

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Highly Specialised Technologies Evaluation

Leriglitzone for treating cerebral adrenoleukodystrophy in people 2 years and over [ID3903]

Stakeholder List

Consultees	Commentators (no right to submit or appeal)
<p><u>Company</u></p> <ul style="list-style-type: none"> • Neuraxpharm UK <p><u>Patient/carer groups</u></p> <ul style="list-style-type: none"> • Addison's Disease Self-Help Group • Alex The Leukodystrophy Charity • Anthony Nolan • Beacon • Brain and Spine Foundation • Brain Charity • Gene People • Genetic Alliance UK • Kidney Care UK • Kidney Research UK • Metabolic Support UK • National Kidney Federation • Neurological Alliance • 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 British Neurologists • Association of Genetic Nurses & Counsellors • British Association of Paediatric Nephrology • British Association of Endocrine and Thyroid Surgeons • British Association of Urological Nurses • British Geriatrics Society • British Inherited Metabolic Disease Group 	<p><u>General</u></p> <ul style="list-style-type: none"> • All Wales Inherited Metabolic Disease Service • All Wales Therapeutics and Toxicology Centre • Allied Health Professionals Federation • Association of Renal Industries • Board of Community Health Councils in Wales • British National Formulary • Care Quality Commission • Cell and Gene Therapy Catapult • Department of Health - Northern Ireland • Healthcare Improvement Scotland • Medicines and Healthcare Products Regulatory Agency • National Association of Primary Care • National Pharmacy Association • National Services Division • Neurological Alliance of Scotland • NHS Confederation • NHS Wales Joint Commissioning Committee • Scottish Medicines Consortium • Wales Neurological Alliance • Welsh Government <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"> • Brain Research UK • Cochrane Metabolic and Endocrine Disorders Group

Stakeholder list for the evaluation of Leriglitzone for treating cerebral adrenoleukodystrophy in people 2 years and over [ID3903]

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Consultees	Commentators (no right to submit or appeal)
<ul style="list-style-type: none"> • British Neuropathological Society • British Paediatric Neurology Association • British Society for Gene and Cell Therapy • British Society for Genetic Medicine • British Society for Paediatric Endocrinology & Diabetes • British Society of Blood and Marrow Transplantation • National Metabolic Biochemistry Network • National Neuroscience Advisory Group • Neonatal and Paediatric Pharmacists Group • NHS Blood and Transplant • Primary Care and Community Neurology Society • 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 Society of Medicine • Society for Endocrinology • UK Clinical Pharmacy Association • UK Kidney Association • UK Renal Pharmacy Group <p><u>Others</u></p> <ul style="list-style-type: none"> • Birmingham Women's and Children's Hospital NHS Foundation Trust • Central Manchester Foundation Trust, Willink Unit, Genetic Medicine • Department of Health and Social Care • Great Ormond Street Hospital for Children NHS Foundation Trust • Guy's and St Thomas' NHS Foundation Trust • Health Technology Wales • Leeds Teaching Hospitals NHS Trust • NHS England 	<ul style="list-style-type: none"> • Cochrane UK • Genomics England • MRC Clinical Trials Unit • National Hospital for Neurology and Neurosurgery • 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

Consultees	Commentators (no right to submit or appeal)
<ul style="list-style-type: none"> • Salford Royal Hospital Mark Holland Metabolic Unit, Northern Care Alliance NHS Foundation Trust • University College London Hospital Charles Dent Metabolic Unit • University Hospital Birmingham Foundation Trust, Department of Endocrinology 	

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:

Consultee or commentator stakeholders are provisional until a signed Confidentiality Agreement & Undertaking form is submitted to NICE at the evaluation stage. Participating stakeholders will be listed on the project information page for the evaluation.

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 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 relevant to the group they are representing, 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]); other groups (for example, the NHS Confederation and the British National Formulary).

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