

Date 24 August 2026
Your Ref
Our Ref 11769

Enquiries to Richard Mutch
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Dear y

FREEDOM OF INFORMATION – RARE DISEASES

I write in response to your request for information in relation to rare diseases.

Question:

1. How many total patients has the trust seen within the latest 24 months of available data (for any reason), with a recorded diagnosis of Dravet Syndrome (DS)
2. Of total DS patients, how many have been treated with Epidyolex (Cannabidiol) in the last 12 months?
3. Of total DS patients, how many have been treated with Fintepla (Fenfluramine) in the last 12 months?
4. How many total patients has the trust seen within the latest 24 months of available data (for any reason), with a recorded diagnosis of Lennox-Gastaut Syndrome (LGS)
5. Of total LGS patients, how many have been treated with Epidyolex (Cannabidiol) in the last 12 months?
6. Of total LGS patients, how many have been treated with Fintepla (Fenfluramine) in the last 12 months?
7. How many adult (aged 18+) patients has the trust seen within the latest 24 months of available data (for any reason), with a recorded diagnosis of Dravet Syndrome (DS)
8. How many adult (aged 18+) patients has the trust seen within the latest 24 months of available data (for any reason), with a recorded diagnosis of Lennox-Gastaut Syndrome (LGS)

Answer:

1.	Unable to confirm*
2.	0
3.	5<
4.	Unable to confirm*
5.	9
6.	0
7.	Unable to confirm*
8.	Unable to confirm*

*I am advised we are unable to provide an answer for this request. To identify how many patients with Dravet Syndrome or Lennox-Gastaut Syndrome have been seen across all services and who have received Epidyolex (Cannabidiol) and Fintepla (Fenfluramine), we would need to undertake complex data linkage between multiple datasets. This would require us to match diagnosis information with prescribing or treatment records at an individual level.

Under the Freedom of Information Act NHS Lothian is not required to create new records to enable it to respond to your enquiry. This information is not collated or held in aggregate form and it would be necessary to review all case files relating to patients over the period you have requested to assemble the information you seek. Even if NHS Lothian did this – and there would be significant cost implications in doing so – it would be unable to respond in full to your request. The information requested is therefore exempt under section 12.1 – Cost.

To protect the identity of the individuals involved any figure of 5 or less has not been shown in the table above. Since we do not have their consent to release this data from their records, the information is exempt under section 38(1)(b) of the Freedom of Information (Scotland) Act i.e. to provide it would breach the Data Protection Act (2018).

I am sorry I cannot help further with your request.

If you are unhappy with our response to your request, you do have the right to request us to review it. Your request should be made within 40 working days of receipt of this letter, and we will reply within 20 working days of receipt. If our decision is unchanged following a review and you remain dissatisfied with this, you then have the right to make a formal complaint to the Scottish Information Commissioner within 6 months of receipt of our review response. You can do this by using the Scottish Information Commissioner's Office online appeals service at www.itspublicknowledge.info/Appeal. If you remain dissatisfied with the Commissioner's response you then have the option to appeal to the Court of Session on a point of law.

If you require a review of our decision to be carried out, please write to the FOI Reviewer at the email address at the head of this letter. The review will be undertaken by a Reviewer who was not involved in the original decision-making process.

FOI responses (subject to redaction of personal information) may appear on NHS Lothian's Freedom of Information website at: <https://org.nhsllothian.scot/FOI/Pages/default.aspx>

Yours sincerely

ALISON MACDONALD
Executive Director, Nursing
Cc: Chief Executive