

King's Mill Hospital
Mansfield Road
Sutton in Ashfield
Nottinghamshire
NG17 4JL

Tel: 01623 622515
Join today: www.sfh-tr.nhs.uk

Direct Line: 01623 672232
Our Ref: 1556
E-mail: sfh-tr.foi.requests@nhs.net

29th September 2026



Dear Sir/Madam

Freedom of Information Act (FOI) 2000 - Request for Information Reference: Rare
Disease Patients and Treatment

I am writing in response to your request for information under the FOI 2000.

I can confirm in accordance with Section 1 (1) of the Freedom of Information Act 2000 that we do not hold the information you have requested. A response to each part of your request is provided below. Please accept our apologies for the delay.

Home, Community, Hospital.

FOI Request / Question	Question Response	Is there an exemption?	Exemption	Exemption Details
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)	The Trust does not hold the information requested. The Trust does not use specific ICD-10 codes to identify the diagnoses referred to within your request and does not stock the medications specified. Consequently, the Trust is unable to provide the requested information.			
2. Of total DS patients, how many have been treated with • Epidyolex (Cannabidiol) in the last 12 months? • Fintepla (Fenfluramine) in the last 12 months?				
3. 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)				
4. Of total LGS patients, how many have been treated with • Epidyolex (Cannabidiol) in the last 12 months? • Fintepla (Fenfluramine) in the last 12 months?				
5. 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)				
6. 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)				

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Home, Community, Hospital.

Patient Experience Team
01623 672222
sfh-tr.pet@nhs.net



We are proud to be
a smoke-free site

Trust Chair Rukshana Kapasi OBE
Chief Executive Jon Melbourne

I trust this information answers your request. Should you have any further enquiries or queries about this response please do not hesitate to contact me. However, if you are unhappy with the way in which your request has been handled, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to: Sally Brook Shanahan, Director of Corporate Affairs, King's Mill Hospital, Mansfield Road, Sutton in Ashfield, Nottinghamshire, NG17 4JL or email sally.brookshanahan@nhs.net.

If you are dissatisfied with the outcome of the internal review, you can apply to the Information Commissioner's Office, who will consider whether we have complied with our obligations under the Act and can require us to remedy any problems. Generally, the Information Commissioner's Office cannot decide unless you have exhausted the internal review procedure. You can find out more about how to do this, and about the Act in general, on the Information Commissioner's Office website at: <https://ico.org.uk/your-data-matters/official-information/>.

Complaints to the Information Commissioner's Office should be sent to FOI/EIR Complaints Resolution, Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF. Telephone 0303 1231113, email casework@ico.org.uk.

If you would like this letter or information in an alternative format, for example large print or easy read, or if you need help with communicating with us, for example because you use British Sign Language, please let us know. You can call us on 01623 672232 or email sfh-tr.foi.requests@nhs.net.

Yours faithfully

Information Governance Team

All information we have provided is subject to the provisions of the Re-use of Public Sector Information Regulations 2015. Accordingly, if the information has been made available for re-use under the [Open Government Licence](#) (OGL) a request to re-use is not required, but the licence conditions must be met. You must not re-use any previously unreleased information without having the consent from Sherwood Forest Hospitals NHS Foundation Trust. Should you wish to re-use previously unreleased information then you must make your request in writing. All requests for re-use will be responded to within 20 working days of receipt.