

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Single Technology Appraisal

Idebenone for treating Duchenne muscular dystrophy [ID1092]

Final Stakeholder list of consultees and commentators

Consultees	Commentators (no right to submit or appeal)
<p><u>Company</u></p> <ul style="list-style-type: none"> • Santhera Pharmaceuticals (idebenone) <p><u>Patient/carer groups</u></p> <ul style="list-style-type: none"> • Action on Pain • Action Duchenne • Action for Sick Children • Alex's Wish • Arthritis & Musculoskeletal Alliance • Contact a Family • DMD Pathfinders • Disability Rights UK • Duchenne Family Support Group • Duchenne Now • Duchenne Research Fund • Duchenne UK • Genetic Alliance UK • Harrison's Fund • Information Advice and Support Service Network • Leonard Cheshire Disability • Muscular Dystrophy UK • Muslim Council of Britain • National Children's Bureau • South Asian Health Foundation • Specialised Healthcare Alliance • Together for Short Lives <p><u>Professional groups</u></p> <ul style="list-style-type: none"> • Association of Anaesthetists of Great Britain & Ireland • Association of Chartered Physiotherapists in Respiratory Care • Association of British Neurologists • Association of Genetic Nurses & 	<p><u>General</u></p> <ul style="list-style-type: none"> • All Wales Therapeutics and Toxicology Centre • Allied Health Professionals Federation • Board of Community Health Councils in Wales • British National Formulary • Care Quality Commission • Department of Health, Social Services and Public Safety for Northern Ireland • Healthcare Improvement Scotland • Medicines and Healthcare products Regulatory Agency • National Association of Primary Care • National Pharmacy Association • NHS Alliance • NHS Commercial Medicines Unit • NHS Confederation • Scottish Medicines Consortium • National Services division for Scotland • Welsh Health Specialised Services Committee <p><u>Possible comparator companies</u></p> <ul style="list-style-type: none"> • None <p><u>Relevant research groups</u></p> <ul style="list-style-type: none"> • British Myology Society • Cochrane Cystic Fibrosis and Genetic Disorders Group • Cochrane Musculoskeletal Group • John Walton Centre for Muscular Dystrophy (Newcastle University) • MRC Centre for Neuromuscular Diseases • MRC Clinical Trials Unit

Consultees	Commentators (no right to submit or appeal)
<p>Counsellors</p> <ul style="list-style-type: none"> • Association of Respiratory Nurse Specialists • Association of Surgeons of Great Britain and Ireland • British Cardiovascular Society • British Dietetic Association • British Institute of Musculoskeletal Medicine • British Orthopaedic Association • British Paediatric Neurology Association • British Paediatric Respiratory Society • British Society for Children's Orthopaedic Surgery • British Society for Gene and Cell Therapy • British Society for Genetic Medicine • British Society for Human Genetics • British Society of Rehabilitation Medicine • British Thoracic Society • Chartered Society of Physiotherapy • 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 • UK Genetic Testing Network • UK Clinical Pharmacy Association • The National Congenital Anomaly and Rare Disease Registration Service • The North Star Project <p><u>Others</u></p> <ul style="list-style-type: none"> • Department of Health • NHS England • NHS South Cheshire CCG • NHS West London CCG 	<ul style="list-style-type: none"> • National Institute for Health Research • TREAT-NMD <p><u>Associated Public Health Groups</u></p> <ul style="list-style-type: none"> • Public Health England • Public Health Wales

Consultees	Commentators (no right to submit or appeal)
<ul style="list-style-type: none"> Welsh Government 	

NICE is committed to promoting equality, eliminating unlawful discrimination and fostering good relations between people who share a protected characteristic and those who do share it. Please let us know if we have missed any important organisations from the lists in the matrix, and which organisations we should include that have a particular focus on relevant equality issues.

PTO FOR DEFINITIONS OF CONSULTEES AND COMMENTATORS

Definitions:

Consultees

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

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 Appraisal Determination (FAD).

All non-company consultees are invited to submit a statement¹, respond to consultations, nominate clinical or patient experts and have the right to appeal against the Final Appraisal Determination (FAD).

Commentators

Organisations that engage in the appraisal process but that are not asked to prepare an evidence submission or statement, are able to respond to consultations and they receive the FAD 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], National Cancer Research Institute); other groups (for example, the NHS Confederation, NHS Alliance and NHS Commercial Medicines Unit, and the British National Formulary.

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

¹ Non company consultees are invited to submit statements relevant to the group they are representing.