid conditions & Alternative Treatments
Dr Richard Appleton - Consultant Paediatric Neurologist, Alderhey Children's Hospital, Liverpool
- 2.40 Ketogenic Diet in Dravet Syndrome Patients
Emma Williams - Founder, Matthews Friends & Trustee, Dravet Syndrome UK
- 3.00 Round Table Option 3
- 3.15 Round Table Option 4
- 3.30 Dravet Syndrome Through the Eyes of a Sibling
Alice Williams - Sister to Matthew Williams
- 3.40 Q & A
- 3.55 Final Comments & Close
Marie Baker - Chairperson, Dravet Syndrome UK

Roundtable Topics:

There will be 4 separate opportunities throughout the day to choose the topics that interest you and join in the roundtable discussion

- Table 1: First Aid
John Bethal - Resuscitation Officer
- Table 2: Transition into adult services
Emma Williams - Mum to Matthew aged 18
- Table 3: Mainstream Schooling
Gill Gallagher - Young Epilepsy
- Table 4: Further Education
Franky Caffyn - Young Epilepsy
- Table 5: Behaviour Management
Neil Fothergill - Cheshire West & Chester CAMHS
- Table 6: Feeding difficulties
Helen Cockerill - Feeding Specialist, Evelina Children's Hospital, London.
- Table 7: Family Perspective on Support Services (including respite & family support)
Kate Watts - Mum to Laura
- Table 8: Importance and Use of Emergency Medication
Andrea McLaren - Epilepsy Nurse Specialist - Greater Manchester NHS Foundation Trust (Sponsored by Viropharma)

Please email Marie Baker at marie.b@dravet.org.uk if you require copies of any of the presentations.