

23 July 2026

Dravet Syndrome and Lennox-Gastaut Syndrome

I, would like to submit a Freedom of Information request for the following data:

Where possible, I would be grateful if the requested data could be provided in an editable format (e.g. .xlsx or .csv). If this is not feasible, a table format would also be acceptable, and an example layout that might work best is suggested below:

I understand the limitation of the ICD 10 codes in classifying Dravet syndrome and Lennox-Gastaut syndrome patients and that G40.3 and G40.4 will contain other epilepsies.

Responses to all questions have been incorporated into a table at the end of this document.

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
 - i. 2-8 years old
 - ii. 9-17 years old
 - iii. 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+

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- 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.

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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+

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:

- 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 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+

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:

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- 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+

Question	Age			
	<2	2-8	9-17	18+
1	Patients with DRAVET Syndrome			
1a	< 5	7	6	< 5
2	Patients with Lennox-Gastaut Syndrome (LGS)			
2a	This data is not held by Paediatric Neurology. Under Section 1(1)(a) of the Freedom of Information Act 2000, the Trust can confirm that it does not hold the information requested.			
3	Patients treated with FENFLURAMINE			
3a	0	< 5	0	0
	With DRAVET			
3b	0	< 5	0	0
	With LGS			
3c	0	<5	0	0
4	Patients treated with CANNABIDIOL			
4a	0	22	33	<5
	With DRAVET			
4b	0	5	<5	0
	With LGS			
4c	0	17	27	<5
5	Patients treated with CENOBAMATE			
5a	0	< 5	24	< 5
	With DRAVET			
5b	0	0	< 5	0

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	With LGS			
5c	0	< 5	< 5	0
6	Patients treated with RUFINAMIDE			
6a	This data is not held by Paediatric Neurology. Under Section 1(1)(a) of the Freedom of Information Act 2000, the Trust can confirm that it does not hold the information requested.			
	With LGS			
6b	This data is not held by Paediatric Neurology. Under Section 1(1)(a) of the Freedom of Information Act 2000, the Trust can confirm that it does not hold the information requested.			
7	Patients treated with STIRIPENTOL			
7a	This data is not held by Paediatric Neurology. Under Section 1(1)(a) of the Freedom of Information Act 2000, the Trust can confirm that it does not hold the information requested.			
	With Dravet			
7b	0	<5	<5	<5

Where numbers are fewer than five, they have been replaced with "<5". Disclosure of the precise figure could increase the risk of identifying individuals and therefore the information has been withheld under section 40(2) of the Freedom of Information Act 2000 which pertain to Personal Information.