

Date 31 July 2026
Your Ref
Our Ref 11667

Enquiries to Richard Mutch
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Dear

FREEDOM OF INFORMATION – PRESCRIBING

I write in response to your request for information in relation to prescribing.

Question:

1. The number of patients under the trust's care with a recorded diagnosis of Dravet syndrome from January-June 2026. Likely coded as ICD-10 code G40.3 or SNOMED code 230437002.
 - a) Patient numbers segmented by age:
 - i. <2 years old
 - ii. 2-8 years old
 - iii. 9-17 years old
 - iv. 18 years+
2. The number of patients under the trust's care with a recorded diagnosis of Lennox-Gastaut syndrome from January-June 2026. Likely coded as ICD-10 code G40.4 or SNOMED code of 230418006.
 - a) Patient numbers segmented by age:
 - i. <2 years old
 - ii. 2-8 years old
 - iii. 9-17 years old
 - iv. 18 years+
3. The number of patients under the trust's care who have been treated with **fenfluramine** from January-June 2026
 - a) Patient numbers segmented by age:
 - i. <2 years old
 - ii. 2-8 years old
 - iii. 9-17 years old
 - iv. 18 years+
 - b) For these patients, how many of them had a diagnosis of Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002. Patient numbers segmented by age:
 - i. <2 years old
 - ii. 2-8 years old
 - iii. 9-17 years old

- iv. 18 years+
 - c) For these patients, how many of them had a diagnosis of Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006. Patient numbers segmented by age:
 - i. <2 years old
 - ii. 2-8 years old
 - iii. 9-17 years old
 - iv. 18 years+
- 4. The number of patients under the trust's care who have been treated with **cannabidiol** from January-June 2026
 - a) Patient numbers segmented by age:
 - i. <2 years old
 - ii. 2-8 years old
 - iii. 9-17 years old
 - iv. 18 years+
 - b) For these patients, how many of them had a diagnosis of Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002. Patient numbers segmented by age:
 - i. <2 years old
 - ii. 2-8 years old
 - iii. 9-17 years old
 - iv. 18 years+
 - c) For these patients, how many of them had a diagnosis of Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006. Patient numbers segmented by age:
 - i. <2 years old
 - ii. 2-8 years old
 - iii. 9-17 years old
 - iv. 18 years+
- 5. The number of patients under the trust's care who have been treated with **cenobamate** from January-June 2026
 - a) Patient numbers segmented by age:
 - i. <2 years old
 - ii. 2-8 years old
 - iii. 9-17 years old
 - iv. 18 years+
 - b) For these patients, how many of them had a diagnosis of Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002. Patient numbers segmented by age:
 - i. <2 years old
 - ii. 2-8 years old
 - iii. 9-17 years old
 - iv. 18 years+

- c) For these patients, how many of them had a diagnosis of Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006. Patient numbers segmented by age:
- <2 years old
 - 2-8 years old
 - 9-17 years old
 - 18 years+
6. The number of patients under the trust's care who have been treated with **rufinamide** from January-June 2026
- a) Patient numbers segmented by age:
- <2 years old
 - 2-8 years old
 - 9-17 years old
 - 18 years+
- b) For these patients, how many of them had a diagnosis of Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006. Patient numbers segmented by age:
- <2 years old
 - 2-8 years old
 - 9-17 years old
 - 18 years+
7. The number of patients under the trust's care who have been treated with **stiripentol** from January-June 2026
- a) Patient numbers segmented by age:
- <2 years old
 - 2-8 years old
 - 9-17 years old
 - 18 years+
- b) For these patients, how many of them had a diagnosis of Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002. Patient numbers segmented by age:
- <2 years old
 - 2-8 years old
 - 9-17 years old
 - 18 years+

Answer:

Question	Age			
	<2	2-8	9-17	18+
1a	0	5<	5<	*5<
2a	5<	5<	5<	5<

Pharmacy are only able to answer Part A of questions 3–7. The remaining parts cannot be answered because they require diagnosis-specific information, which is not available to us.

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.

Please note for cannabidiol, we have not included the combination product SATIVEX (Dronabinol and Cannabidiol), only the singular cannabidiol products (Epidyolex).

□

January 2026 - June 2026					
Q3-7.a					
Question	Medication/Age Group	Number of Patients by Month			
		<2	2-8	9-17	18+
3.a	Fenfluramine	0	0	5<	5<
4.a	Cannabidiol	0	5<	5<	23
5.a	Cenobamate	Information Unavailable due to high level of incomplete patient identifiable data			
6.a	Rufinamide	0	0	0	0
7.a	Stiripentol	0	0	5<	5<

To protect the identity of the individuals involved any figure of 5 or less has not been shown in the tables 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 hope the information provided helps 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