

Email: foi.tsdfd@nhs.net
Our Ref: TSD10683

Dear Sir/Madam

Request for Information

We are writing to confirm that we have now completed our search for the information you requested.

A copy of the information is below:

Note: I understand the limitation of the ICD 10 codes in classifying Dravet syndrome and Lennox-Gastaut syndrome patients and that G40.3 and G40.4 will contain other epilepsies.

1. The number of patients under the trust's care with a recorded diagnosis of Dravet syndrome from January-June 2026. Likely coded as ICD-10 code G40.3 or SNOMED code 230437002.

a) Patient numbers segmented by age:

<2 years old	2-8 years old	9-17 years old	18+ years old
zero	<5	<5	29

2. The number of patients under the trust's care with a recorded diagnosis of Lennox-Gastaut syndrome from January-June 2026. Likely coded as ICD-10 code G40.4 or SNOMED code of 230418006.

a) Patient numbers segmented by age:

<2 years old	2-8 years old	9-17 years old	18+ years old
zero	zero	<5	<5

3. The number of patients under the trust's care who have been treated with fenfluramine from January-June 2026

a) Patient numbers segmented by age:

<2 years old	2-8 years old	9-17 years old	18+ years old

The information requested is exempt under Section 12.

b) For these patients, how many of them had a diagnosis of Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002. Patient numbers segmented by age:

<2 years old	2-8 years old	9-17 years old	18+ years old

The information requested is exempt under Section 12.

c) For these patients, how many of them had a diagnosis of Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006. Patient numbers segmented by age:

<2 years old	2-8 years old	9-17 years old	18+ years old

The information requested is exempt under Section 12.

4. The number of patients under the trust's care who have been treated with cannabidiol from January-June 2026

a) Patient numbers segmented by age:

<2 years old	2-8 years old	9-17 years old	18+ years old

The information requested is exempt under Section 12.

b) For these patients, how many of them had a diagnosis of Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002. Patient numbers segmented by age:

<2 years old	2-8 years old	9-17 years old	18+ years old

The information requested is exempt under Section 12.

c) For these patients, how many of them had a diagnosis of Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006. Patient numbers segmented by age:

<2 years old	2-8 years old	9-17 years old	18+ years old

The information requested is exempt under Section 12.

5. The number of patients under the trust's care who have been treated with cenobamate from January-June 2026

a) Patient numbers segmented by age:

<2 years old	2-8 years old	9-17 years old	18+ years old

The information requested is exempt under Section 12.

b) For these patients, how many of them had a diagnosis of Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002. Patient numbers segmented by age:

<2 years old	2-8 years old	9-17 years old	18+ years old

The information requested is exempt under Section 12.

c) For these patients, how many of them had a diagnosis of Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006. Patient numbers segmented by age:

<2 years old	2-8 years old	9-17 years old	18+ years old

The information requested is exempt under Section 12.

6. The number of patients under the trust's care who have been treated with rufinamide from January-June 2026. Patient numbers segmented by age:

<2 years old	2-8 years old	9-17 years old	18+ years old

The information requested is exempt under Section 12.

a) For these patients, how many of them had a diagnosis of Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006. Patient numbers segmented by age:

<2 years old	2-8 years old	9-17 years old	18+ years old

The information requested is exempt under Section 12.

7. The number of patients under the trust's care who have been treated with stiripentol from January-June 2026

a) Patient numbers segmented by age:

<2 years old	2-8 years old	9-17 years old	18+ years old

The information requested is exempt under Section 12.

b) For these patients, how many of them had a diagnosis of Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002. Patient numbers segmented by age:

<2 years old	2-8 years old	9-17 years old	18+ years old

The information requested is exempt under Section 12.

Section 12: The age breakdown requested for questions 3 to 7 is not held in an accessible or centrally reportable format. Based on the patient numbers identified in response to questions 1 and 2, the Trust would need to retrieve and review records for at least 30 patients, and potentially more, to determine whether the requested drug information is recorded and to provide the requested age breakdown. This would require the Trust to manually request and retrieve individual medical records and review clinical notes to identify the relevant drug information and patient age. We estimate that reviewing each set of notes could take up to one hour, depending on the size and complexity of the record, and larger records may take longer. This estimate does not include the additional time required to request, retrieve and make the notes available for review. On this basis, we estimate that the time required to locate, retrieve and extract the requested information would exceed the appropriate limit set out under Section 12 of the Freedom of Information Act 2000. Section 12 provides that a public authority is not obliged to comply with a request where it estimates that the cost of compliance would exceed the appropriate limit.

Low Numbers: Where there are less than 5, we are unable to provide the exact information you require as this may enable the identification of our employees, members of the public or patients. This would constitute personal information and would be considered exempt under Section 40 of the Freedom of Information Act. Section 40 (FOI Act) provides an exemption to disclosure, where disclosure would contravene any of the Data Protection principles. This exemption is an absolute exemption that is not subject to the public interest test. Where the information relates to an individual who can be identified from that data, or from that data when added to other information, in the possession of, or likely to come into the possession of the data controller, this meets the definition of personal data as defined by the Data Protection Act.

The information supplied to you continues to be protected by the Copyright, Designs and Patents Act 1988. You are free to use it for your own purposes, including any non-commercial research you are doing and for the purposes of news reporting.

If you wish to discuss any of the above, please contact us, quoting the FOI reference number above.

If you are unhappy with the way in which we have handled your request, please contact the Data Protection and Freedom of Information Lead in the first instance. If you wish to make a formal complaint, you should write to our Complaints Manager at Torbay and South Devon NHS Foundation Trust, First Floor Bowyer Building, Torbay Hospital, Torquay TQ2 7AA or by email to tsdft.feedback@nhs.net

If you are not content with the outcome of your complaint or the internal review, you may apply directly to the Information Commissioner for a decision. Generally, the Information Commissioner will only make a decision once you have exhausted the complaints and/or internal review process provided by us. The Information Commissioner can be contacted at: The Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF or through this link <https://ico.org.uk/global/contact-us/>

Yours sincerely,

Freedom of Information Team