

## NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

### Highly Specialised Technology

#### Fosdenopterin for treating molybdenum cofactor deficiency type A ID6264

#### Provisional Stakeholder List

Consultees	Commentators (no right to submit or appeal)
<p><u>Company</u></p> <ul style="list-style-type: none"> <li>• Sentyln Therapeutics (Fosdenopterin)</li> </ul> <p><u>Patient/carer groups</u></p> <ul style="list-style-type: none"> <li>• Anthony Nolan</li> <li>• Beacon</li> <li>• Brain and Spine Foundation</li> <li>• Brain Charity</li> <li>• Contact</li> <li>• Epilepsy Action</li> <li>• Epilepsy Society</li> <li>• Gene People</li> <li>• Genetic Alliance UK</li> <li>• Metabolic Support UK</li> <li>• National Council of Palliative Care</li> <li>• Neurological Alliance</li> <li>• Sue Ryder</li> <li>• Together for Short Lives</li> <li>• South Asian Health Foundation</li> <li>• Specialised Healthcare Alliance</li> <li>• Young Epilepsy</li> </ul> <p><u>Healthcare professional groups</u></p> <ul style="list-style-type: none"> <li>• Association of British Neurologists</li> <li>• Association of Genetic Nurses &amp; Counsellors</li> <li>• British Inherited Metabolic Disease Group</li> <li>• British Neuropathological Society</li> <li>• British Paediatric Epilepsy Group</li> <li>• British Society for Genetic Medicine</li> <li>• Epilepsy Nurses Association</li> <li>• International League Against Epilepsy British Branch</li> <li>• Institute of Neurology</li> <li>• National Neuroscience Advisory Group</li> </ul>	<p><u>General</u></p> <ul style="list-style-type: none"> <li>• All Wales Inherited Metabolic Disease Service</li> <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>• 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>• National Services Division</li> <li>• Neurological Alliance of Scotland</li> <li>• NHS Confederation</li> <li>• Scottish Medicines Consortium</li> <li>• Wales Neurological Alliance</li> <li>• Welsh Government</li> <li>• Welsh Health Specialised Services Committee</li> </ul> <p><u>Possible comparator companies</u></p> <ul style="list-style-type: none"> <li>• None</li> </ul> <p><u>Relevant research groups</u></p> <ul style="list-style-type: none"> <li>• Brain Research UK</li> <li>• Cochrane Metabolic &amp; Endocrine Disorders Group</li> <li>• Cochrane UK</li> <li>• Genomics England</li> <li>• MRC Clinical Trials Unit</li> <li>• National Hospital for Neurology and</li> </ul>

Provisional stakeholder list for the evaluation of fosdenopterin for treating molybdenum cofactor deficiency type A ID6264. Issue date: July 2023

Consultees	Commentators (no right to submit or appeal)
<ul style="list-style-type: none"> <li>• National Metabolic Biochemistry Network</li> <li>• Neonatal and Paediatric Pharmacists Group</li> <li>• Primary Care and Community Neurology Society</li> <li>• Royal College of General Practitioners</li> <li>• Royal College of Nursing</li> <li>• Royal College of Paediatrics &amp; Child Health</li> <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>• Birmingham Children’s Hospital NHS Foundation Trust</li> <li>• Bradford Royal Infirmary</li> <li>• Bristol Royal Hospital for Children, Southwest Regional Metabolic Department</li> <li>• Department of Health and Social Care</li> <li>• Evelina London Children’s Hospital, Guy’s and St Thomas’ NHS Foundation Trust</li> <li>• Great Ormond Street Hospital Metabolic Unit</li> <li>• NHS England</li> <li>• Sheffield Children’s NHS Foundation Trust</li> <li>• University Hospitals of Leicester NHS Trust</li> <li>• University Hospital Southampton NHS Foundation Trust</li> <li>• Willink Unit, Genetic Medicine, Manchester University Hospitals NHS Foundation Trust</li> </ul>	<p>Neurosurgery</p> <ul style="list-style-type: none"> <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>

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.

### 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 statement<sup>1</sup>, 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).

All non-company commentators are invited to nominate clinical 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.