

19 May 2022

Treatment of Patients Diagnosed with Epilepsy, Dravet Syndrome, Lennox Gastaut Syndrome and Tuberous Sclerosis Complex

Under the Freedom of Information Act 2000, please can you tell us the number of unique patients since January 2020 with a recorded diagnosis of:

1. Epilepsy. Likely coded as ICD G40
2. Dravet syndrome. Likely coded as ICD10 code G40.3, or SNOMED code (SCTID) of 230437002 (if applicable)
3. Lennox Gastaut Syndrome. Likely coded as ICD10 code G40.4 or SNOMED code (SCTID) of 230418006
4. Tuberous Sclerosis Complex. Likely coded as ICD10 code Q85.1 or SNOMED code (SCTID) of 7199000

Patients from January 2020 – December 2021:

Metric	Patients	Method/Comments
Epilepsy	315	
Dravet Syndrome	52	Also included in Epilepsy figure
Lennox Gastaut Syndrome	28	Also included in Epilepsy figure
Tuberous Sclerosis Complex	2	

How many patients have been treated with Cannabidiol (Epidyolex) in the latest 3 months?

For these patients, how many of them had a diagnosis of:-

- Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006

Or how many of them had a diagnosis of

- Dravet Syndrome (ICD10 Code: G40.8) SCTID: 230437002

Belfast Trust is unable to answer this second part of the query, as our Patient Administration System (PAS) does not capture this information.