

Freedom of Information Request

Ref: 25-131

10 March 2025

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

Under the Freedom of Information Act 2000, I would like to request the following information in relation to the Early Access Programme (EAP) for givinostat operated by ITF Pharma UK. Givinostat is a treatment for Duchenne muscular dystrophy (DMD) granted market authorisation by the MHRA in December 2024. The EAP is a free of charge scheme/compassionate use scheme which your organisation is eligible to take part in.

- **What assessment has your organisation made of participating in the EAP for givinostat?**

Clinical service capacity is under review

- **Does your organisation have plans to take part in the EAP for givinostat?**

This is still under review

- **If not, what was the rationale for not taking part? Clinical service capacity to safely deliver this treatment**

Not applicable

- **Has your organisation made an estimate of the cost of taking part in the EAP?**

This is still under review

- **If so, what is that cost?**

Not applicable

- **Has your organisation estimated how many patients may be eligible for the EAP?**

Yes

• **If so, how many patients are currently eligible for the EAP?**

19

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