

## 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, 21<sup>st</sup> January 2021

\*\*\*Taking Place Online\*\*\*



WESTMINSTER  
HEALTH FORUM

*Draft agenda subject to change*

- 8.30 Registration
- 9.00 **Chair's opening remarks**  
Senior Parliamentarian
- 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**  
Senior representative, regulation
- 10.10 Questions and comments from the floor
- 10.40 **Chair's closing remarks**  
Senior Parliamentarian
- 10.45 Break
- 10.55 **Chair's opening remarks**  
Senior Parliamentarian
- 11.00 **Opportunities for utilising national genomic policy developments to improve diagnosis and treatment for rare disease patients**  
**Dr Richard Scott**, Clinical Lead, 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**  
**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
- 11.40 **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  
Senior representative, workforce  
Senior representative, diagnostics  
Questions and comments from the floor
- 12.55 **Chair's and Westminster Health Forum closing remarks**  
Senior Parliamentarian  
**Michael Ryan**, Deputy Editor, Westminster Health Forum