Westminster Health Forum policy conference: Improving outcomes for rare diseases in England - research and treatment, specialised commissioning and access to medicine
Timing: Morning, Thursday, 9th January 2020
Venue: Central London

Draft agenda subject to change

WESTMINSTER HEALTH FORUM

8.30 - 9.00	Registration and coffee
9.00 - 9.05	**Chair's opening remarks** **Rt Hon the Baroness Neville-Jones**, Vice-Chair, All-Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions
9.05 - 9.35	**The future for rare diseases policy in England and implementing the National Genomic Healthcare Strategy** **Professor Dame Sue Hill**, Chief Scientific Officer, NHS England Questions and comments from the floor
9.35 - 9.45	**Assessing the implementation of the *UK Strategy for Rare Diseases* and key issues for patients** **Dr Jayne Spink**, Chief Executive, Genetic Alliance UK
9.45 - 10.40	**Next steps for delivering specialised services for rare diseases: workforce and training, patient engagement and co-ordinating care** **Dr Robin Lachmann**, Consultant, Metabolic Medicine, University College London Hospitals NHS Foundation Trust **Dr Anneke Seller**, Scientific Director, Genomics Education Programme, Health Education England **Sara Hunt**, Chief Executive Officer, Alex, The Leukodystrophy Charity **Angela McFarlane**, Senior Market Development Director, UK and Ireland, IQVIA Questions and comments from the floor with **Dr Jayne Spink**, Chief Executive, Genetic Alliance UK
10.40 - 10.45	**Chair's closing remarks** **Rt Hon the Baroness Neville-Jones**, Vice-Chair, All-Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions
10.45 - 11.10	Coffee
11.10 - 11.15	**Chair's opening remarks** **Alex Sobel MP**, Officer, All-Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions
11.15 - 11.25	**Priorities for rare disease research: investment, collaboration and innovation** **Dr Larissa Kerecuk**, Rare Disease Lead and Consultant Paediatric Nephrologist, Birmingham Women's and Children's NHS Foundation Trust and Clinical Research Speciality Lead, Paediatrics, National Institute of Health Research Clinical Research Network West Midlands
11.25 - 11.35	**Utilising genomics and personalised medicine in diagnosis and treatment** **Dr Richard Scott**, Clinical Lead, Rare Diseases, Genomics England
11.35 - 11.45	**Improving access to medicines for rare diseases** **Richard Eaton**, Rare Conditions Franchise Lead, Roche
11.45 - 12.05	Questions and comments from the floor
12.05 - 12.20	**The role of NICE in improving treatment for rare diseases: cost effectiveness, value and evaluation** **Helen Knight**, Programme Director, Technology Appraisals and Highly Specialised Technologies, NICE
12.20 - 12.35	**Next steps for specialised commissioning: funding, integration and reducing variation** Senior representative, commissioning
12.35 - 12.55	Questions and comments from the floor
12.55 - 13.00	**Chair's and Westminster Health Forum closing remarks** **Alex Sobel MP**, Officer, All-Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions **Michael Ryan**, Deputy Editor, Westminster Health Forum