Westminster Health Forum policy conference
Next steps for rare diseases and specialised commissioning - policy priorities, utilising genomics, patient engagement and co-ordinating care
Timing: Morning, Thursday, 21st January 2021
*****Taking Place Online*****

Draft agenda subject to change

WESTMINSTER HEALTH FORUM

8.30 Registration

9.00 **Chair's opening remarks**
Liz Twist MP, Chair, All-Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions

9.05 **Assessing progress and policy priorities going forward for improving outcomes in rare diseases**
Professor Dame Sue Hill, Chief Scientific Officer, NHS England
Questions and comments from the floor

9.35 Break

9.40 **Maintaining momentum in improving outcomes, and the implications of COVID-19 for patients**
Dr Jayne Spink, Chief Executive, Genetic Alliance UK

9.50 **Commissioning specialised services through the pandemic and the ongoing drive to improve quality and delivery in care**
Dr Ayesha Ali, Medical Advisor, Highly Specialised Services, NHS England

10.00 **Improving patient access to treatment, developing collaborative approaches, and learning from the experience of COVID-19**
Alastair Kent, Independent Patient Advocacy Consultant; Co-Chair, UK Rare Disease Policy Board; and Member, Rare Disease Advisory Group, NHS England

10.10 Questions and comments from the floor

10.40 **Chair's closing remarks**
Liz Twist MP, Chair, All-Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions

10.45 Break

10.55 **Chair's opening remarks**
Baroness Neville-Jones, Vice-Chair, All-Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions

11.00 **Opportunities for utilising national genomic policy developments to improve diagnosis and treatment for rare disease patients**
Dr Richard Scott, Clinical Director, Rare Diseases, Genomics England
Questions and comments from the floor

11.25 Break

11.30 **Key priorities for rare disease research, and the way forward for funding and collaboration**
Professor Matthew Hurles, Head of Human Genetics, Wellcome Sanger Institute

11.40 **Improving patient involvement in disease specific research areas**
Dr Beverly Searle, CEO, Unique - The Rare Chromosome & Gene Disorder Support Group

11.50 Questions and comments from the floor

12.05 **Next steps for adopting innovation and delivering improved health outcomes for rare disease patients - workforce training, effective diagnostics, sharing best practice, and coordinating care**
Angela McFarlane, Senior Market Development Director, UK and Ireland, IQVIA
Melanie Watson, Lead Consultant Genetic Counsellor, Wessex Clinical Genetics Service, University Hospital Southampton NHS Foundation Trust
Dr Janet Allen, Senior Research Associate in Digital Health, University of Cambridge and formerly Director of Strategic Innovation, Cystic Fibrosis Trust
Dr William Evans, GP, Leeds; Member, Genomics England GP Committee; Academic, University of Nottingham; Clinical Lead, Mendelian
Rene Sonders, Lead Nurse for Rare Disorders, LloydsPharmacy Clinical Homecare
Questions and comments from the floor

12.55 **Chair's and Westminster Health Forum closing remarks**
Baroness Neville-Jones, Vice-Chair, All-Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions
Jessica Lear, Senior Researcher, Westminster Health Forum