

14 August 2024

## Treatment of Dravet Syndrome and Lennox-Gastaut Syndrome with Specific Pharmaceuticals

I am writing to submit an FOI request with the following questions:

**NOTE:** Since Belfast Trust does not code outpatient diagnoses, we can only estimate the numbers.

1. How many patient's does the Trust have with a recorded diagnosis of Dravet Syndrome (DS)

Adult Service

7

Paediatric Service

14

- a) Of these, how many have been treated with Epidyolex (Canabidiol) in the last 6 months?

Adult Service

<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 the small numbers involved could make patients personally identifiable. Disclosure would constitute a breach of the principles of the General Data Protection Regulation 2018.

Paediatric Service

6

- b) Of these, how many have been treated with Fintepla (Fenfluramine) in the last 6 months?

Adult Service

<5

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Paediatric Service

<5

**2. How many patient's does the Trust have with a recorded diagnosis of Lennox-Gasteau Syndrome (LGS)**

Adult Service

14 – 20

Paediatric Service

Estimated - 50

**a) Of these, how many have been treated with Epidyolex (Canabidiol) in the last 6 months?**

Adult Service

10 – 15

Paediatric Service

36

**b) Of these, how many have been treated with Fintepla (Fenfluramine) in the last 6 months?**

Adult Service

0

Paediatric Service

0