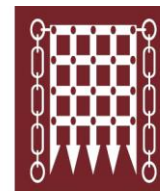


Westminster Health Forum policy conference
Priorities for rare disease research, diagnosis, and care in the UK

Timing: Morning, Monday, 31st January 2022

Taking Place Online



**WESTMINSTER
HEALTH FORUM**

Draft agenda subject to change

- 8.30 Registration
- 9.00 **Chair's opening remarks**
Senior Parliamentarian
- 9.05 **Taking forward the UK Rare Diseases Framework**
Dr Kath Bainbridge, Head of Genomic Science and Emerging Technologies, Department of Health and Social Care
Questions and comments from the floor
- 9.30 Break
- 9.35 **Priorities for improving diagnosis and patient care - accessibility, utilising innovation, and coordinating care**
Dr William Evans, GP, Leeds; Member, Genomics England GP Committee; Academic, University of Nottingham; and Clinical Lead, Mendelian
Professor Timothy Barrett, Leonard Parsons Professor of Paediatrics, University of Birmingham; and Honorary Consultant in Paediatric Endocrinology and Diabetes, Birmingham Women's and Children's Hospital
Alastair Kent, Independent Patient Advocacy Consultant; Co-Chair, UK Rare Disease Policy Board; and Member, Rare Disease Advisory Group, NHS England
Dr Boyd Ghosh, Consultant Neurologist, University Hospital Southampton NHS Foundation Trust; and Trustee, PSP Association
Questions and comments from the floor
- 10.30 **Raising awareness of rare diseases across the health system, meeting new workforce needs, and developing expertise to support high-quality care**
Dr Emma Baple, Rare Disease Lead, NHS South West Genomic Laboratory Hub; and Clinical Senior Lecturer in Genomic Medicine, University of Exeter
Professor Kate Tatton-Brown, Clinical Lead, Genomics Education Programme, Health Education England; and Consultant Clinical Geneticist, St George's University Hospitals NHS Foundation Trust
Questions and comments from the floor
- 11.00 **Chair's closing remarks**
Senior Parliamentarian
- 11.05 Break
- 11.15 **Chair's opening remarks**
Senior Parliamentarian
- 11.20 **Harnessing genomics to further understanding, detection and treatment of rare genetic conditions, and the implementation of Genome UK**
Dr Ellen Thomas, Clinical Director and Director of Quality, Genomics England
- 11.35 **Opportunities for rare disease research and the development of innovative treatments to improve patient outcomes - patient involvement, priorities for data use, collaboration, and the potential for global leadership**
Nick Meade, Joint Interim Chief Executive and Director of Policy, Genetic Alliance UK
Annabel Griffiths, Head of Rare Diseases, Costello Medical
Dr Imran Kausar, Vice President and General Manager UK, Novartis Gene Therapies
Senior representative, research
- 12.00 Questions and comments from the floor
- 12.25 Break
- 12.30 **Next steps for supporting developments in genomics to improve health outcomes for rare disease patients**
Professor Dame Sue Hill, Chief Scientific Officer for England and Senior Responsible Officer for Genomics, NHS England and NHS Improvement
Questions and comments from the floor
- 12.55 **Chair's and Westminster Health Forum closing remarks**
Senior Parliamentarian
Jessica Lear, Forum Lead, Westminster Health Forum