

Treatments for Haemophilia B & Von Willebrand disease

Reference Number: RDF2461-24

Date of Response: 23/04/24

Further to your Freedom of Information Act request, please find the Trust's response(s) below:

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

<i>Alphanate</i>	0
<i>Alprolix</i>	*<5
<i>BeneFIX</i>	0
<i>HaemateP</i>	*<5
<i>Idelvion</i>	0
<i>Refixia</i>	0
<i>Rixubis</i>	0
<i>Veyvondi</i>	0
<i>Voncento</i>	*<5
<i>Wilate</i>	*<5
<i>Willfact</i>	0

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

<i>Gene therapy for Haemophilia B ONLY</i>	0
<i>Desmopressin for Von Willebrand Disease ONLY</i>	*<5
<i>Tranexamic Acid for Von Willebrand Disease ONLY</i>	9

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

<i>During surgery</i>	0
<i>On demand to treat bleeding episodes</i>	0

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

<i>During surgery</i>	*<5
<i>On demand to treat bleeding episodes</i>	*<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)

<i>Haemophilia B</i>	14
<i>Von Willebrand Disease</i>	71
<i>Von Willebrand Disease - paediatric patients (age 17 or under)</i>	14

*<5 - Section 40 (2)

Please note that in accordance with Section 40 (2) where activity is 5 or less than 5, the Trust is unable to provide the exact information. We consider the data exempt on the following grounds:

The Trust considers that disclosure of the information risks identifying individuals. The reason for this is that the number of patients for which this applies is very low.

This and the fact that the data requested relates to the RDUH Health NHS Trust only and therefore relates to patients treated in a specific location (rather than covering a larger geographical area), increases the risk of identification or self-identification.

The Trust's view is that s.40(2) is applicable because disclosure of information which could lead to a patient being identified would be a breach of the patient's rights under the Data Protection Act Data Protection Principles set out in Schedule 1 of the GDPR, namely Principle 1.