

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