

25 January 2023

Treatment of Epilepsy in Belfast Trust

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.

	Total Unique Patients
Lennox-Gastaut Syndrome (G40.4)	7
Dravet Syndrome (G40.3)	35
Tuberous Sclerosis Complex (Q85.1)	5

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

	Total Unique Patients Treated in Paediatric environment
Lennox-Gastaut Syndrome (G40.4)	7
Dravet Syndrome (G40.3)	11
Tuberous Sclerosis Complex (Q85.1)	<5

Use of < 5 (less than five): We are unable to provide an exact figure - exempt from release under Section 40(2) of the Freedom of Information Act - as this could make patients personally identifiable. Disclosure would constitute a breach of the principles of the General Data Protection Regulation 2018.

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

Belfast Trust is unable to answer this as our Patient Administration System (PAS) does not capture this information.

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

	Trust of Residence				
	Belfast	Northern	South Eastern	Southern	Western
Lennox-Gastaut Syndrome (G40.4)	<5	<5	0	0	<5
Dravet Syndrome (G40.3)	11	<5	<5	15	<5
Tuberous Sclerosis Complex (Q85.1)	<5	<5	0	<5	0

As above, we are unable to provide an exact figure - exempt from release under Section 40(2) of the Freedom of Information Act.