

Ref. No: 2717
Date: 27/07/26
Subject: Rare Disease Patients and Treatment

REQUEST

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)

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

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

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)

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

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

Q7. 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)

Q8. 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)

RESPONSE

Q1.

	2024	2025	2026
January		21	16
February		<5	22
March		17	20
April		12	18
May		17	21
June	21	20	
July	20	24	
August	14	27	
September	13	27	
October	14	10	
November	15	10	
December	13	16	

Q2. Of total DS patients, how many have been treated with Epidyolex (Cannabidiol) in the last 12 months? **0**

Q3. Of total DS patients, how many have been treated with Fintepla (Fenfluramine) in the last 12 months? **0**

Q4.

	2024	2025	2026
January		0	<5
February		<5	0
March		0	<5
April		5	<5
May		<5	<5
June	0	0	
July	<5	0	
August	0	<5	
September	<5	<5	
October	<5	<5	
November	<5	0	
December	<5	0	

Q5. Of total LGS patients, how many have been treated with Epidyolex (Cannabidiol) in the last 12 months? **0**

Q6. Of total LGS patients, how many have been treated with Fintepla (Fenfluramine) in the last 12 months? **0**

Q7.

	2024	2025	2026
January		21	13
February		<5	20
March		13	17
April		7	11
May		10	17
June	19	14	
July	14	17	
August	13	20	
September	12	21	
October	12	9	
November	14	8	
December	10	12	

Q8.

	2024	2025	2026
January		0	<5
February		0	0
March		0	0
April		<5	0
May		<5	<5
June	0	0	
July	<5	0	
August	0	<5	
September	0	<5	
October	0	<5	
November	<5	0	
December	<5	0	