

26 August 2026

Rare Disease Patients and Treatment

1. How many total patients has the trust seen within the latest 24 months of available data (for any reason), with a recorded diagnosis of Dravet Syndrome (DS)?

15.

2. Of total DS patients, how many have been treated with Epidyolex (Cannabidiol) in the last 12 months?

8.

3. Of total DS patients, how many have been treated with Fintepla (Fenfluramine) in the last 12 months?

* <5.

4. How many total patients has the trust seen within the latest 24 months of available data (for any reason), with a recorded diagnosis of Lennox-Gastaut Syndrome (LGS)?

Under Section 1(1) (a) of the Freedom of Information Act 2000, Belfast Trust does not hold the requested information and is therefore unable to provide the requested figure.

5. Of total LGS patients, how many have been treated with Epidyolex (Cannabidiol) in the last 12 months?

46.

6. Of total LGS patients, how many have been treated with Fintepla (Fenfluramine) in the last 12 months?

* <5.

7. How many adult (aged 18+) patients has the trust seen within the latest 24 months of available data (for any reason), with a recorded diagnosis of Dravet Syndrome (DS)?

* <5.

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8. How many adult (aged 18+) patients has the trust seen within the latest 24 months of available data (for any reason), with a recorded diagnosis of Lennox-Gastaut Syndrome (LGS)?

* <5.

* Some figures have been withheld and replaced with less than five (<5). This is because disclosure of small numbers has the potential to identify individuals. The information is therefore exempt under Section 40(2) of the Freedom of Information Act 2000 - Personal Information relating to a third party. Its release would contravene the data protection principles set out in the UK GDPR.