

**NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE**

**Highly Specialised Technology Evaluation**

**Lenadogene nolparvovec for treating Leber's hereditary optic neuropathy caused by the G11778A ND4 mitochondrial mutation [ID1410]**

**Final stakeholder list of consultees and commentators**

<b>Consultees</b>	<b>Commentators (no right to submit or appeal)</b>
<p><u>Company</u></p> <ul style="list-style-type: none"> <li>• GenSight Biologics (lenadogene nolparvovec)</li> </ul> <p><u>Patient/carer groups</u></p> <ul style="list-style-type: none"> <li>• Eyecare Trust</li> <li>• Fight for Sight</li> <li>• LHON Society</li> <li>• Lily Foundation</li> <li>• Macular Society</li> <li>• National Federation of the Blind of the UK</li> <li>• OBAC</li> <li>• Royal National Institute of Blind People</li> <li>• SeeAbility</li> <li>• Sense</li> <li>• South Asian Health Foundation</li> <li>• Specialised Healthcare Alliance</li> <li>• Thomas Pocklington Trust</li> </ul> <p><u>Professional groups</u></p> <ul style="list-style-type: none"> <li>• Association of Optometrists</li> <li>• British and Irish Orthoptic Society</li> <li>• British Ophthalmic Anaesthesia Society</li> <li>• British Geriatrics Society</li> <li>• College of Optometrists</li> <li>• Health Lumen</li> <li>• Optical Confederation</li> <li>• Royal College of General Practitioners</li> <li>• Royal College of Nursing</li> <li>• Royal College of Ophthalmologists</li> </ul>	<p><u>General commentators</u></p> <ul style="list-style-type: none"> <li>• All Wales Therapeutics and Toxicology Centre</li> <li>• Allied Health Professionals Federation</li> <li>• Board of Community Health Councils in Wales</li> <li>• British National Formulary</li> <li>• Care Quality Commission</li> <li>• Department of Health, Social Services and Public Safety for Northern Ireland</li> <li>• European Conference on Rare Disease and Orphan Products (EURORDIS)</li> <li>• Fighting Blindness in Ireland</li> <li>• Healthcare Improvement Scotland</li> <li>• Medicines and Healthcare products Regulatory Agency</li> <li>• National Association of Primary Care</li> <li>• National Pharmacy Association</li> <li>• NHS Alliance</li> <li>• NHS Confederation</li> <li>• Scottish Medicines Consortium</li> <li>• Wales Council for the Blind</li> <li>• Welsh Health Specialised Services Committee</li> </ul> <p><u>Potential comparator companies</u></p> <ul style="list-style-type: none"> <li>• Chiesi (idebenone)</li> </ul> <p><u>Relevant research groups</u></p> <ul style="list-style-type: none"> <li>• Cochrane Eyes and Vision Group</li> <li>• Cochrane UK</li> <li>• Eye Hope</li> <li>• Genomics England</li> </ul>

<ul style="list-style-type: none"> <li>• Royal College of Pathologists</li> <li>• Royal College of Physicians</li> <li>• Royal Pharmaceutical Society</li> <li>• Royal Society of Medicine</li> <li>• UK Clinical Pharmacy Association</li> </ul> <p><u>Others</u></p> <ul style="list-style-type: none"> <li>• Department of Health and Social Care</li> <li>• NHS England</li> <li>• NHS Rare Mitochondrial Disorders Service</li> <li>• NHS East Lancashire CCG</li> <li>• NHS Hartlepool and Stockton-on-Tees CCG</li> <li>• Welsh Government</li> </ul>	<ul style="list-style-type: none"> <li>• Institute of Ophthalmology, University College London</li> <li>• MRC Clinical Trials Unit</li> <li>• National Eye Research Centre</li> <li>• National Institute for Health Research</li> </ul> <p><u>Associated Public Health Groups</u></p> <ul style="list-style-type: none"> <li>• Public Health Wales</li> <li>• UK Health Security Agency</li> </ul>
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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 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 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 specialists and has the right to appeal against the Final Appraisal Document (FAD).

All non-company consultees are invited to submit a statement<sup>1</sup>, respond to consultations, nominate clinical specialists or patient experts and have the right to appeal against the Final Appraisal Document (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; other 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).

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

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