

13 March 2026

Dravet syndrome and Lennox-Gastaut syndrome

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 example layouts are suggested below for reference.

For all questions, patient numbers should represent unique patients within the specified reporting period. Where a monthly breakdown is not available, please provide unique patient numbers aggregated by quarter instead. If the tables below are not showing correctly due to formatting issues, then please let me know and I can send them in a word document.

Priority questions:

1. The number of patients under the trust's care with a recorded diagnosis of Dravet syndrome in each month of 2025 (January–December). Patients may be counted in more than one month. 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 in each month of 2025 (January-December). Patients may be counted in more than one month. 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 in 2025 (January-December), separated by month
 - a. Patient numbers segmented by age:
 - i. <2 years old
 - ii. 2-8 years old
 - iii. 9-17 years old

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- 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 patients with a recorded diagnosis of Dravet syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication
 - d. For patients with a recorded diagnosis of Lennox–Gastaut syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication.
4. The number of patients under the trust’s care who have been treated with cannabidiol in 2025 (January-December), separated by month
- 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:
 - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002
 - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006
 - c. For patients with a recorded diagnosis of Dravet syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication
 - d. For patients with a recorded diagnosis of Lennox–Gastaut syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication.
5. The number of patients under the trust’s care who have been treated with cenobamate in in 2025 (January-December), separated by month
- 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:
 - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002
 - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006

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- c. For patients with a recorded diagnosis of Dravet syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication**
- d. For patients with a recorded diagnosis of Lennox–Gastaut syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication.**
- 6. The number of patients under the trust’s care who have been treated with rufinamide in 2025 (January-December), separated by month**
 - 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:**
 - i. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006**
 - c. For patients with a recorded diagnosis of Lennox–Gastaut syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication.**
- 7. The number of patients under the trust’s care who have been treated with stiripentol in 2025 (January-December), separated by month**
 - 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:**
 - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002**
 - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006**
 - c. For patients with a recorded diagnosis of Dravet syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication**
 - d. For patients with a recorded diagnosis of Lennox–Gastaut syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication.**

Good to know questions:

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- 8. The number of patients under the trust's care who have been treated with clobazam in 2025 (January-December), separated by month**
 - 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:**
 - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002**
 - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006**
 - c. For patients with a recorded diagnosis of Dravet syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication**
 - d. For patients with a recorded diagnosis of Lennox–Gastaut syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication.**
- 9. The number of patients under the trust's care who have been treated with sodium valproate in 2025 (January-December), separated by month**
 - 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:**
 - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002**
 - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006**
 - c. For patients with a recorded diagnosis of Dravet syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication**
 - d. For patients with a recorded diagnosis of Lennox–Gastaut syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication.**
- 10. The number of patients under the trust's care who have been treated with topiramate in 2025 (January-December), separated by month**
 - a. Patient numbers segmented by age:**
 - i. <2 years old**
 - ii. 2-8 years old**

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- iii. 9-17 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 patients with a recorded diagnosis of Dravet syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication
 - d. For patients with a recorded diagnosis of Lennox–Gastaut syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication.
- 11. The number of patients under the trust’s care who have been treated with lamotrigine in 2025 (January-December), separated by month
 - 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:
 - i. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006
 - c. For patients with a recorded diagnosis of Lennox–Gastaut syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication.

Please refer to the attached spreadsheet:

36119 FOI Request Dravet syndrome and Lennox-Gastaut syndrom_attachment 1.xls

Belfast Trust is unable to provide the precise number as it is fewer than five (<5). Releasing such a small number could potentially identify individuals, and is therefore exempt under Section 40(2) (personal information).