Westminster Health Forum policy conference:
Priorities for rare disease diagnosis, care and treatment in England

Timing: Morning, Thursday, 5th June 2025

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

WESTMINSTER
HEALTH FORUM

Draft agenda subject to change

8.30 Registration

9.00 **Chair's opening remarks**
Baroness Neville-Jones

9.05 **'Four years of the UK Rare Diseases Framework – progress through England's Action Plans and commitments for 2025'**
Dr Kath Bainbridge, Head, Rare Diseases and Emerging Therapies, Department of Health and Social Care
Questions and comments from the floor

9.30 **Priorities for patient engagement in shaping rare disease policy**
Nick Meade, Interim CEO and Director, Policy, Genetic Alliance UK

9.40 **Strategies for improving early detection, diagnosis and care coordination**
priorities from the England Rare Diseases Action Plan 2025 | *delivering faster diagnostics and growing capacity* | *incentivising clinics for multi-system disorders* | *improving workforce awareness of rare diseases* | *equitable access to specialist care and treatment* | *innovative approaches to patient support* | *the future for specialised commissioning in NHS reform* | *priorities for the NHS Genomic Networks of Excellence* | *approaches to digitalising genomics*
Dr Emma Baple, Professor, Genomic Medicine and Medical Director, South West Genomic Laboratory Hub, University of Exeter
Dr Ed Miller, Senior Education and Development Officer, Genomics Education Programme, NHS England
Dr Peter Fish, CEO, Mendelian
Senior representative, diagnostics
Senior representative, patient

10.10 Questions and comments from the floor

10.35 **Next steps for whole genome sequencing in newborn screening**
Professor Jim Bonham, President, International Society of Neonatal Screening
Questions and comments from the floor

11.00 **Chair's closing remarks**
Baroness Neville-Jones

11.05 Break

11.15 **Chair's opening remarks**
Senior Parliamentarian

11.20 **Advancing development of targeted therapies and genetic medicine pathways for rare diseases**
Dr Ana Lisa Tavares, Clinical Lead, Rare Disease Research, Genomics England
Questions and comments from the floor

11.45 **Priorities for Highly Specialised Technology evaluation and transparency**
Senior representative, guidance
Questions and comments from the floor

12.10 **The future for personalised treatments, innovative research, and clinical trials for rare diseases**
preparing the NHS to deliver personalised treatments | *addressing potential treatment eligibility issues* | *advancing rare disease medicine development* | *improving recruitment to clinical trials* | *regulatory and operational challenges in delivering highly personalised treatments* | *opportunities for national and international collaboration* | *priorities for data sharing of real world evidence* | *centring patient experience and safety* | *future pathways for accelerated, safe, and approved therapies*
Dr Simon Lande, CEO and Co-Founder, HealthLumen
Stephanie Caird, Partner, Mills & Reeve
Senior speaker confirmed from **Healx**
Senior representative, research
Senior representative, advocacy
Questions and comments from the floor

12.55 **Chair's and Westminster Health Forum closing remarks**
Senior Parliamentarian
Jessica Lear, Westminster Health Forum

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