



Department  
of Health

## Members of the UK Rare Diseases Stakeholder Forum

<b>Name</b>	<b>Representing</b>
Rosemary Arbuthnot	Northern Ireland Rare Disease Partnership
Mark Barrett	ABPI Orphan Medicines Industry Group
Phil Beales	University College London
Meindhart Boysen	National Institute for Health and Care Excellence
Paul Buckley	General Medical Council
John Burn	British Society for Human Genetics / and Clinical Genetics Society
Hilary Burton	PHG Foundation
Geoffrey Carroll	Welsh Government
Jill Clayton-Smith	Clinical Genetics Society
Christine Collins	Northern Ireland Rare Disease Partnership
John Colvin	Academy of Medical Royal Colleges (Scotland)
Paul Currie	Scottish Government
Lindsey Davies	Academy of Medical Royal Colleges (PH)
Deirdre Evans	Northern Ireland Government
Peter Farndon	National Genetics Education & Development Centre
Natalie Fine	General Medical Council
Natalie Frankish	Genetic Alliance (Scotland)
Veronica Gillen	Northern Ireland Government
Josie Godfrey	National Institute for Health and Care Excellence
David Goldblatt	Biomedical Research Centre
Christine Harvey	Public Health England
Bethan Hughes	Wellcome Trust
Emma Hughes	Genetic Alliance (Wales)



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Edmund Jessop	National Specialised Commissioning Team
Daniel Kelly	Northern Ireland Government
Alastair Kent	Rare Disease UK
Gill Leng	National Institute for Health and Clinical Excellence
Anne Mackie	UK National Screening Committee
Joe McNamara	Medical Research Council
Teresa Magirr	Northern Ireland Government
Fiona Marley	NHS England
Jonathan Mogford	Medicines and Healthcare products Regulation Agency
Declan Mulkeen	Medical Research Council
John Murray	Specialised Healthcare Alliance
Simon Newell	Royal College of Paediatrics and Child Health
John Newton	Public Health England PHE
Willem Ouwehand	National Institute for Health Research
Colin Pavelin (Chair)	Department of Health
Elizabeth Porterfield	Scottish Government
Jem Rashbass	Public Health England PHE
Chris Riley	Welsh Government
Tom Robinson	Northern Ireland Government
Beverly Searle	Unique (the Rare Chromosome Disorder Support Group)
Fiona Stewart	Northern Ireland Government
Jacquie Westwood	UK Genetic Testing Network
Tara Willmott	General Medical Council
Kent Woods	Medicines & Healthcare products Regulation Agency