

Freedom of Information Request: Our Reference CTMUHB_22_23

You asked:

I would like to please request the following information, with regards to treatment of Epilepsy in your trust/ board.

In the last 12 months of available data:

1a. What number of unique patients have been treated for Lennox-Gastaut syndrome, Dravet Syndrome and Tuberous Sclerosis Complex? Please give answers for each condition separately.

The Health Board only record diagnoses via clinical coding at the inpatient stage. Therefore, we are unable to provide the number of patients treated as requested.

However, to aid and assist you with your request, the number of inpatient admissions with the conditions listed above has been provided in the table below:

Patients admitted with Lennox-Gastaut syndrome/Dravet Syndrome/Tuberous Sclerosis Complex: 2022			
ICD10	ICD10 Description	Total Patients	Paediatric
G40.3	Generalized idiopathic epilepsy and epileptic syndromes	37	11
G40.4	Other generalized epilepsy and epileptic syndromes	**	**

Please note the data shows the number of patients admitted, not the number of episodes for:

- Lennox-Gastaut syndrome: G40.4
- Dravet Syndrome: G40.3
- Tuberous Sclerosis Complex: Q85.1

Where the figures are less than 5, this has been denoted by **. The exact figures have been withheld due to the low numbers involved.

Where numbers are low we have considered that there is the potential for the individuals to be identified from the information provided, when considered with other information that may also be in the public domain. Also, responses under the Freedom of Information Act are made available to the public at large. The data is classed as personal data as defined under the General Data Protection Regulation (GDPR) and Data Protection Act 2018 and its disclosure would be contrary to the data protection principles and constitute as unfair and unlawful processing in regard to Articles 5, 6, and 9 of GDPR. We are therefore withholding this detail under Section 40(2) of the Freedom of Information Act 2000. This exemption is absolute and therefore there is no requirement to apply the public interest test.

1b. For each indication (Lennox-Gastaut syndrome, Dravet Syndrome and Tuberous Sclerosis Complex), what number of these have been treated in a paediatric environment?

Please see response to question 1a.

2a. How many patients have been treated with Epidyolex in a paediatric environment?

NIL. It is started and prescribed in tertiary centres (Neurology - Cardiff and Vale University Health Board).

3a. Can you please detail which NHS Trusts/ Health Boards these patients have been referred from?

Cwm Taf Morgannwg University Health Board.