

**Freedom of Information Act 2000**

**The Royal Cornwall Hospitals NHS Trust Response to Information request**

**Date Request Received: 28<sup>th</sup> May 2025**

**FOI Ref No 29003**

**Requested Information:**

- The number of patients treated for Dravet syndrome in 2024, ideally separated by month, or quarter.
  - Patient numbers segmented by age:
    - 0-3 years old
    - 4-8 years old
    - 9-18 years old

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

- The number of patients treated for Dravet syndrome in 2025, ideally separated by month, or quarter.
  - Patient numbers segmented by age:
    - 0-3 years old
    - 4-8 years old
    - 9-18 years old
    - 18 years+

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

- The number of patients treated for Lennox-Gastaut syndrome in 2024, ideally separated by month, or quarter.
  - Patient numbers segmented by age:
    - 0-3 years old
    - 4-8 years old
    - 9-18 years old
    - 18 years+

– 18 years+

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

- The number of patients treated for Lennox-Gastaut syndrome in 2025, ideally separated by month, or quarter
  - Patient numbers segmented by age:
    - 0-3 years old
    - 4-8 years old
    - 9-18 years old
    - 18 years+

	Jan
Age: 0-3	1
Age: 18+	1

- The above data separated by treatment, focusing on the following treatments:
  - fenfluramine
  - sodium valproate
  - stiripentol
  - clobazam
  - cannabidiol
  - levetiracetam
  - topiramate
  - potassium bromide
  - Other treatments
    - carbamazepine
    - gabapentin
    - lacosamide
    - lamotrigine
    - oxcarbazepine
    - phenobarbital
    - pregabalin
    - tiagabine
    - vigabatrin
    - rufinamide

**2024**

Drug Group	Age group	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
CANNABIDIOL	4 to 8	0	0	0	0	0	0	1	0	0	0	0	0
	18+	0	0	1	0	0	0	0	0	0	0	0	0
CARBAMAZEPINE	18+	1	0	0	0	0	0	0	1	1	0	0	0
CLOBAZAM	0 to 3	0	0	1	0	0	0	0	0	0	0	1	0
	18+	0	0	0	0	0	0	1	0	0	0	1	0
LACOSAMIDE	18+	0	0	1	0	0	0	1	0	0	0	0	0
LAMOTRIGINE	4 to 8	0	0	0	1	0	0	0	0	0	0	0	0
	18+	1	0	1	0	0	0	0	0	0	1	0	0
LEVETIRACETAM	0 to 3	0	0	0	0	0	0	0	0	0	0	0	1
	4 to 8	0	0	1	1	0	0	0	0	0	0	0	0
	18+	0	1	2	7	2	3	1	0	3	1	2	3
PHENOBARBITAL	4 to 8	0	0	0	0	0	0	0	1	0	1	0	0
PREGABALIN	18+	0	0	0	0	0	0	0	1	0	0	0	0
SODIUM VALPORATE	4 to 8	0	0	0	0	0	0	0	0	0	0	1	0
	9 to 18	0	0	0	0	0	0	0	0	0	1	0	0
	18+	0	2	2	3	1	1	4	0	1	1	0	3
TOPIRAMATE	4 to 8	0	0	0	0	0	0	0	0	2	0	0	0
	18+	0	0	0	0	0	0	0	0	1	1	0	0
(blank)	0 to 3	0	1	1	0	0	0	0	0	0	0	0	0
	4 to 8	2	0	0	1	2	0	5	1	2	1	2	0
	9 to 18	0	0	1	0	2	0	1	2	1	0	0	4
	18+	3	6	3	3	3	4	8	6	3	3	3	3

### 2025 Gravet

Drug Group	Age group	Jan	Feb	Mar	Apr
CARBAMAZEPINE	18+	0	1	1	0
CLOBAZAM	4 to 8	0	1	0	0
LAMOTRIGINE	9 to 18	0	0	0	1
	18+	1	0	1	2
LEVETIRACETAM	4 to 8	1	0	1	0
	18+	2	5	0	2
SODIUM VALPORATE	18+	0	0	1	1
(blank)	0 to 3	1	0	0	0
	4 to 8	0	1	2	0
	9 to 18	0	0	1	1
	18+	6	6	4	4

### 2024 LGS G40.4

		Ja n	Fe b	Ma r	Ap r	Ma y	Ju n	Ju l	Au g	De c
Drug Group	Age group									
CLOBAZAM	18+	0	0	0	0	0	0	0	1	0
LAMOTRIGINE	9 to 18	1	0	0	0	0	0	0	0	0
LEVETIRACETAM	0 to 3	0	0	2	0	0	0	0	0	0
	18+	0	0	0	0	0	0	0	0	0
OXCARBAZEPINE	0 to 3	0	0	0	0	0	0	0	1	0
SODIUM VALPORATE	0 to 3	0	0	0	0	0	0	0	0	1
TOPIRAMATE	18+	0	0	0	1	0	0	0	0	0
(blank)	0 to 3	0	1	0	1	0	0	0	0	3
	18+	0	0	0	0	1	1	0	0	1
	4 to 8	0	0	1	0	0	0	1	0	0
	9 to 18	1	0	0	0	0	0	0	0	0

### 2025 LGS G40.4

		Jan
Drug Group	Age group	
LEVETIRACETAM	18+	1
(blank)	0 to 3	1

- Numbers of patients moving from one specific treatment to another e.g. fenfluramide gains from cannabidiol, sodium valproate losses to cannabidiol
- Alternatively, just the numbers of patients on each treatment for each month/quarter will be able to show how the numbers on each treatment are changing

I have provided a breakdown above by month.

### **Response:**

Note: Dravet Syndrome (DS): this isn't in our ICD classification, but SNOMED CT browser has a cross-map to:

G40.3 Generalised idiopathic epilepsy with epileptic syndromes.

Lennox Gastaut syndrome :

G40.4 Other generalised epilepsy and epileptic syndromes.

Neither code is exclusive to the syndrome.

**Attachment(s):**

No Attachment(s)

**Date Response sent: 30<sup>th</sup> May 2025**