

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Proposed Highly Specialised Technology Evaluation

Sebelipase alfa for treating lysosomal acid lipase deficiency [ID737]

Provisional matrix of consultees and commentators

Consultees	Commentators (no right to submit or appeal)
<p><u>Company</u></p> <ul style="list-style-type: none"> • Synageva BioPharma (sebelipase alfa) <p><u>Patient/carer groups</u></p> <ul style="list-style-type: none"> • Afiya Trust • Black Health Agency • British Liver Trust • Children's Liver Disease Foundation • Children Living with Inherited Metabolic Diseases • Contact a Family • Equalities National Council • Genetic Alliance UK • Heart UK • Jewish Genetic Disorders UK • Liver4Life • MPS Society • Muslim Council of Britain • Muslim Health Network • South Asian Health Foundation • Specialised Healthcare Alliance <p><u>Professional groups</u></p> <ul style="list-style-type: none"> • Addenbrooke's Lysosomal Disorders Unit • Association of Genetic Nurses and Counsellors • Association of Surgeons of Great Britain and Ireland • Birmingham Children's Hospital NHS Foundation Trust • British Inherited Metabolic Disease Group • British Society for Genetic Medicine • Charles Dent Metabolic Unit, UCLH • London Guy's Hospital Genetic Centre • Manchester Centre for Genomic Medicine • Department of Endocrinology, UHBFT • Mark Holland Metabolic Unit for Adult 	<p><u>General</u></p> <ul style="list-style-type: none"> • Allied Health Professionals Federation • Association of Renal Industries • Board of Community Health Councils in Wales • British National Formulary • Care Quality Commission • 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 Alliance • NHS Commercial Medicines Unit • NHS Confederation • Scottish Medicines Consortium • Welsh Government <p><u>Possible comparator manufacturers</u></p> <ul style="list-style-type: none"> • None <p><u>Relevant research groups</u></p> <ul style="list-style-type: none"> • Cochrane Cystic Fibrosis and Genetic Disorders Group • Health Research Authority • MRC Clinical Trials Unit • National Institute for Health Research • Society for the Study of Inborn Errors of Metabolism <p><u>Evidence Review Group</u></p> <ul style="list-style-type: none"> • Evidence Review Group tbc • National Institute for Health Research Health Technology Assessment <p><u>Associated Guideline Groups</u></p> <ul style="list-style-type: none"> • National Clinical Guidelines Centre

Consultees	Commentators (no right to submit or appeal)
<p>Inherited Metabolic Disorders, SRFT</p> <ul style="list-style-type: none"> • Metabolic Medicine Unit, GOSH • National Metabolic Biochemistry Network • 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 Free Lysosomal storage disorders unit • Royal Pharmaceutical Society • Royal Society of Medicine • Society for DGH Nephrologists • UK Genetic Testing Network • UK Clinical Pharmacy Association • Willink Unit, Genetic Medicine, CMFT <p><u>Others</u></p> <ul style="list-style-type: none"> • Department of Health • NHS England • NHS Hastings & Rother CCG • NHS West Hampshire CCG 	<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 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 evaluation; the manufacturer(s) or sponsor(s) of the technology; national professional organisations; national patient organisations; the Department of Health and relevant NHS organisations in England.

The company that manufacture the technology is invited to make an evidence submission, respond to consultations, nominate clinical specialists and has the right to appeal against the recommendations.

All non-manufacturer/sponsor consultees are invited to make an evidence submission or submit a statement¹, respond to consultations, nominate clinical specialists or patient experts and have the right to appeal against the recommendations.

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 final evaluation documentation for information only, without right of appeal. These organisations are: manufacturers of comparator technologies; Healthcare Improvement Scotland; the relevant National Collaborating Centre (a group commissioned by the Institute to develop clinical guidelines); other related research groups where appropriate (for example, the Medical Research Council [MRC], other groups (for example, the NHS Confederation, NHS Alliance and NHS Commercial Medicines Unit, and the British National Formulary).

All non-manufacturer/sponsor commentators are invited to nominate clinical specialists or patient experts.

Evidence Review Group (ERG)

An independent academic group commissioned by the National Institute for Health Research (NIHR) Health Technology Assessment Programme (HTA Programme) to assist the HST Evaluation Committee in reviewing the manufacturer/sponsor evidence submission to the Institute.

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