

Subject: Specialised Services Circular (SSC 2885)

Sent on behalf of: Chair of the SW Specialised Service Circular Group

Dear Colleagues,

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

SSC Number	SSC Title	Trusts approved to prescribe in accordance with the SSC, providing appropriate internal governance arrangements are in place
SSC 2885	NICE Technology Appraisal Final Guidance Idefenone for treating visual impairment in Leber's hereditary optic neuropathy in people 12 years and over	University Hospitals Bristol and Weston

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

Please note this circular supersedes SSC 2881 (Specialised Commissioning Update on future NICE Appraisals, published in August 2025, which are due to be commissioned in November 2025). The commissioned provider is UHBW.

Specialised Commissioning South West
NHS England
100 Temple Street
Bristol
BS1 6AG
Email: england.speccomm-southwest@nhs.net

22 September 2025

All Chief Executives

All Medical Directors

All Chief Pharmacists

Dear Colleagues,

Re: NICE Technology Appraisal Final Guidance: Idebenone for treating visual impairment in Leber's hereditary optic neuropathy in people 12 years and over

I am writing to advise you regarding the funding position on the recently published NICE Technology Appraisal Final Guidance (TA1093) for idebenone for treating visual impairment in Leber's hereditary optic neuropathy in people 12 years and over.

TA1093 can be found at: <https://www.nice.org.uk/guidance/ta1093>.

NICE in their guidance published on 28th August 2025 has stated that:

Idebenone is recommended, within its marketing authorisation, as an option for treating visual impairment in Leber's hereditary optic neuropathy (LHON) in people 12 years and over.

Idebenone will be available via the Innovative Medicines Fund (IMF) from 10th September 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 idebenone in patients with LHON via

commissioned centres (Appendix 1), incorporating these treatment criteria, including those contained within this letter from Wednesday 26th November. Regions should explore opportunities to expand provision through shared-care prescribing with appropriate specialised ophthalmology providers within the region.

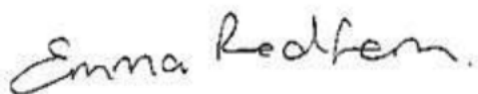
In addition, commissioned centres must:

- Ensure that they are purchasing idebenone 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 after publication of the final guidance from NICE, only invoices for the drug procurement costs of idebenone 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 (IDE1) 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

Appendix 1 – List of commissioned centres

- Cambridge University Hospitals NHS Foundation Trust
- Manchester University NHS Foundation Trust
- Moorfields Eye Hospital NHS Foundation Trust.
- Oxford University Hospitals NHS Foundation Trust
- The Newcastle upon Tyne Hospitals NHS Foundation Trust
- University College London Hospitals NHS Foundation Trust,
- University Hospitals Birmingham NHS Foundation Trust
- University Hospitals Bristol and Weston NHS Foundation Trust