

Date: Tuesday, 05th March 2024
Our Ref: MB/SH FOI 6181

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Re: Freedom of Information Request FOI 6181

We are writing in response to your request submitted under the Freedom of Information Act, received in this office on 20th February 2024.

Your request was as follows:

Q1. How many patient's does the trust have with a recorded diagnosis of Dravet Syndrome (DS)

a) Of these, how many have been treated with Epidyolex (Canabidiol) in the last 6 months?

b) Of these, how many have been treated with Fintepla (Fenfluramine) in the last 6 months?

I can confirm in accordance with Section 1 of the Freedom of Information Act 2000 (FOIA) that we do not hold the information you have requested as the Walton Centre NHS Foundation Trust do not have a specific coding outcomes for LGS or Dravet Syndrome. Therefore, we cannot provide this information.

Under the FOIA, we are not required to create this information in order to answer your request. I should explain that the FOIA is to do with transparency of information held by public authorities. It gives an individual the right to access recorded information held by public authorities. The FOIA does not require public authorities to generate information, or to answer questions, provide explanations or give opinions, unless this is recorded information that they already hold.

Q2. How many patient's does the trust have with a recorded diagnosis of Lennox-Gasteau Syndrome (LGS)

a) Of these, how many have been treated with Epidyolex (Canabidiol) in the last 6 months?

b) Of these, how many have been treated with Fintepla (Fenfluramine) in the last 6 months?

As above.

Please see our response above in [blue](#).

Re-Use of Public Sector Information

All information supplied by the Trust in answering a request for information (RFI) under the Freedom of Information Act 2000 will be subject to the terms of the Re-use of Public Sector Information Regulations 2005, Statutory Instrument 2005 No. 1515 which came into effect on 1st July 2005.

Under the terms of the Regulations, the Trust will licence the re-use of any or all information supplied if being used in a form and for the purpose other than which it was originally supplied. This license for re-use will be in line with the requirements of the Regulations and the licensing terms and fees as laid down by the Office of Public Sector Information (OPSI). Most licenses will be free; however the Trust reserves the right, in certain circumstances, to charge a fee for the re-use of some information which it deems to be of commercial value.

Further information can be found at www.opsi.gov.uk where a sample license terms and fees can be found with guidance on copyright and publishing notes and a Guide to Best Practice and regulated advice and case studies, at www.opsi.gov.uk/advice/psi-regulations/index.htm

If you are dissatisfied with the handling of your request, 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 the Freedom of Information Office at the address above.

Please remember to quote the reference number, FOI 6181 in any future communications.

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted by:

Post: Information Commissioners Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF.

Online: <https://ico.org.uk/make-a-complaint/foi-and-eir-complaints/>

Telephone: 0303 123 1113

Yours sincerely

Mike Burns

Mr. Mike Burns, Executive Lead for Freedom of Information