

Freedom of Information Act 2000

The Royal Cornwall Hospitals NHS Trust Response to Information request

Date Request Received: 2nd June 2025

FOI Ref No 29048

Requested Information/Response:

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.

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Age group												
0 to 3		1	2								1	1
4 to 8	2		1	3	2		6	2	4	2	3	
9 to 18			1		2		1	2	1	1		4
18+	5	9	10	13	6	8	15	8	9	7	6	9

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2025

	Jan	Feb	Mar	Apr
Age group				
0 to 3	1			
4 to 8	1	2	3	
9 to 18			1	2
18+	9	12	7	9

3. 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+

2024

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Dec
Age group									
0 to 3		1	2	1				1	4
4 to 8			1				1		
9 to 18	2								
18+				1	1	1		1	1

2025

	Jan
Age group	
0 to 3	1
18+	1

4. The number of unique patients who have been treated with fenfluramine in 2024-2025, separated by month
 - a. Patient numbers segmented by age:
 - **Please see appendix one**
 - 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:
 - **Unable to provide as our coding is not unique to just these specific diagnoses so may include other diagnosis and we do not record indication, so would not know what a drug was given to treat. Going through individual notes would take longer than the designated time to be spent on an FOI.**
 - 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

- **Unable to provide**

5. The number of unique patients who have been treated with cannabidiol in 2024-2025, separated by month
 - a. Patient numbers segmented by age:
 - **Please see appendix one**
 - 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:
 - **Unable to provide as our coding is not unique to just these specific diagnoses so may include other diagnosis and we do not record indication, so would not know what a drug was given to treat. Going through individual notes would take longer than the designated time to be spent on an FOI.**
 - c.
 - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002
 - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006
 - d. 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
 - **Unable to provide**
6. The number of unique patients who have been treated with cenobamate in 2024-2025, separated by month
 - a. Patient numbers segmented by age:
 - **Please see appendix one**
 - 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:
 - **Unable to provide as our coding is not unique to just these specific diagnoses so may include other diagnosis and we do not record indication, so would not know what a drug was given to treat. Going through individual notes would take longer than the designated time to be spent on an FOI.**
 - 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

- **Unable to provide**
- 7. The number of unique patients who have been treated with rufinamide in 2024-2025, separated by month
 - a. Patient numbers segmented by age:
 - **Please see appendix one**
 - 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:
 - **Unable to provide as our coding is not unique to just these specific diagnoses so may include other diagnosis and we do not record indication, so would not know what a drug was given to treat. Going through individual notes would take longer than the designated time to be spent on an FOI.**
 - 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
 - **Unable to provide**
- 8. The number of unique patients who have been treated with stiripentol in 2024-2025, separated by month
 - a. Patient numbers segmented by age:
 - **Please see appendix one**
 - 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:
 - **Unable to provide as our coding is not unique to just these specific diagnoses so may include other diagnosis and we do not record indication, so would not know what a drug was given to treat. Going through individual notes would take longer than the designated time to be spent on an FOI.**
 - 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

- **Unable to provide**

9. The number of unique patients who have been treated with clobazam in 2024-2025, separated by month

a. Patient numbers segmented by age:

- **Please see appendix one**

- 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:

- **Unable to provide as our coding is not unique to just these specific diagnoses so may include other diagnosis and we do not record indication, so would not know what a drug was given to treat. Going through individual notes would take longer than the designated time to be spent on an FOI.**

- 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

- **Unable to provide**

10. The number of unique patients who have been treated with sodium valproate in 2024-2025, separated by month

a. Patient numbers segmented by age:

- **Please see appendix one**

- 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:

- **Unable to provide as our coding is not unique to just these specific diagnoses so may include other diagnosis and we do not record indication, so would not know what a drug was given to treat. Going through individual notes would take longer than the designated time to be spent on an FOI.**

- 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

- **Unable to provide**

11. The number of unique patients who have been treated with levetiracetam in 2024-2025, separated by month

a. Patient numbers segmented by age:

- **Please see appendix one**

- 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:

- **Unable to provide as our coding is not unique to just these specific diagnoses so may include other diagnosis and we do not record indication, so would not know what a drug was given to treat. Going through individual notes would take longer than the designated time to be spent on an FOI.**

- 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

- **Unable to provide**

12. The number of unique patients who have been treated with topiramate in 2024-2025, separated by month

a. Patient numbers segmented by age:

- **Please see appendix one**

- 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:

- **Unable to provide as our coding is not unique to just these specific diagnoses so may include other diagnosis and we do not record indication, so would not know what a drug was given to treat. Going through individual notes would take longer than the designated time to be spent on an FOI.**

- 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

- **Unable to provide**

13. The number of unique patients who have been treated with lamotrigine in 2024-2025, separated by month

a. Patient numbers segmented by age:

- **Please see appendix one**

- 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:

- **Unable to provide as our coding is not unique to just these specific diagnoses so may include other diagnosis and we do not record indication, so would not know what a drug was given to treat. Going through individual notes would take longer than the designated time to be spent on an FOI.**

- 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

- **Unable to provide**

Preferably I would like the data in .xlsx or .csv format. Alternatively, a table will suffice:

E.g. For 1.a. Number of patients diagnosed with Dravet syndrome:

Age/Month	J	F	M	A	M	J	J	A	S	O	N	D
0-3 years old												
4-8 years old												
9-18 years old												
18+ years old												

Attachment(s):

Appendix one – FOI 29048 Spreadsheet

Date Response sent: