

Trust Headquarters  
 Russells Hall Hospital  
 Dudley  
 West Midlands  
 DY1 2HQ

**Ref:** FOI-062025-0001650

**Date:** 29.7.25

**Address / Email:**

Dear

**Request Under Freedom of Information Act 2000**

Thank you for requesting information under the Freedom of Information Act 2000.

Please disregard my previous FOI request to the trust. I would like to submit an FOI request for the following data for The Dudley Group NHS Foundation Trust:

**Please note - As per NHS Digital rules the Trust does not publish numbers lower than 5 as this could lead to the identification of the persons involved Exemption Section 40(2) of the Freedom of Information Act is applied if the numbers are less than 5.**

1. The number of unique patients with a recorded diagnosis of Dravet syndrome in 2024-2025. Likely coded as ICD-10 code G40.3 or SNOMED code of 230437002, ideally separated by month.

a) Patient numbers segmented by age:

- i. 0-3 years old
- ii. 4-8 years old
- iii. 9-18 years old
- iv. 18 years+

<b>Dravet Syndrome (G403)</b>	Jan-24	Feb-24	Mar-24	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25	Apr-25	Grand Total
Age Groups																	
0-3 years old	<5	<5			<5							<5			<5		8
4-8 years old				<5	<5			<5	<5	<5			<5		<5		9
9-18 years old	<5	<5	<5	<5	<5			<5	<5		<5	<5	<5	<5	<5		22
18 years+	6	11	7	9	9	7	11	14	12	12	17	10	11	10	15	<5	164
<b>Grand Total</b>	<b>8</b>	<b>15</b>	<b>8</b>	<b>12</b>	<b>13</b>	<b>7</b>	<b>11</b>	<b>17</b>	<b>15</b>	<b>13</b>	<b>19</b>	<b>15</b>	<b>15</b>	<b>11</b>	<b>21</b>	<b>&lt;5</b>	<b>203</b>

2. The number of unique patients with a recorded diagnosis of Lennox-Gastaut syndrome in 2024-2025. Likely coded as ICD-10 code G40.4 or SNOMED code of 230418006, ideally separated by month.

a) Patient numbers segmented by age:

- i. 0-3 years old
- ii. 4-8 years old
- iii. 9-18 years old
- iv. 18 years+

<b>Lennox-Gastaut Syndrome (G404)</b>	2024 Total	2025 Total	Grand Total
Age Groups			
0-3 years old	<5	<5	<5
4-8 years old	<5		<5
9-18 years old	<5	<5	<5
18 years+	<5		<5
<b>Grand Total</b>	<b>8</b>	<b>&lt;5</b>	<b>11</b>

PLEASE NOTE FOR QUESTIONS 3-11, MONTHLY FIGURES CANNOT BE ADDED TO GIVE A YEAR TOTAL, SINCE PTs ISSUED TREATMENTS IN MORE THAN ONE MONTH WOULD BE COUNTED MULTIPLE TIMES

3) The number of unique patients who have been treated with fenfluramine in 2024-2025, separated by month

a) Patient numbers segmented by age:

- i. 0-3 years old
- ii. 4-8 years old
- iii. 9-18 years old
- iv. 18 years+

FENFLURAMINE													
PT COU	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25	
AGE 0-3	0	0	0	0	0	0	0	0	0	0	0	0	0
AGE 4-8	0	0	0	0	0	0	0	0	0	0	0	0	0
AGE 9-18	0	0	0	0	0	0	0	0	0	0	0	0	0
AGE >18	0	0	0	0	0	0	0	0	0	0	0	0	0

b) For these patients, how many of them had a diagnosis of:

- i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002 - N/A
- ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006 - N/A

c) For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside fenfluramine, and indicate the number of patients receiving each - N/A

3. The number of unique patients who have been treated with cannabidiol in 2024-2025, separated by month

a) Patient numbers segmented by age:

- i. 0-3 years old
- ii. 4-8 years old
- iii. 9-18 years old
- iv. 18 years+

CANNABIDIOL													
PT COUNT BY #	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25	
AGE 0-3	0	0	0	0	0	0	0	0	0	0	0	0	0
AGE 4-8	0	0	0	0	0	0	0	0	0	0	0	0	0
AGE 9-18	0	0	0	0	0	0	0	0	0	0	0	0	0
AGE >18	<5	<5	0	<5	<5	<5	<5	<5	<5	<5	<5	<5	<5

b) For these patients, how many of them had a diagnosis of:

- i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002 - 0
- ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006 - 0

c)For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside cannabidiol, and indicate the number of patients receiving each - N/A

4. The number of unique patients who have been treated with cenobamate in 2024-2025, separated by month

a) Patient numbers segmented by age:

- i. 0-3 years old
- ii. 4-8 years old
- iii. 9-18 years old
- iv. 18 years+

CENOBAMATE													
PT COUNT	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25	
AGE 0-3	0	0	0	0	0	0	0	0	0	0	0	0	0
AGE 4-8	0	0	0	0	0	0	0	0	0	0	0	0	0
AGE 9-18	0	0	0	0	0	0	0	0	0	0	0	0	0
AGE >18	<5	<5	<5	<5	<5	<5	<5	<5	<5	<5	<5	<5	<5

b) For these patients, how many of them had a diagnosis of:

- i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002 - <5
- ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006 - 0

c)For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside cenobamate, and indicate the number of patients receiving each

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5. The number of unique patients who have been treated with rufinamide in 2024-2025, separated by month

a) Patient numbers segmented by age:

- i. 0-3 years old
- ii. 4-8 years old
- iii. 9-18 years old
- iv. 18 years+

RUFINAMIDE													
PT COUNT	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25	
AGE 0-3	0	0	0	0	0	0	0	0	0	0	0	0	
AGE 4-8	0	0	0	0	0	0	0	0	0	0	0	0	
AGE 9-18	0	0	0	0	0	0	0	0	0	0	0	0	
AGE >18	0	0	0	0	<5	0	0	0	0	<5	<5	<5	

b) For these patients, how many of them had a diagnosis of:

- i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002 - 0
- ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006 - <5

c) For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside rufinamide, and indicate the number of patients receiving each

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6. The number of unique patients who have been treated with stiripentol in 2024-2025, separated by month

a) Patient numbers segmented by age:

- i. 0-3 years old
- ii. 4-8 years old
- iii. 9-18 years old
- iv. 18 years+

STIRIPENTOL													
PT COU	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25	
AGE 0-3	0	0	0	0	0	0	0	0	0	0	0	0	
AGE 4-8	0	0	0	0	0	0	0	0	0	0	0	0	
AGE 9-18	0	0	0	0	0	0	0	0	0	0	0	0	
AGE >18	0	0	0	0	0	0	0	0	0	0	0	0	

b) For these patients, how many of them had a diagnosis of:

- i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002 - N/A
- ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006 - N/A

c) For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside stiripentol, and indicate the number of patients receiving each - N/A

7. The number of unique patients who have been treated with clobazam in 2024-2025, separated by month

a) Patient numbers segmented by age:

- i. 0-3 years old
- ii. 4-8 years old
- iii. 9-18 years old
- iv. 18 years+

CLOBAZAM													
PT COUNT	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25	
AGE 0-3	0	0	<5	<5	<5	0	<5	0	0	0	<5	<5	
AGE 4-8	<5	0	0	0	0	0	<5	0	0	<5	0	0	
AGE 9-18	0	<5	<5	<5	<5	<5	<5	<5	0	0	<5	<5	
AGE >18	<5	6	8	10	7	7	12	15	14	14	13	14	

- b) For these patients, how many of them had a diagnosis of:
- i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002 - **23**
  - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006 - **<5**

c) For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside clobazam, and indicate the number of patients receiving each

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8. The number of unique patients who have been treated with sodium valproate in 2024-2025, separated by month

a) Patient numbers segmented by age:

- i. 0-3 years old
- ii. 4-8 years old
- ii. 9-18 years old
- iv. 18 years+

SODIUM VALPROATE													
PT COUNT	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25	
AGE 0-3	0	0	<5	0	<5	<5	<5	0	0	<5	0	0	
AGE 4-8	0	0	0	0	0	0	<5	0	0	0	0	0	
AGE 9-18	<5	<5	0	0	0	0	0	<5	<5	0	0	<5	
AGE >18	23	22	28	16	25	32	28	16	22	22	37	31	

