

**Subject: Specialised Services Circular (SSC)**  
**Sent on behalf of: Chair of the SW Specialised Service Circular Group**

Dear Colleagues,

Please find attached the following Specialised Services Circular(s):

<b>SSC Number</b>	<b>SSC Title</b>	<b>Trusts approved to prescribe in accordance with the SSC, providing appropriate internal governance arrangements are in place</b>
2788	<b>NICE Technology Appraisal Final Draft Guidance: Fenfluramine for treating seizures associated with Lennox–Gastaut syndrome in people 2 years and over</b>	North Bristol Trust – adult patients University Hospitals Bristol and Weston – paediatric patients

**Is an implementation plan required from all SW trusts (regardless of commissioned status) for this SSC? No**

**For all other South West region trusts this is for information only.**

Trusts should ensure that use is registered on the Blueteq system (if appropriate).

Treatment will only be funded where the drugs minimum dataset is fully and accurately populated.

Please direct any queries to: [england.speccomm-southwest@nhs.net](mailto:england.speccomm-southwest@nhs.net)

All Chief Executives

All Medical Directors

All Chief Pharmacists

Specialised Commissioning  
South West  
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Email: [england.speccomm-southwest@nhs.net](mailto:england.speccomm-southwest@nhs.net)

04 March 2025

Dear Colleagues,

**Re: NICE Technology Appraisal Final Draft Guidance: Fenfluramine for treating seizures associated with Lennox–Gastaut syndrome in people 2 years and over**

I am writing to advise you regarding the funding position on the recently published NICE Technology Appraisal Final Draft Guidance (FDG) for fenfluramine for treating seizures associated with Lennox–Gastaut syndrome in people 2 years and over.

The FDG can be found at: <https://www.nice.org.uk/guidance/indevelopment/gid-ta10653>.

NICE in their FDG published on 20<sup>th</sup> February 2025 has stated that:

Fenfluramine is recommended as an option for treating seizures associated with Lennox–Gastaut syndrome (LGS), as an add-on to other antiseizure medicines, for people 2 years and over. It is recommended only if:

- the frequency of drop seizures is checked every 6 months, and fenfluramine is stopped if the frequency is not reduced by at least 30% compared with the 6 months before starting treatment

Fenfluramine will be available via the Innovative Medicines Fund (IMF) from 20<sup>th</sup> February 2025 in line with these recommendations and according to a set of treatment criteria which translates the NICE recommendation into a clinical guide as to use in practice. These treatment criteria can be found on the application form(s) on the Blueteq site.

NHS England will then routinely commission fenfluramine in patients with Lennox–Gastaut syndrome via commissioned centres (Appendix 1), incorporating these treatment criteria, including those contained within this letter from 90 days after the day of publication of the final guidance.

In addition, commissioned centres must:

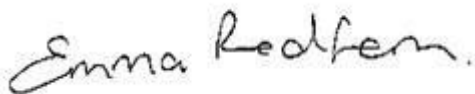
- Ensure that they are purchasing fenfluramine at the agreed proposed patient access scheme (PAS) discounted price. This discounted price will be applied automatically at point of invoice and applies to all indications.

- Ensure that, until 90 days<sup>1</sup> after publication of the final guidance from NICE, only invoices for the drug procurement costs of fenfluramine in this indication are directed to the IMF and that they are also submitting complete and accurate information via the IMF minimum dataset (MDS).
- In line with the terms and conditions included in the NHS Standard Contract, Schedule 6a Reporting Requirements for drugs will apply. Payment of Trust invoices will be contingent on the completion of the MDS record and this information being made available in a timely way.
- Patients are registered via Blueteq (FEN1) and meet the clinical criteria on the registration form during the interim funding period.
- **Payment of Trust invoices will be contingent on Blueteq registration and IMF MDS record applicable to the drug being completed and this information being made available in timely way.**
- Ensure that local governance aspects (e.g. technical issues, education & training, patient information) have been identified and addressed for all staff groups (as appropriate) in order to permit the safe delivery of this therapy.

Trusts should refer to the CAP portal for further information on the PAS price. The CAP portal is available at <https://nhsengland.sharefile.eu/Authentication/Login>

I would be grateful if you could cascade this information to relevant clinical teams within your organisation to support the consistent adoption of the policy nationally.

With best wishes,



Emma Redfern  
Medical Director NHS England South West  
Region



Tracey Williams  
Principal Pharmacist

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<sup>1</sup> Delete as appropriate – funding for EAMS drugs will continue for 30 days and all other drugs for 90 days

## **Appendix 1 – Commissioned centres**

ALDER HEY CHILDREN'S NHS FOUNDATION TRUST

BARTS HEALTH NHS TRUST

BIRMINGHAM WOMEN'S AND CHILDREN'S NHS FOUNDATION TRUST

BRIGHTON AND SUSSEX UNIVERSITY HOSPITALS NHS TRUST

CAMBRIDGE UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

GREAT ORMOND STREET HOSPITAL FOR CHILDREN NHS FOUNDATION TRUST

GUY'S AND ST THOMAS' NHS FOUNDATION TRUST

HULL UNIVERSITY TEACHING HOSPITALS NHS TRUST

IMPERIAL COLLEGE HEALTHCARE NHS TRUST

KING'S COLLEGE HOSPITAL NHS FOUNDATION TRUST

LANCASHIRE TEACHING HOSPITALS NHS FOUNDATION TRUST

LEEDS TEACHING HOSPITALS NHS TRUST

MANCHESTER UNIVERSITY FOUNDATION TRUST

NORFOLK AND NORWICH UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

NORTH BRISTOL NHS TRUST

NORTHERN CARE ALLIANCE NHS FOUNDATION TRUST

NOTTINGHAM UNIVERSITY HOSPITALS NHS TRUST

OXFORD UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

SHEFFIELD CHILDREN'S NHS FOUNDATION TRUST

SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST

SOUTH TEES HOSPITALS NHS FOUNDATION TRUST

ST GEORGE'S UNIVERSITY HOSPITALS NHS FOUNDATION TRUST

THE NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST

THE WALTON CENTRE NHS FOUNDATION TRUST

UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST

UNIVERSITY HOSPITAL SOUTHAMPTON NHS FOUNDATION TRUST

UNIVERSITY HOSPITALS BIRMINGHAM NHS FOUNDATION TRUST

UNIVERSITY HOSPITALS BRISTOL AND WESTON NHS FOUNDATION TRUST

UNIVERSITY HOSPITALS COVENTRY AND WARWICKSHIRE NHS TRUST

UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST

UNIVERSITY HOSPITALS OF NORTH MIDLANDS NHS TRUST