

## ***Rare diseases Stakeholders***

Action Duchenne  
Addison's Disease Self-Help Group  
Adult Rare Bone Disease Rare Disease Collaborative Network  
Alexion AstraZeneca Rare Disease  
Association of Anaesthetists of Great Britain and Ireland  
Association of British Neurologists  
Ataxia UK  
Batten Disease Family Association  
Beacon for Rare Diseases  
Behcet's UK  
Blood Cancer UK  
British Association For Paediatric Nephrology  
British Medical Association  
British Medical Journal  
British National Formulary  
British Nuclear Cardiology Society  
British Society for Genetic Medicine  
British Society for Immunology Clinical Immunology Professional Network  
British Society for Paediatric Endocrinology and Diabetes  
Brittle Bone Society  
Care Quality Commission  
CDKL5 UK  
Clinical Genetics Society  
College of Paramedics  
Costello Medical  
Cure and Action for Tay-Sachs Foundation  
DEBRA UK  
Department of Health and Social Care  
Dyskeratosis Congenita Action  
Gene People  
Genetic Alliance UK  
Huntingtons Disease Association  
Inflammatory Neuropathies UK  
Kidney Research UK  
LifeArc  
Lipodystrophy UK  
Lupus UK  
Max Appeal  
Medicines and Healthcare products Regulatory Agency  
Medics 4 Rare Diseases  
Metabolic Support UK  
MPS Society  
Muscular Dystrophy UK  
National Institute for Health & Care Research  
Neurological Alliance  
NHS England  
NHS England and NHS Improvement  
NHS Health at Work  
NICE- Adoption and Impact  
NICE Diagnostics Assessment Programme  
Nursing and Midwifery Council  
OpalMedica Limited  
PNH Support  
Progressive Supranuclear Palsy Association  
Public Health Wales

Royal College of Anaesthetists  
Royal College of Emergency Medicine  
Royal College of General Practitioners  
Royal College of General Practitioners in Wales  
Royal College of Midwives  
Royal College of Nursing  
Royal College of Obstetricians and Gynaecologists  
Royal College of Paediatrics and Child Health  
Royal College of Pathologists  
Royal College of Physicians  
Royal College of Physicians and Surgeons of Glasgow  
Royal College of Psychiatrists  
Royal College of Radiologists  
Royal College of Speech and Language Therapists  
Royal College of Surgeons of Edinburgh  
Royal College of Surgeons of England  
Royal Pharmaceutical Society  
Scottish Intercollegiate Guidelines Network  
South Eastern Health and Social Care Trust  
Southern Health & Social Care Trust  
Spinal Muscular Atrophy UK  
Spotlight YOPD  
Tuberous Sclerosis Association  
UK Health Security Agency  
UK Mastocytosis Support Group  
UK Thalassaemia Society  
Unique - Rare Chromosome Disorder Support Group  
Welsh Government  
WMUK