

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Highly Specialised Technologies Evaluation

Palovarotene for preventing heterotopic ossification associated with fibrodysplasia ossificans progressiva [ID3739]

Final Stakeholder List

Consultees	Commentators (no right to submit or appeal)
<p><u>Company</u></p> <ul style="list-style-type: none"> • Ipsen (palovarotene) <p><u>Patient/carer groups</u></p> <ul style="list-style-type: none"> • Action on Pain • Arthritis and Musculoskeletal Alliance • Beacon • Contact • Disability Rights UK • FOP Friends • Genetic Alliance UK • Gene People • Leonard Cheshire Disability • National Children's Bureau • Muscular Dystrophy UK • Pain Concern • Pain UK • South Asian Health Foundation • Specialised Healthcare Alliance <p><u>Professional groups</u></p> <ul style="list-style-type: none"> • Association of Genetic Nurses & Counsellors • British Association of Occupational Therapists and College of Occupational Therapists • British Geriatric Society • British Institute of Musculoskeletal Medicine • British Myology Society • British Orthopaedic Association • British Society for Children's Orthopaedic Surgery • British Society for Gene and Cell Therapy • British Society for Genetic Medicine • British Society for Human Genetics 	<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 • Cell and Gene Therapy Catapult • Department of Health, Social Services and Public Safety for Northern Ireland • Disease Service, Cardiff and Vale UHB • Healthcare Improvement Scotland • Medicines and Healthcare Products Regulatory Agency • National Association of Primary Care • National Pharmacy Association • National Services Division (specialised services in Scotland) • NHS Alliance • NHS Confederation • Scottish Medicines Consortium • Welsh Government • Welsh Health Specialised Services Committee <p><u>Comparator companies</u></p> <ul style="list-style-type: none"> • None <p><u>Relevant research groups</u></p> <ul style="list-style-type: none"> • Bone Research Society • Chronic Pain Policy Coalition • Cochrane Cystic Fibrosis & Genetic Disorders Group • Cochrane Musculoskeletal Group • Cochrane UK • Genomics England

Final stakeholder list for the highly specialised technologies evaluation of palovarotene for preventing heterotopic ossification associated with fibrodysplasia ossificans progressiva ID3739.

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Consultees	Commentators (no right to submit or appeal)
<ul style="list-style-type: none"> • British Society for Paediatric and Adolescent Rheumatology • British Society of Rehabilitation Medicine • Neonatal and Paediatric Pharmacists Group • Physiotherapy Pain Association • 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 Pharmaceutical Society • Royal Society of Medicine • Society for Endocrinology • UK Clinical Pharmacy Association • UK Genetic Testing Network <p><u>Others</u></p> <ul style="list-style-type: none"> • Department of Health and Social Care • Great Ormond Street Hospital - Rheumatology Department • NHS England • Royal Manchester Children's hospital • Royal National Orthopaedic Hospital • University Hospitals Bristol, Rheumatology Department • University of Edinburgh Western General Hospital, Rheumatic Diseases Unit 	<ul style="list-style-type: none"> • MRC Clinical Trials Unit • National Institute for Health Research • Orthopaedic Research UK • Pain Relief Foundation • University of Oxford FOP Research Team <p><u>Associated Public Health Groups</u></p> <ul style="list-style-type: none"> • Public Health Wales • Public Health Wales

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 provisional stakeholder list, and which organisations we should include that have a particular focus on relevant equality issues.

Consultees

Organisations that accept an invitation to participate in the evaluation; the manufacturer(s) or sponsor(s) of the technology; national professional organisations;

national patient organisations; the Department of Health and Social Care and relevant NHS organisations in England.

The company that markets the technology is invited to prepare a submission dossier, can respond to consultations, nominate clinical experts and has the right to appeal against the Final Appraisal Document (FAD).

All non- company consultees are invited to prepare a submission dossier respond to consultations on the draft scope, the Assessment Report and the Appraisal Consultation Document. They can nominate clinical or patient experts and have the right to appeal against the Final Appraisal Document (FAD).

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 final evaluation documentation for information only, without right of appeal. These organisations are: manufacturers of comparator technologies; Healthcare Improvement Scotland; the relevant National Collaborating Centre (a group commissioned by the Institute to develop clinical guidelines); other related research groups where appropriate (for example, the Medical Research Council [MRC], other groups (for example, the NHS Confederation, NHS Alliance, and the British National Formulary).

All non-company organisations can nominate clinical or patient experts to present their personal views to the Appraisal Committee