

20 June 2025

Dravet Syndrome & Lennox Gastaut Syndrome: Patients & Treatment

Q1. 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)

14

Q2. Of total DS patients, how many have been treated with Epidyolex (Cannabidiol) in the last 12 months?

7

Q3. Of total DS patients, how many have been treated with Fintepla (Fenfluramine) in the last 12 months?

<5

We are unable to state the exact figure as to do so has the potential to make patients identifiable. It is therefore exempt from release under Section 40(2) of the FOI Act which relates to personal information pertaining to a third party.

Q4. 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)

Unknown, potentially 50+

Q5. Of total LGS patients, how many have been treated with Epidyolex (Cannabidiol) in the last 12 months?

39

Q6. Of total LGS patients, how many have been treated with Fintepla (Fenfluramine) in the last 12 months?

0