

FREEDOM OF INFORMATION REQUEST

RF23-486

Request:

Q1. 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

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

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

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

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)



Response:

We can confirm East Kent Hospitals University NHS Foundation Trust (EKHUFT) holds the information you have requested.

1.

Alphanate	0
Alprolix	6
BeneFIX	7
HaemateP	0
Idelvion	<5*
Refixia	0
Rixubis	0
Veyvondi	<5*
Voncento	<5*
Wilate	0
Willfact	0

2.

Gene therapy for Haemophilia B ONLY	0
Desmopressin for Von Willebrand Disease ONLY	5
Tranexamic Acid for Von Willebrand Disease ONLY	Information is not recorded. Tranexamic Acid is prescribed on prescription and is used as and when the patient needs it.

3.

During surgery	0
On demand to treat bleeding episodes	<5*

4.

During surgery	0
On demand to treat bleeding episodes	0

5.

Haemophilia B	33
Von Willebrand Disease	245
Von Willebrand Disease paediatric patients (age 17 or under)	40

* EKHUFT is unable to confirm the exact number where fewer than five patients are recorded. Given the low number, we consider that disclosure of such information, which constitutes personal data, would contravene the first data protection principle under GDPR. This states that personal data should be processed fairly and lawfully. It is the fairness aspect of this principle, which in our view, would be breached by disclosure. We believe that not disclosing this information is in line with Sections 40(2) and 40(3) of the Freedom of Information Act 2000.

(DATE OF RESPONSE: 14 AUGUST 2023)

