

31st July 2026

Eastbourne District General Hospital

Kings Drive
Eastbourne
East Sussex
BN21 2UD

Tel: 0300 131 4500
Website: www.esht.nhs.uk

Further to your recent request for information made under the Freedom of Information Act (FOIA) 2000, I now set out our answers to your specific questions, and any clarifications sought and provided, as follows:

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.

I would like to request the following data:

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**
- ii) 2-8 years old**
- iii) 9-17 years old**
- iv) 18 years+**

[Please see the attached document - 'FOI 26-475 Response'.](#)

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+**

[Please see the attached document - 'FOI 26-475 Response'.](#)

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+**

[Please see the attached document - 'FOI 26-475 Response'.](#)

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+**

[Please see the attached document - 'FOI 26-475 Response'.](#)

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+**

[Please see the attached document - 'FOI 26-475 Response'.](#)

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+**

[Please see the attached document - 'FOI 26-475 Response'.](#)

- 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+

[Please see the attached document - 'FOI 26-475 Response'.](#)

- 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+

[Please see the attached document - 'FOI 26-475 Response'.](#)

- 5) The number of patients under the trust's care who have been treated with cenobamate 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+

[Please see the attached document - 'FOI 26-475 Response'.](#)

- 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+

[Please see the attached document - 'FOI 26-475 Response'.](#)

- 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+

[Please see the attached document - 'FOI 26-475 Response'.](#)

- 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+

[Please see the attached document - 'FOI 26-475 Response'.](#)

- 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+

[Please see the attached document - 'FOI 26-475 Response'.](#)

- 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:

- i) <2 years old
- ii) 2-8 years old
- iii) 9-17 years old
- iv) 18 years+

[Please see the attached document - 'FOI 26-475 Response'.](#)

- 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+

Please see the attached document - 'FOI 26-475 Response'.

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:

	Age			
Question	<2	2-8	9-17	18+
1a				
2a				
3a				
3b				
3c				
4a				
4b				
4c				
5a				
5b				
5c				
6a				
6b				
7a				
7b				

Please see the attached document - 'FOI 26-475 Response' for a response in the above format, as requested.

I trust this information is helpful in its detail or explanation however, if you are dissatisfied with the response, then you have the right to request an internal review. If you wish to seek an internal review, please write to the Freedom of Information Team at esh-tr.foi@nhs.net quoting the above FOI reference number, within 40 working days. Please note the Trust is not obliged to accept a request for an internal review after this time period.

Yours faithfully

Freedom of Information (FOI) Team
East Sussex Healthcare NHS Trust
0300 131 4716
Core Hours of Business: Monday to Friday 9.00am to 4.00pm

FOI 26/475 - East Sussex Healthcare NHS Trust

	Age			
Question	<2	2-8	9-17	18+
1a	1	5	5	70
2a	2	2	2	2
3a	0	0	0	1
3b	0	0	0	0
3c	0	0	0	0
4a	0	0	1	3
4b	0	0	0	0
4c	0	0	1	2
5a	0	0	0	6
5b	0	0	0	2
5c	0	0	0	0
6a	0	0	0	1
6b	0	0	0	0
7a	0	0	0	0
7b	0	0	0	0