

## NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

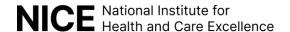
# **Single Technology Appraisal**

# Triheptanoin for treating long-chain fatty acid oxidation disorders ID3891

## **Provisional Stakeholder List**

Provisional Consultees	Provisional Commentators (no right to submit or appeal)
Company	General
Ultragenyx (triheptanoin)	All Wales Inherited Metabolic Disease
	Service Cardiff
Patient/carer groups	All Wales Therapeutics and Toxicology
Action on Pain	Centre
Alex – The Leukodystrophy Charity	Allied Health Professionals Federation
ArchAngel MLD Trust	Board of Community Health Councils in
Gene People	Wales
Genetic Alliance UK	British National Formulary
Metabolic Support UK	Care Quality Commission
Pain Concern	Department of Health - Northern Ireland
Pain UK	Healthcare Improvement Scotland
South Asian Health Foundation	Medicines and Healthcare products
Specialised Healthcare Alliance	Regulatory Agency
	National Association of Primary Care
Healthcare professional groups	National Pharmacy Association
Association of Genetic Nurses &	National Services Division
Counsellors	NHS Confederation
British Association of Perinatal	Scottish Medicines Consortium
Medicine	Scottish Society of Gastroenterology
British Geriatrics Society  British Inheritad Madelalia Bianaga	Welsh Government
British Inherited Metabolic Disease     Crount	Welsh Health Specialised Services
Group	Committee
British Nutrition Foundation     British Society for Deadiatric	Descible comparator companies
British Society for Paediatric  Endestinatory & Diabetes	Possible comparator companies  None
Endocrinology & Diabetes	• None
<ul><li>British Society of Gastroenterology</li><li>British Society for Genetic Medicine</li></ul>	Relevant research groups
Clinical Genetics Society	Cochrane Metabolic & Endocrine
Institute of Child Health	Disorders Group
ALC: INACLE: DOLLEC	Genomics England
National Metabolic Biochemistry     Network (MetBio)	MRC Clinical Trials Unit
Nutrition Society	National Institute for Health Research
Primary Care Society for	. Isaariai matata isi matati Koodi ofi
Gastroenterology	Associated Public Health groups
<ul> <li>Royal College of General Practitioners</li> </ul>	Faculty of Public Health
Royal College of Midwives	Public Health Wales

Provisional stakeholder list for the evaluation of triheptanoin for treating long-chain fatty acid oxidation disorders ID3891



Provisional Consultees	Provisional Commentators (no right to submit or appeal)
<ul> <li>Royal College of Nursing</li> <li>Royal College of Paediatrics and 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> <li>Society for Endocrinology</li> </ul>	UK Health Security Agency
<ul> <li>Others</li> <li>Department of Health and Social Care</li> <li>Great Ormond Street Hospital –         Metabolic Medicine Department</li> <li>NHS England</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.

#### **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.

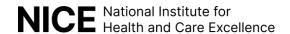
#### Consultees

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).

Provisional stakeholder list for the evaluation of triheptanoin for treating long-chain fatty acid oxidation disorders ID3891



### 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.