

Westminster Health Forum policy conference:
Priorities for rare disease diagnosis, care and treatment in England
Timing: Morning, Tuesday, 16th July 2024
*****Taking place online*****



Draft agenda subject to change

- 8.30 Registration
- 9.00 **Chair's opening remarks**
Senior Parliamentarian
- 9.05 **Assessing the current landscape for the treatment of rare diseases - progress of the England Rare Diseases Action Plan 2024**
Kath Bainbridge, Head of Rare Diseases and Emerging Therapies, Department of Health and Social Care
Questions and comments from the floor
- 9.30 **Progress and next steps for newborn screening for early detection and diagnosis of rare diseases**
Senior representative, screening
- 9.40 **Improving the delivery of care for patients with rare diseases**
developing effective care pathways | patient accessibility to care | specialised commissioning | transitions from paediatric to adult care | coordinated care services | implementing a holistic approach to care | Early Access to Medicines Scheme
Dr Larissa Kerecuk, Rare Disease Lead and Consultant Paediatric Nephrologist, Birmingham Children's Hospital
Adam Galloway, Clinical academic children's physiotherapist, Leeds Children's Hospital
Senior representative, NHS
Senior representative, patient group
Senior representative, holistic care
- 10.05 Questions and comments from the floor
- 10.30 **Approaches to workforce education for rare diseases and therapies - raising awareness among healthcare professionals to improve diagnosis and treatment**
Dr Lucy McKay, CEO, Medics4RareDiseases
Questions and comments from the floor
- 10.50 **Chair's closing remarks**
Senior Parliamentarian
- 10.55 Break
- 11.05 **Chair's opening remarks**
Senior Parliamentarian
- 11.10 **Priorities for regulation and licencing pathways for innovative treatments**
Senior representative, guidelines
Questions and comments from the floor
- 11.35 **Advancing research and innovation across the rare disease pathway**
exploring the future potential of genomic medicine | clinical trials | next steps for children's treatments through the Rare Therapies Launch Pad | improving research eco-system collaboration and the role of the Rare Disease Research UK Platform | coordinating data and disease registries | licencing and regulation pathways
Catriona Crombie, Head of Rare Disease, LifeArc
Deborah Richards, UK General Manager, Alexion, AstraZeneca Rare Disease
Senior representative, patient group
Senior representative, research
Senior representative, NHS
Questions and comments from the floor
- 12.30 **Next steps for utilising innovation in genomics for care and treatment of rare diseases**
Ana Lisa Tavares, Clinical Lead for Rare Disease Research, Genomics England
Questions and comments from the floor
- 12.55 **Chair's and Westminster Health Forum closing remarks**
Senior Parliamentarian
Jessica Lear, Westminster Health Forum