

Date 30/06/2025
Your Ref
Our Ref 10178

Enquiries to Richard Mutch
Extension 35687
Direct Line 0131 465 5687
loth.freedomofinformation@nhs.scot
richard.mutch@nhs.scot

Dear

FREEDOM OF INFORMATION – SYNDROMES

I write in response to your request for information in relation to Dravet syndrome and Lennox-Gastaut syndrome.

Question:

1. The number of unique patients with a recorded diagnosis of Dravet syndrome in 2024-2025. Likely coded as ICD-10 code G40.3 or SNOMED code of 230437002, ideally separated by month.
 - a. Patient numbers segmented by age:
 - i. 0-3 years old
 - ii. 4-8 years old
 - iii. 9-18 years old
 - iv. 18 years+
2. The number of unique patients with a recorded diagnosis of Lennox-Gastaut syndrome in 2024-2025. Likely coded as ICD-10 code G40.4 or SNOMED code of 230418006, ideally separated by month.
 - a. Patient numbers segmented by age:
 - i. 0-3 years old
 - ii. 4-8 years old
 - iii. 9-18 years old
 - iv. 18 years+

Answer:

Diagnosis	Patients (Under 18)	Patients (18 or over)
G404	23	5<
G408	6	10

Headquarters
Mainpoint
102 West Port
Edinburgh EH3 9DN

Chair Professor John Connaghan CBE
Chief Executive Professor Caroline Hiscox
Lothian NHS Board is the common name of Lothian Health Board

These figures;

Include all unique inpatients (coded with a diagnosis code below) where the date of discharge is between 1st Apr 2024 and 31st Mar 2025.

Lennox-Gastaut Syndrome we code to G40.4 (Other generalized epilepsy and epileptic syndromes)

Dravet Syndrome we code to G40.8 (Other epilepsy), but note this includes a broad group of epileptic conditions with different causes and treatment strategies.

We cannot provide a month breakdown or finer age breakdown due to the small number of inpatient discharges.

Also we do not use SNOMED codes, only ICD10 codes

Question:

3. The number of unique patients who have been treated with fenfluramine in 2024-2025, separated by month
 - a. Patient numbers segmented by age:
 - i. 0-3 years old
 - ii. 4-8 years old
 - iii. 9-18 years old
 - iv. 18 years+
 - b. For these patients, how many of them had a diagnosis of:
 - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002
 - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006
 - c. For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside fenfluramine, and indicate the number of patients receiving each
4. The number of unique patients who have been treated with cannabidiol in 2024-2025, separated by month
 1. Patient numbers segmented by age:
 - i. 0-3 years old
 - ii. 4-8 years old
 - iii. 9-18 years old
 - iv. 18 years+
 - b. For these patients, how many of them had a diagnosis of:
 - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002
 - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006
 - c. For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside cannabidiol, and indicate the number of patients receiving each
5. The number of unique patients who have been treated with cenobamate in 2024-2025, separated by month
 1. Patient numbers segmented by age:
 - i. 0-3 years old

- ii. 4-8 years old
 - iii. 9-18 years old
 - iv. 18 years+
 - b. For these patients, how many of them had a diagnosis of:
 - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002
 - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006
 - c. For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside cenobamate, and indicate the number of patients receiving each
- 6. The number of unique patients who have been treated with rufinamide in 2024-2025, separated by month
 - 1. Patient numbers segmented by age:
 - i. 0-3 years old
 - ii. 4-8 years old
 - iii. 9-18 years old
 - iv. 18 years+
 - b. For these patients, how many of them had a diagnosis of:
 - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002
 - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006
 - c. For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside rufinamide, and indicate the number of patients receiving each
- 7. The number of unique patients who have been treated with stiripentol in 2024-2025, separated by month
 - 1. Patient numbers segmented by age:
 - i. 0-3 years old
 - ii. 4-8 years old
 - iii. 9-18 years old
 - iv. 18 years+
 - b. For these patients, how many of them had a diagnosis of:
 - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002
 - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006
 - c. For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside stiripentol, and indicate the number of patients receiving each
- 8. The number of unique patients who have been treated with clobazam in 2024-2025, separated by month
 - 1. Patient numbers segmented by age:
 - i. 0-3 years old
 - ii. 4-8 years old
 - iii. 9-18 years old
 - iv. 18 years+
 - b. For these patients, how many of them had a diagnosis of:

- i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002
 - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006
 - c. For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside clobazam, and indicate the number of patients receiving each
9. The number of unique patients who have been treated with sodium valproate in 2024-2025, separated by month
 1. Patient numbers segmented by age:
 - i. 0-3 years old
 - ii. 4-8 years old
 - iii. 9-18 years old
 - iv. 18 years+
 - b. For these patients, how many of them had a diagnosis of:
 - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002
 - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006
 - c. For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside sodium valproate, and indicate the number of patients receiving each
10. The number of unique patients who have been treated with levetiracetam in 2024-2025, separated by month
 1. Patient numbers segmented by age:
 - i. 0-3 years old
 - ii. 4-8 years old
 - iii. 9-18 years old
 - iv. 18 years+
 - b. For these patients, how many of them had a diagnosis of:
 - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002
 - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006
 - c. For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside levetiracetam, and indicate the number of patients receiving each
11. The number of unique patients who have been treated with topiramate in 2024-2025, separated by month
 1. Patient numbers segmented by age:
 - i. 0-3 years old
 - ii. 4-8 years old
 - iii. 9-18 years old
 - iv. 18 years+
 - b. For these patients, how many of them had a diagnosis of:
 - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002
 - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006

