

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Single Technology Appraisal

Fenfluramine for treating Dravet syndrome [ID1109]

Final Stakeholder List

Consultees	Commentators (no right to submit or appeal)
<p><u>Company</u></p> <ul style="list-style-type: none"> • Zogenix International (fenfluramine) <p><u>Patient/carer groups</u></p> <ul style="list-style-type: none"> • Brain and Spine Foundation • Disability Rights UK • Dravet Syndrome UK • Epilepsy Action • Joint Epilepsy Council • Leonard Cheshire Disability • Muslim Council of Britain • Neurological Alliance • S.T.A.B.L.E (Supporting those affected by Lifelong Epilepsy) • South Asian Health Foundation • Specialised Healthcare Alliance • SUDEP Action • The Brain Charity • Young Epilepsy <p><u>Professional groups</u></p> <ul style="list-style-type: none"> • Association of British Neurologists • British Neuropathological Society • British Paediatric Neurology Association • Epilepsy Nurses Association • Epilepsy Society • Institute of Neurology • International League Against Epilepsy UK • Neuromodulation Society of UK and Ireland • Primary Care Neurology Society • Royal College of General Practitioners • Royal College of Nursing • Royal College of Paediatrics and Child Health • Royal College of Pathologists 	<p><u>General</u></p> <ul style="list-style-type: none"> • All Wales Therapeutics and Toxicology Centre • Allied Health Professionals Federation • Board of Community Health Councils in Wales • British National Formulary • Care Quality Commission • Department of Health, Social Services and Public Safety for Northern Ireland • Epilepsy Wales • Healthcare Improvement Scotland • Medicines and Healthcare Products Regulatory Agency • National Association of Primary Care • National Pharmacy Association • Neurological Alliance of Scotland • NHS Alliance • NHS Confederation • Scottish Medicines Consortium • Wales Neurological Alliance • Welsh Health Specialised Services Committee <p><u>Comparator Companies</u></p> <ul style="list-style-type: none"> • GW Pharma (cannabidiol) • Accord Healthcare (clobazam, topiramate) • Atnahs Pharma UK (clobazam) • Aurobindo Pharma - Milpharm (topiramate) • Biocodex (stiripentol) • Desitin Pharma (sodium valproate) • Janssen (topiramate) • Martindale Pharma (clobazam) • Mylan (topiramate) • Rosemont Pharmaceuticals (clobazam) • Sandoz (topiramate)

<ul style="list-style-type: none"> • Royal College of Physicians • Royal Pharmaceutical Society • Royal Society of Medicine • United Kingdom Clinical Pharmacy Association <p><u>Others</u></p> <ul style="list-style-type: none"> • Department of Health and Social Care • NHS Central London CCG • NHS England • NHS West Leicestershire CCG • Welsh Government 	<ul style="list-style-type: none"> • Sanofi (clobazam, sodium valproate) • Thame Laboratories (clobazam) • Wockhardt UK (sodium valproate) • Zentiva (sodium valproate) <p><u>Relevant Research Groups</u></p> <ul style="list-style-type: none"> • British Neurological Research Trust • Cochrane Epilepsy Group • Epilepsy Research UK • MRC Clinical Trials Unit • 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
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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 statement¹, 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.

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