

# The Midlands Rare Disease Showcase

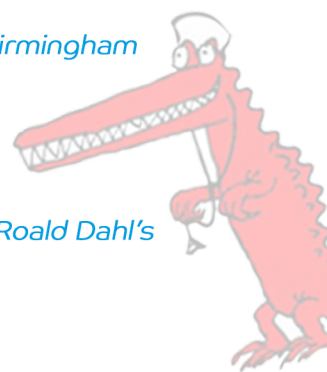


**Birmingham Children's Hospital**  
**22<sup>nd</sup> October 2016**

Birmingham  
Children's  
Hospital **NHS**  
NHS Foundation Trust

## Event Programme

- 09:30 Registration
- 10:00 Dr Larissa Kerecuk *Rare Disease Lead, BCH*  
*An introduction to the first UK Children's Rare Disease Centre*
- 10:20 Alastair Kent OBE *Director, Genetic Alliance UK*  
*Rare reality*
- 10:50 Melanie Dillon *RaDaR Project Lead, The UK Renal Registry*  
*The National Registry of Rare Kidney Disease: perfect partnerships*
- 11:10 Vivienne Beckett *Patient Advocacy & Patient Affairs, Genzyme*  
*Expression of Hope exhibiton*
- 11:15 Tea and coffee break
- 11:45 Dr David Milford *Consultant, BCH*  
*aHUS: a breakthrough in treatment of a rare disease*
- 11:55 Dr Cathy Quinlan *Consultant, Royal Children's Hospital, Melbourne*  
*An introduction to the Kidney Genetics Collaborative*
- 12:15 Neil Dugdale *General Manager UK & RoI, Sobi*  
*Patient centricity: the Sobi way*
- 12:25 Lunch
- 13:25 Prof. Tim Barrett *Director NIHR Clinical Research Facility, University of Birmingham*  
*Progress within the Rare Disease Translational Research Collaboration*
- 13:45 Kay Parkinson *CEO, CRDN & Director, Alstrom Europe*  
*Is rare disease care initially DIY for parents and carers?*
- 14:05 Sophie Dziwinski & Jane Miles *Senior Programmes Manager & CEO, Roald Dahl's Marvellous Children's Charity*  
*Rare diseases & Roald Dahl's Marvellous Children's Charity*
- 14:25 Networking session with delegate lightning talks  
*Accompanied by drinks and canapés*
- 16:30 Closing remarks



With thanks to our sponsors



Our sponsors have supported the organisation of this event but had no involvement in determining the agenda or content.