

First meeting of The Rett Disorders UK Working Group



On Thursday 10th March 2016, the Rett Disorders Alliance brought together the first meeting of a UK Working Group for Rett Disorders.

This group comprised of UK clinicians and therapists from across the UK who have special interest and/or expertise in Rett Syndrome and related disorders. The meeting was held at Wellington House, London and was kindly hosted by Edmund Jessop, Specialised Commissioning, NHS England.

The focus of this initial meeting was to explore ways in which UK clinical provision for Rett Disorders can be improved and expanded, in particular by:

- Developing a more cohesive clinical network with existing and emerging Rett clinicians working together to address the complex lifelong needs of people with Rett Disorders.
- Working with NHS England to find ways to develop and support Expert Centres for patients with Rett Disorders.
- Developing disease-specific Standards of Care or Best Practise Guidelines to enable improved clinical care to patients with Rett Disorders across the country.

The Rett Disorders Working Group will meet again in person in October 2016. Work to drive the above agenda forward is on going.

In attendance at this meeting were: Edmund Jessop NHS England, Dr Andreas Brunklaus, Mr Thomas Carroll, Dr Hilary Cass, Dr Stacey Clough, Dr Alex Gibson, Dr Adrian Kendrick, Professor Mike Kerr, Gilly Martin, Cindy-Jo Morison, Dr Paramala Santosh, Gill Townend, Dr Jane Williams.

Rett Disorders Alliance representatives: John Sharpe, Becky Jenner, Rachael Stevenson, Lorna Jaffa, Carol Ann Partridge, Judith Sheppard.

Apologies: Professor Sameer M Zuberi, Catherine Sim, Dr Jill Clayton Smith, Mr Martin Newey, Prof Angus Clarke.

The Rett Disorders Alliance of the UK is actively seeking clinicians from across the UK who have special interest in and/or expertise in Rett Disorders to be part of the Working Group. Please contact becky.jenner@rettuk.org and/or rachael@reverserett.org.uk for more information or to register interest.