

Freedom of Information Request

Ref: 23-028

17 January 2023

By Email

Dear Sir/Madam

Thank you for your request for information under the Freedom of Information Act 2000. The Trust's response is as follows:

- We can confirm that we do hold the information you are requesting

In the last 12 months of available data:

1a. What number of unique patients have been treated for Lennox-Gastaut syndrome, Dravet Syndrome and Tuberous Sclerosis Complex? Please give answers for each condition separately.

Approximate figures are below:

Lennox-Gastaut syndrome 50

Dravet Syndrome 20-30

Tuberous Sclerosis Complex 70

1b. For each indication (Lennox-Gastaut syndrome, Dravet Syndrome and Tuberous Sclerosis Complex), what number of these have been treated in a paediatric environment?

All.

2a. How many patients have been treated with Epidyolex in a paediatric environment?

80-90% of Lennox-Gastaut Syndrome and Dravet cases.

10% of Tuberous Sclerosis Complex cases.

3a. Can you please detail which NHS Trusts/ Health Boards these patients have been referred from?

Lennox-Gastaut Syndrome and Dravet Syndrome – From South West District Hospitals.

Tuberous Sclerosis Complex – from the South West hospitals and some other centres in the UK.

This concludes our response. We trust that you find this helpful, but please do not hesitate to contact us directly if we can be of any further assistance.

If, after that, 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:

Data Protection Officer
University Hospitals Bristol and Weston NHS Foundation Trust
Trust Headquarters
Marlborough Street
Bristol
BS1 3NU

Please remember to quote the reference number above 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 at: Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF

Publication

Please note that this letter and the information included/attached will be published on our website as part of the Trust's Freedom of Information Publication Log. This is because information disclosed in accordance with the Freedom of Information Act is disclosed to the public, not just to the individual making the request. We will remove any personal information (such as your name, email and so on) from any information we make public to protect your personal information.

To view the Freedom of Information Act in full please click [here](#).

Yours sincerely

Freedom of Information Team
University Hospitals Bristol and Weston NHS Foundation Trust