

Our Reference North East and North Cumbria ICB\  
FOI ICB 24–183

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By Email

31 July 2024

Dear Applicant

**Freedom of Information Act 2000 – Request for Information – NHS North East and North Cumbria Integrated Care Board (NENC ICB)**

Thank you for your request received by North of England Commissioning Support (NECS) on 24 July 2024 for information held by NHS North East and North Cumbria Integrated Care Board (the ICB) under the provisions of the Freedom of Information Act 2000.

The ICB covers the areas of County Durham, Gateshead, Newcastle, North Cumbria, North Tyneside, Northumberland, South Tyneside, Sunderland, and Tees Valley (which covers the five local authorities of Darlington, Hartlepool, Middlesbrough, Redcar and Cleveland and Stockton-on-Tees).

Please find the information you requested on behalf of the ICB as follows.

**Your Request**

Please find below a freedom of information request relating to local policies and guidelines for the treatment of Dravet syndrome and Lennox-Gastaut syndrome.

1. Does NHS North East and North Cumbria ICB have any local guidelines or policies for the treatment of Dravet syndrome and/or Lennox-Gastaut syndrome? (Yes/No) If yes, please provide a copy.
2. Does NHS North East and North Cumbria ICB have any policies for the use of cannabidiol (Epidyolex)? (Yes/No) If yes, please provide a copy.
3. Does NHS North East and North Cumbria ICB have any policies for the use of fenfluramine (Fintepla)? (Yes/No) If yes, please provide a copy.

**Our Response**

We can confirm, as per Section 1(1) of the Freedom of Information Act 2000, the ICB holds some of the information you have requested.

1. NHS NENC ICB has no local guidelines or policies for the treatment of Davet syndrome and / or Lennox-Gastaut syndrome. NICE guidelines are followed.
2. Epidyolex is listed on formulary. Details available at: [North East and North Cumbria Formulary \(northeastnorthcumbriaformulary.nhs.uk\)](http://northeastnorthcumbriaformulary.nhs.uk)
3. Fenfluramine is listed on formulary. Details available at: [North East and North Cumbria Formulary \(northeastnorthcumbriaformulary.nhs.uk\)](http://northeastnorthcumbriaformulary.nhs.uk)

In accordance with s.21 of the FOIA, we are not required to provide information in response to a request if it is reasonably accessible to you by other means.

In accordance with the Information Commissioner's directive on the disclosure of information under the Freedom of Information Act 2000 your request will form part of our disclosure log. Therefore, a version of our response which will protect your anonymity will be posted on the NHS ICB website <https://northeastnorthcumbria.nhs.uk/>.

If you have any queries or wish to discuss the information supplied, please do not hesitate to contact me on the above telephone number or at the above address.

If you are unhappy with the service you have received in relation to your request and wish to request a review of our decision, you should write to the Senior Governance Manager using the contact details at the top of this letter quoting the appropriate reference number.

If you are not content with the outcome your review, you do have the right of complaint to the Information Commissioner as established by section 50 of the Freedom of Information Act 2000. Generally, the Information Commissioner cannot make a decision unless you have exhausted the complaints procedure provided by the North of England Commissioning Support Unit.

The Information Commissioner can be contacted at:

Information Commissioner's Office  
Wycliffe House  
Water Lane  
Wilmslow  
Cheshire  
SK9 5AF

[www.ico.org.uk](http://www.ico.org.uk)

Any information we provide following your request under the Freedom of Information Act will not confer an automatic right for you to re-use that information, for example to publish it. If you wish to re-use the information that we provide and you do not specify this in your initial application for information then you must make a further request for its re-use as per the Re-Use of Public Sector Information Regulations 2015 [www.legislation.gov.uk](http://www.legislation.gov.uk) . This will not affect your initial information request.

Yours sincerely

*S Davies*

**S Davies**  
**Information Governance Officer**