

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

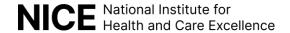
Single Technology Appraisal

Givinostat for treating Duchenne muscular dystrophy in people 6 years and over [ID6323]

Final Stakeholder List

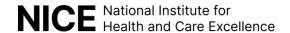
Consultees	Commentators (no right to submit or appeal)
Company	General
Company ITF Pharma UK (givinostat) Patient/carer groups Action Duchenne Alex's Wish Arthritis & Musculoskeletal Alliance Beacon Duchenne Family Support Group Duchenne Now Duchenne Research Fund Duchenne UK Gene People Genetic Alliance UK Harrison's Fund Joining Jack	 General All Wales Inherited Metabolic Disease Service All Wales Therapeutics and Toxicology Centre Allied Health Professionals Federation Board of Community Health Councils in Wales British National Formulary Care Quality Commission Cell and Gene Therapy Catapult Department of Health - Northern Ireland Healthcare Improvement Scotland Medicines and Healthcare products Regulatory Agency National Association of Primary Care
Muscular Dystrophy UK Pathfinders Neuromuscular Alliance	National Pharmacy AssociationNational Services Division
South Asian Health Foundation	NHS Alliance
Specialised Healthcare Alliance	NHS Confederation
Together for Short Lives	Scottish Medicines Consortium
	Welsh Government
Healthcare professional groups	 Welsh Health Specialised Services
 Association of Anaesthetists of Great Britain & Ireland 	Committee
Association of British Neurologists	Comparator companies
Association of Chartered	 PTC Therapeutics (ataluren)
Physiotherapists in Respiratory Care	
 Association of Genetic Nurses & Counsellors 	Relevant research groups Bone Research Society
 Association of Respiratory Nurse Specialists 	 Cochrane Cystic Fibrosis and Genetic Disorders Group
Association of Surgeons of Great	Cochrane Musculoskeletal Group
Britain and Ireland	Cochrane UK
British Cardiovascular SocietyBritish Dietetic Association	Genomics England

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Consultees Commentators (no right to submit or appeal) MRC Centre for Neuromuscular **British Geriatrics Society** British Institute of Musculoskeletal **Diseases** MRC Clinical Trials Unit Medicine **British Myology Society** National Institute for Health Research British Orthopaedic Association Orthopaedic Research UK British Paediatric and Adolescent TREAT-NMD **Bone Group British Paediatric Neurology** Associated Public Health groups Association Public Health Wales **British Paediatric Respiratory Society UK Health Security Agency** British Society for Children's Orthopaedic Surgery British Society for Gene and Cell Therapy British Society for Genetic Medicine British Society for Paediatric **Endocrinology and Diabetes** British Society of Physical and Rehabilitation Medicine **British Thoracic Society** Chartered Society of Physiotherapy Neonatal and Paediatric Pharmacists Group Primary Care Respiratory Society UK Royal College of General Practitioners Royal College of Nursing Royal College of Paediatrics and Child Health Royal College of Pathologists Royal College of Physicians Royal College of Surgeons Royal Pharmaceutical Society Royal Society of Medicine Society for Endocrinology The National Congenital Anomaly and Rare Disease Registration Service The North Star Clinical Network **UK Clinical Pharmacy Association Others** Alder Hey Children's Hospital NHS Foundation Trust, Liverpool Bristol Royal Hospital for Children, Bristol

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Consultees	Commentators (no right to submit or appeal)
 Department of Health and Social Care Dubowitz Neuromuscular Centre (DNC) MD UK Oxford Neuromuscular Centre, Oxford MRC Centre for Neuromuscular Diseases NHS England Queen Square Centre for Neuromuscular Diseases UCL Robert Jones and Agnes Hunt Orthopaedic Hospital, Oswestry Royal Manchester Children's Hospital NHS Foundation Trust, Manchester Ryegate Centre, Sheffield Children's NHS Foundation Trust, Sheffield The Addenbrooke's Neuromuscular Service, Cambridge The John Walton Muscular Dystrophy Research Centre, Newcastle The National Hospital for Neurology and Neurosurgery, London The Walton Centre, Liverpool Wessex Neurological Centre, Southampton General Hospital, Southampton 	

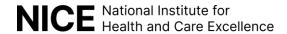
NICE is committed to promoting equality, eliminating unlawful discrimination and fostering good relations between people who share a protected characteristic and those who do not. Please let us know if we have missed any important organisations from the stakeholder list, and which organisations we should include that have a particular focus on relevant equality issues.

Definitions:

Consultees

Organisations that accept an invitation to participate in the evaluation; the company that markets the technology; national professional organisations; national patient organisations; the Department of Health and Social Care and relevant NHS organisations in England.

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The company that markets the technology is invited to make an evidence submission, respond to consultations, nominate clinical experts and has the right to appeal against the Final Draft Guidance (FDG).

All non-company consultees are invited to submit a statement relevant to the group they are representing, respond to consultations, nominate clinical or patient experts and have the right to appeal against the Final Draft Guidance (FDG).

Commentators

Organisations that engage in the evaluation process but that are not asked to prepare an evidence submission or statement, are able to respond to consultations and they receive the FDG for information only, without right of appeal. These organisations are: companies that market comparator technologies; Healthcare Improvement Scotland; related research groups where appropriate (for example, the Medical Research Council [MRC]); other groups (for example, the NHS Confederation and the British National Formulary).

All non-company commentators are invited to nominate clinical or patient experts.