

AGENDA

| Morning Session | |
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| 9.30 – 10.00 | Registration and Welcome Coffee |
| <u>Plenary Session 1</u> | |
| 10.00 – 10.30 | Welcome and Introduction to the European Commission's Communication on Rare Disease and the EU Council Recommendation "Opportunity for developing a national strategy for rare disease in the UK" Alastair Kent, Chair of Rare Disease UK & Director of Genetic Alliance UK |
| 10.30 – 11.00 | The Europlan Project and developing national strategies for rare diseases Dr Edmund Jessop, National Commissioning Group, Department of Health. |
| 11.00 – 11.15 | Tea and coffee break |
| <u>Workshop/Breakout Session 1</u> | |
| 11.15 – 12.45 | Governance of a UK Strategy Chair: Alastair Kent, Chair of Rare Disease UK Rapporter: Stephen Nutt, Rare Disease UK |
| | Definition, codification and inventorying of rare disease strategy (information and training) Chair: Dr Mark Taylor, Birmingham Children's Hospital Rapporter: Lauren Limb, Rare Disease UK |
| | Standards of Care / Centres of expertise (orphan drugs and provision of treatment) Chair: Professor Kate Bushby, Treat NMD Rapporter: Melissa Hillier, Rare Disease UK & Genetic Alliance UK |
| 12.45 – 2.00 | Lunch |



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| Afternoon Session | |
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| <u>Workshop/Breakout Session 2</u> | |
| 2.00 – 3.30 | Research Chair: Dr Hilary Burton, PHG Foundation (tbc) Rapporter: Lauren Limb, Rare Disease UK |
| | Patient Empowerment Chair: Lesley Greene, CLIMB & Eurordis and Andrew Wilson Webb, Rarer Cancers Forum Rapporter: Stephen Nutt, Rare Disease UK |
| <u>Plenary Session 2</u> | |
| 3.30 – 4.00 | Report from breakout sessions Chair: Alastair Kent, Chair of Rare Disease UK & Director of Genetic Alliance UK Chair and/or Rapporter: feedback on each workshop |
| 4.00 – 4.30 | Discussion and feedback |
| 4.30 | Tea and close |

To book a place at this conference please contact [Melissa Hillier](#) on melissa@raredisease.org.uk or 020 7704 3141