

Freedom of Information Request

Ref: 21-554

26 October 2021

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
- **What services are provided by your hospital for patients with Dravet syndrome?**
 - o **Treatment initiation** - Yes
 - o **Titration of dose (consider both starting and maintenance treatment)** - Yes
 - o **Monitoring (incl. echocardiographies, liver function tests, etc.)** - Yes
 - o **Review of clinical presentations (frequency, duration)** - Yes
 - o **On-going prescription of treatments** - Yes
 - o **Completing the Blueteq forms** - Yes
 - o **Other** Yes (e.g. epilepsy surgery assessments, ketogenic diet)

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:

Director of Corporate Governance
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