

FOI REF: 24/893

10th January 2025

Tel: 0300 131 4500
Website: www.esht.nhs.uk

FREEDOM OF INFORMATION ACT

I am responding to your request for information under the Freedom of Information Act. The answers to your specific questions are as follows:

Q1. How many patients has your Trust treated (for any medical condition) in the past 3 months with the following drugs:

• Alprolix	0
• BeneFIX	1
• Haemate P	0
• Idelvion	0
• Refixia	0
• Rixubis	0
• Veyvondi	1
• Voncento	1
• Wilate	0
• Willfact	0

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

- **Gene therapy for Haemophilia B ONLY**

East Sussex Healthcare NHS Trust no longer centrally records the number of patients with Haemophilia B. To enable the Trust to provide this information would require a manual review of all Haematology clinic letters which we estimate would take in excess of 18 hours. We are therefore applying Section 12(1) to this part of your request.

Section 12(1) of the Act allows a public authority to refuse to comply with a request for information if the authority estimates that the cost of compliance would exceed the 'appropriate limit', as defined by the Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulations 2004 (the Regulations). These state that this cost limit is £450 for public authorities which are not part of central government or the armed forces. The costs are calculated at £25 per hour per person regardless of the rate of pay, which means that the limit will be exceeded if the work involved would exceed 18 hours. The Trust estimates that the cost of complying with this request would significantly exceed the above limit.

- **Desmopressin for Von Willebrand Disease ONLY** 2
- **Tranexamic Acid for Von Willebrand Disease ONLY** 3

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

- **Prophylactically** 0
- **During surgery** 0
- **On demand to treat bleeding episodes** 1

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

- **Prophylactically** 0
- **During surgery** 0
- **On demand to treat bleeding episodes** 1

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

- **Haemophilia B**
Section 12 (1) applied, please refer to question 2.
- **Von Willebrand Disease** 16
- **Von Willebrand Disease - paediatric patients (age 17 or under)** 0

If I can be of any further assistance, please do not hesitate to contact me.

Should you be dissatisfied with the Trust's response to your request, you have the right to request an internal review. Please write to the Freedom of Information Department (esh-tr.foi@nhs.net), quoting the above reference, within 40 working days. The Trust is not obliged to accept an internal review after this date.

Should you still be dissatisfied with your FOI request, you have the right of complaint to the Information Commissioner at the following address:

The Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire SK9 5AF

Telephone: 0303 123 1113

Yours sincerely

Freedom of Information Department
esh-tr.foi@nhs.net