NHS
Bolton
NHS Foundation Trust

FREEDOM OF INFORMATION

REF: 2026-90
Subject: Dravet Syndrome & Lennox-Gastaut Syndrome

Dear Sir/Madam,

Thank you for your email dated **29/01/2026** where you requested information about **Dravet Syndrome & Lennox-Gastaut Syndrome.**

The information you requested is enclosed.

Question	Answer
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+	Please find attached
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 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 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.	
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.	
. 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 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.	
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.	

If you have any queries or concerns please do not hesitate to contact the Freedom of Information Department. It would be helpful to quote the above reference number in any future communication.

If you are unhappy with the service you have received in relation to your request and wish to make a complaint or request a review of our decision, you should write to The Chief Executive, Bolton NHS Foundation Trust, The Royal Bolton Hospital, Minerva Road, Farnworth, Bolton. BL4 0JR.

If you are not content with the outcome of your complaint you may apply directly to the Information Commissioner. Generally the Information Commissioner cannot make a decision unless you have exhausted the complaints procedure provided by Bolton NHS Foundation Trust. The Information Commissioner can be contacted at The Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire. SK9 5AF.

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Yours sincerely,

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transforming lives...for a better Bolton

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