

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Single Technology Appraisal

Idebenone for treating visual impairment in Leber's hereditary optic neuropathy in people 12 years and over ID547

Provisional Stakeholder List

Consultees	Commentators (no right to submit or appeal)
<p><u>Company</u></p> <ul style="list-style-type: none"> • Chiesi (idebenone) <p><u>Patient / carer groups</u></p> <ul style="list-style-type: none"> • Eyecare Trust • Fight for Sight • Genetic Alliance UK • LHON Society • Lily Foundation • Macular Society • National Federation of the Blind of the UK • OBAC (Organisation of Blind African Caribbeans) • Retina UK • Royal National Institute of Blind People • SeeAbility • Sense • South Asian Health Foundation • Specialised Healthcare Alliance • Thomas Pocklington Trust <p><u>Healthcare professional groups</u></p> <ul style="list-style-type: none"> • Association of Optometrists • British and Irish Orthoptic Society • British Geriatrics Society • British Ophthalmic Anaesthesia Society • College of Optometrists • Optical Confederation • Royal College of General Practitioners • Royal College of Nursing • Royal College of Ophthalmologists • Royal College of Pathologists • Royal College of Physicians 	<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 • Healthcare Improvement Scotland • Medicines and Healthcare products Regulatory Agency • National Association of Primary Care • National Pharmacy Association • NHS Confederation • Scottish Medicines Consortium • Wales Council for the Blind • Welsh Government • Welsh Health Specialised Services Committee <p><u>Possible comparator companies</u></p> <ul style="list-style-type: none"> • GenSight Biologics (lenadogene nolparvovec) <p><u>Relevant research groups</u></p> <ul style="list-style-type: none"> • Cochrane Eyes and Vision Group • Cochrane UK • Eye Hope • Genomics England • Institute of Ophthalmology, University College London • MRC Clinical Trials Unit • National Eye Research Centre

Provisional stakeholder list for the evaluation of idebenone for treating visual impairment in Leber's hereditary optic neuropathy in people 12 years and over ID547

Issue date: May 2023

Consultees	Commentators (no right to submit or appeal)
<ul style="list-style-type: none"> • Royal Pharmaceutical Society • Royal Society of Medicine • UK Clinical Pharmacy Association <p><u>Others</u></p> <ul style="list-style-type: none"> • Department of Health and Social Care • NHS England • NHS Rare Mitochondrial Disorders Service 	<ul style="list-style-type: none"> • National Institute for Health Research <p><u>Associated Public Health groups</u></p> <ul style="list-style-type: none"> • Public Health Wales • UK Health Security Agency

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 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 Draft Guidance (FDG).

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 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], National Cancer Research Institute); other groups (for example, the NHS Confederation, NHS Alliance, and the British National Formulary).

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

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