

Freedom of Information Request

Ref: UHB 19-548

24 September 2019

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:

1. I understand these diseases have a form of register. How many are on your registers for:
 - Haemophilia A: 80 severe 20 moderate 115 mild = 215
 - Haemophilia B: 11 severe 7 moderates, 17 mild = 35
 - Von Willebrand Disease - are you able to say how many are under 18 years old as well? : 256 and 52 under 18 2 severe.

2. Over the last 3 months, how many patients with Haemophilia A have been treated with:
 - Advate: 38
 - Afstyla: 0
 - Elocta: 10
 - Emicizumab (Hemlibra): 4
 - Helixate: 0
 - Kogenate: 0
 - Novoseven RT: 1
 - Novoeight: 12
 - Nuwiq: 0
 - Refacto AF: 20
 - Factor Eight Inhibitor Bypass Activity: 0

3. If you are able to split the above by patients who have mild, moderate and severe Haemophilia, that would be useful, thanks.
Please see above response of question 1.

4. Over the last year, how many patients have been treated with:
 - Alphanate: 1

- DDAVP (desmopressin): 17
- Haemate P: 0
- Trabexamic acid: The Trust does not hold this information as this is an oral tablet which is issued via stock.
- Veyvondi: 0
- Voncento: 3
- Willate: 24
- Willfact: 0
- Willfactin: 0
- Alprolix: 7
- BeneFIX: 9
- Idelvion: 1
- Refixia: 0
- Rixubis: 0

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:

Trust Secretary
University Hospitals Bristol 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

FOI Team
UH Bristol NHS Foundation Trust