- b) For these patients, how many of them had a diagnosis of:
- i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002 - **22**
  - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006 - **0**

c) For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside sodium valproate, and indicate the number of patients receiving each

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9. The number of unique patients who have been treated with levetiracetam in 2024-2025, separated by month

a) Patient numbers segmented by age:

- i. 0-3 years old
- ii. 4-8 years old
- iii. 9-18 years old
- iv. 18 years+

LEVETIRACETAM													
PT COUNT	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25	
AGE 0-3	<5	<5	0	<5	0	<5	<5	<5	<5	<5	<5	<5	
AGE 4-8	<5	<5	0	<5	0	<5	<5	<5	6	<5	<5	<5	
AGE 9-18	<5	5	<5	5	<5	<5	<5	<5	5	5	6	<5	
AGE >18	80	59	65	72	75	75	72	80	72	75	61	72	

- b) For these patients, how many of them had a diagnosis of:
- i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002 - **75**
  - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006 - **<5**

c) For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside levetiracetam, and indicate the number of patients receiving each

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10. The number of unique patients who have been treated with topiramate in 2024-2025, separated by month

a) Patient numbers segmented by age:

- i. 0-3 years old
- ii. 4-8 years old
- iii. 9-18 years old
- iv. 18 years+

TOPIRAMATE													
PT COUNT	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25	
AGE 0-3	0	0	0	0	0	0	0	0	0	0	0	0	
AGE 4-8	<5	0	0	0	<5	0	0	0	0	0	0	<5	
AGE 9-18	0	<5	<5	<5	0	0	<5	0	0	<5	<5	6	
AGE >18	12	11	10	9	6	11	13	8	6	10	10	16	

b) For these patients, how many of them had a diagnosis of:

- i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002    **5**
- ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006    - **<5**

c) For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside topiramate, and indicate the number of patients receiving each

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11. The number of unique patients who have been treated with lamotrigine in 2024-2025, separated by month

a) Patient numbers segmented by age:

- i. 0-3 years old
- ii. 4-8 years old
- iii. 9-18 years old
- iv. 18 years+

LAMOTRIGINE													
PT COUNT	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25	
AGE 0-3	0	0	0	0	0	0	0	0	0	0	0	0	
AGE 4-8	<5	<5	0	0	0	<5	<5	<5	<5	<5	0	<5	
AGE 9-18	<5	<5	<5	<5	<5	0	<5	0	0	<5	<5	<5	
AGES >18	17	23	20	25	31	29	24	35	28	21	36	38	

b) For these patients, how many of them had a diagnosis of:

- i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002    - **36**
- ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006    - **0**

c) For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside lamotrigine, and indicate the number of patients receiving each

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Preferably I would like the data in .xlsx or .csv format. Alternatively, a table will suffice:

E.g. For 1.a. Number of patients diagnosed with Dravet syndrome:

Age/Month	J	F	M	A	M	J	J	A	S	O	N	D
0-3 years old												
4-8 years old												
9-18 years old												
18+ years old												

If you are dissatisfied with our response, you have the right to appeal in line with guidance from the Information Commissioner. In the first instance you may contact the Information Governance Manager of the Trust.

Information Governance Manager  
Trust Headquarters  
Russell's Hall Hospital  
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West Midlands  
DY1 2HQ  
Email: [dgft.dpo@nhs.net](mailto:dgft.dpo@nhs.net)

Should you disagree with the contents of our response to your appeal, you have the right to appeal to the Information Commissioners Office at.

Information Commissioners Office  
Wycliffe House  
Water Lane  
Wilmslow  
Cheshire  
SK9 5AF  
Tel: 0303 123 1113  
[www.ico.org.uk](http://www.ico.org.uk)

If you require further clarification, please do not hesitate to contact us.

Yours sincerely

**Freedom of Information Team**  
**The Dudley Group NHS Foundation Trust**