- c. For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside topiramate, and indicate the number of patients receiving each
12. The number of unique patients who have been treated with lamotrigine in 2024-2025, separated by month
1. Patient numbers segmented by age:
 - i. 0-3 years old
 - ii. 4-8 years old
 - iii. 9-18 years old
 - iv. 18 years+
 - b. For these patients, how many of them had a diagnosis of:
 - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002
 - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006
 - c. For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside lamotrigine, and indicate the number of patients receiving each

Answer:

See enclosed spreadsheet Primary Care data.

January 2024 - December 2024 – Hospital Data					
Q3-12.a					
Question	Medication	Number of Patients by Age Grouping			
		0-3	4-8	9-18	18+
3.a	Fenfluramine	0	0	5<	5<
4.a	Cannabidiol	5<	5<	12	21
5.a	Cenobamate	0	0	7	31
6.a	Rufinamide	0	0	5<	0
7.a	Stiripentol	0	0	5<	5<
8.a	Clobazam	17	28	51	196
9.a	Sodium Valproate	Information Unavailable due to high level of incomplete patient identifiable data			
10.a	Levetiracetam	Information Unavailable due to high level of incomplete patient identifiable data			
11.a	Topiramate	5<	5<	10	134
12.a	Lamotrigine	Information Unavailable due to high level of incomplete patient identifiable data			

To protect the identity of the individuals involved any figure of 5 or less has not been shown in this response. 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). For the same reason it is not possible to provide a further breakdown.

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
Enc.

Data Source Prescribing Information System (PIS)

Report last updated 10/06/2025

Notes

1. Data shown are based on prescriptions dispensed by community pharmacists, appliance suppliers and dispensing doctors only, and therefore does not take into account medicines dispensed by hospitals or hospital based clinics.
2. Paid Dates between 01/04/2024 and 31/03/2025 have been used identify items prescribed in the financial year 2024/25
3. If a drug does not appear in the table, this indicates that no prescriptions were dispensed for that drug in the financial year 2024/25.
4. To protect patient confidentiality and prevent potential disclosure, any values fewer than 5 have been replaced with an asterisk (*).

	30/04/2024	31/05/2024	30/06/2024	31/07/2024	31/08/2024	30/09/2024	31/10/2024	30/11/2024	31/12/2024	31/01/2025	28/02/2025	31/03/2025
CLOBAZAM	X	5<	X	5<	X	X	X	X	X	X	X	X
LAMOTRIGINE	-	X	-	X	-	-	-	-	-	-	-	-
LEVETIRACETAM	6	9	13	7	6	7	10	6	10	12	14	13
SODIUM VALPROATE	X	X	X	X	X	X	-	X	X	X	5<	X
TOPIRAMATE	X	X	X	X	X	X	X	-	-	-	-	-

[illegible]

	30/04/2024	31/05/2024	30/06/2024	31/07/2024	31/08/2024	30/09/2024	31/10/2024	30/11/2024	31/12/2024	31/01/2025	28/02/2025	31/03/2025
CANNABIDIOL	X	X	-	X	X	X	X	X	X	X	X	X
CENOBAMATE	X	X	X	X	X	X	X	-	X	X	X	X
CLOBAZAM	38	41	44	39	41	43	41	39	42	39	43	36
LAMOTRIGINE	54	68	51	65	50	53	58	56	64	58	65	58
LEVETIRACETAM	73	79	89	83	83	75	88	75	78	79	73	82
RUFINAMIDE	-	X	X	X	-	X	X	X	X	X	X	X
SODIUM VALPROATE	79	89	72	91	75	77	68	79	67	69	64	66
TOPIRAMATE	15	15	18	12	10	13	11	14	18	15	9	10

	30/04/2024	31/05/2024	30/06/2024	31/07/2024	31/08/2024	30/09/2024	31/10/2024	30/11/2024	31/12/2024	31/01/2025	28/02/2025	31/03/2025
CANNABIDIOL	X	X	-	X	-	-	-	-	-	-	-	-
CENOBAMATE	56	63	66	74	67	75	78	73	89	77	79	80
CLOBAZAM	216	226	196	219	210	197	212	218	222	217	217	219
LAMOTRIGINE	2264	2399	2300	2422	2359	2330	2417	2368	2469	2446	2290	2393
LEVETIRACETAM	1305	1393	1289	1397	1362	1299	1404	1296	1440	1356	1304	1348
RUFINAMIDE	X	-	X	-	X	-	X	-	X	X	-	-
SODIUM VALPROATE	1105	1149	1115	1093	1136	1062	1145	1068	1136	1084	1046	1065
TOPIRAMATE	597	623	569	626	592	556	577	558	606	547	549	559