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| Freedom of Information Request | FOI 23-414 | 11 October 2023 |
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## Your request

You requested the following:

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
- 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
- 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
- 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
- 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)

## Our response

1. We are not able to provide information on the treatment drugs prescribed to individual patients for any medical condition as it is not recorded centrally. To comply with your request, we would need to review every patient record which we have established would take in excess of 18 hours to undertake and therefore exceeds the appropriate costs limit under Section 12 of the Freedom of Information Act 2000, which is currently £450. This is not an exemption which requires us to consider the application of the public interest test.
2. Our response to question 2 is provided in the table below:

| Treatment                                  | No. of Patients |
|--|-----------------|
| Gene therapy for Haemophilia B             | 0               |
| Desmopressin for Von Willebrand Disease    | 2               |
| Tranexamic Acid for Von Willebrand Disease | 4               |

3. Our response to both points in question 3 is 0.
4. Our response to both points in question 4 is 0.
5. Our response to question 5 is provided in the table below:

| Disease                                | No. of Patients |
|--|-----------------|
| Haemophilia B                          | 0               |
| Von Willebrand Disease (Total)         | 43              |
| Von Willebrand Disease (<17 Years Old) | 3               |