

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Highly Specialised Technologies Evaluation

Leriglitzone for adrenoleukodystrophy ID3903

Provisional Stakeholder List

Consultees	Commentators (no right to submit or appeal)
<p><u>Company</u></p> <ul style="list-style-type: none"> • Minoryx (leriglitzone) <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 • Brain and Spine Foundation • Brain Charity • Contact • Findacure • Genetic Alliance UK • Kidney Care UK • Kidney Research UK • Metabolic Support UK • National Kidney Federation • Neurological Alliance • Polycystic Kidney Disease Charity • South Asian Health Foundation • Specialised Healthcare Alliance <p><u>Professional groups</u></p> <ul style="list-style-type: none"> • Association of Genetic Nurses & Counsellors • Association of Renal Technologists • British Association of Neurologists • British Association of Urological Nurses • British Geriatrics Society • British Neuropathological Society • British Society for Gene and Cell Therapy • British Society for Genetic Medicine • British Society for Human Genetics • British Society of Blood and Marrow Transplantation 	<p><u>General</u></p> <ul style="list-style-type: none"> • 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, Social Services and Public Safety for Northern Ireland • Healthcare Improvement Scotland • Inherited Metabolic and Lysosomal Disease Service, Cardiff and Value UHB • Medicines and Healthcare Products Regulatory Agency • National Association of Primary Care • National Pharmacy Association • National Services Division • Neurological Alliance of Scotland • NHS Alliance • NHS Confederation • Scottish Medicines Consortium • Wales Neurological Alliance • Welsh Government • Welsh Health Specialised Services Committee • Welsh Kidney Patients Association <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

Consultees	Commentators (no right to submit or appeal)
<ul style="list-style-type: none"> • Institute of Neurology • NHS Blood and Transplant • Primary Care and Community Neurology Society • Royal College of General Practitioners • Royal College of Nursing • Royal College of Pathologists • Royal College of Physicians • Royal Society of Medicine • Society for DGH Nephrologists • UK Clinical Pharmacy Association • UK Genetic Testing Network • UK Kidney Association • UK Renal Pharmacy Group <p><u>Others</u></p> <ul style="list-style-type: none"> • Central Manchester Foundation Trust, Willink Unit, Genetic Medicine • Department of Health and Social Care • NHS England • Salford Royal NHS Foundation Trust Mark Holland Metabolic Unit • University College London Hospital Charles Dent Metabolic Unit • University Hospital Birmingham Foundation Trust, Department of Endocrinology, 	<ul style="list-style-type: none"> • Cochrane Cystic Fibrosis & Genetic Disorders Group • Cochrane Kidney and Transplant Group • 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 England • 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 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 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 experts and has the right to appeal against the Final Appraisal Document (FAD).

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 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; 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.

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