

Ref: FOI-011-202425- Clinical Data and Processes- Haemophilia B

Date: 9th April 2024

Email foi@uhnm.nhs.uk

Dear

I am writing to acknowledge receipt of your email dated 4th April 2024 requesting information under the Freedom of Information Act (2000) regarding Haemophilia B and Von Willebrand Disease

As of 1st November 2014 University Hospitals of North Midlands NHS Trust (UHM) manages two hospital sites – Royal Stoke University Hospital, and County Hospital (Stafford). Therefore the response below is for the two sites combined from that date where appropriate.

Q1 Could you please provide answers to the following five questions related to the incidence and treatment of Haemophilia B and Von Willebrand Disease?

How many patients has your Trust treated (for any medical condition) in the past 3 months with the following drugs:

- **Alphanate**
- **Alprolix**
- **BeneFIX**
- **HaemateP**
- **Idelvion**
- **Refixia**
- **Rixubis**
- **Veyvondi**
- **Voncento**
- **Wilate**
- **Willfact**

A1 We are unable to provide the information you require in the requested format as to release this data could lead to the identification of the person(s) involved due to the low numbers involved, and would breach the Trusts obligations under Data Protection Act 2018. Accordingly, this aspect of your request is exempt from disclosure under the terms of Section 40(2) of the FOI Act. *Personal information*. However as the Trust is committed to openness and transparency we can band the numbers as being <5
This exemption is an absolute exemption and therefore no consideration of the public interest test is needed.

- Alphanate=0

- Alprolix=5
- BeneFIX=0
- HaemateP=0
- Idelvion=0
- Refixia=0
- Rixubis=0
- Veyvondi=0
- Voncento= <5
- Wilate=0
- Willfact=0

Q2 How many patients have been treated in the past 3 months with:

- **Gene therapy for Haemophilia B ONLY**
- **Desmopressin for Von Willebrand Disease ONLY**
- **Tranexamic Acid for Von Willebrand Disease ONLY**

A2 See below:

- Gene therapy for Haemophilia B ONLY=0
- Desmopressin for Von Willebrand Disease ONLY=6
- Tranexamic Acid for Von Willebrand Disease ONLY=8

Q3 Of the patients that were treated with Veyvondi in the past 3 months, how many patients received treatment:

- **During surgery**
- **On demand to treat bleeding episodes**

A3 Nil for both listed above

Q4 Of the patients that were treated with Voncento in the past 3 months, how many patients received treatment:

- **During surgery**
- **On demand to treat bleeding episodes**

A4 We are unable to provide the information you require in the requested format as to release this data could lead to the identification of the person(s) involved due to the low numbers involved, and would breach the Trusts obligations under Data Protection Act 2018. Accordingly, this aspect of your request is exempt from disclosure under the terms of Section 40(2) of the FOI Act. *Personal information*. However as the Trust is committed to openness and transparency we can band the numbers as being <5

This exemption is an absolute exemption and therefore no consideration of the public interest test is needed.

- During surgery= <5
- On demand to treat bleeding episodes= <5

Q5 How many patients are registered with your Trust for the following diseases:

- **Haemophilia B**
- **Von Willebrand Disease**
- **Von Willebrand Disease - paediatric patients (age 17 or under)**

A5 See below:

- Haemophilia B=9
- Von Willebrand Disease=156(adults and peads)
- Von Willebrand Disease - paediatric patients (age 17 or under)=44

*Please note that any individuals identified do not give consent for their personal data to be processed for the purposes of direct marketing.

UHNM NHS Trust is a public sector body and governed by EU law. FOI requestors should note that any new Trust requirements over the EU threshold will be subject to these regulations and will be advertised for open competition accordingly.

Where the Trust owns the copyright in information provided, you may re-use the information in line with the conditions set out in the Open Government Licence v3 which is available at <http://www.nationalarchives.gov.uk/doc/open-government-licence/version/3/>. Where information was created by third parties, you should contact them directly for permission to re-use the information.

An anonymised copy of this request can be found on the Trust's disclosure log, please note that all requests can be found at the following link: <http://www.uhnm.nhs.uk/aboutus/Statutory-Policies-and-Procedures/Pages/Freedom-of-Information-Disclosure-Log.aspx>

This letter confirms the completion of this request. A log of this request and a copy of this letter will be held by the Trust.

If you have any queries related to the response provided please in the first instance contact my office.

Should you have a complaint about the response or the handling of your request, please also contact my office to request a review of this. If having exhausted the Trust's FOIA complaints process you are still not satisfied, you are entitled to approach the Information Commissioner's Office (ICO) and request an assessment of the manner in which the Trust has managed your request.

The Information Commissioner may be contacted at:

Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF or via www.ico.org.uk.

Yours,



Rachel Montinaro
Data Security and Protection Manager - Records