

Dear

## FREEDOM OF INFORMATION – HAEMOPHILIA B TREATMENT

I write in response to your request for information in relation to haemophilia B treatment in NHS Lothian.

Question:

1. How many patients has your Trust treated (for any medical condition) in the past 3 months with the following drugs: Alprolix; BeneFIX; Haemate P; Idelvion; Refixia; Rixubis; Veyvondi; Voncento; Wilate; Willfact?

Answer:

The information you have requested is detailed in the table below. I have not released numbers of 5 or fewer in the table, as this information could lead to the identification of the individuals involved. Since we do not have their consent to release their personal data, the information is exempt under section 38 of the Freedom of Information (Scotland) Act 2002 as to provide it would breach the principles of the Data Protection Act 2018.

Number of patients treated, NHS Lothian Treatment	Number of patients
Alprolix	≤5
BeneFIX	≤5
Haemate P	≤5
Idelvion	≤5
Refixia	≤5
Rixubis	≤5
Veyvondi	11
Voncento	≤5
Wilate	≤5
Willfact	≤5

Question:

2. How many patients have been treated in the past 3 months with: Marstacimab for Haemophilia B ONLY; Gene therapy for Haemophilia B ONLY; Desmopressin for Von Willebrand Disease ONLY; Tranexamic Acid for Von Willebrand Disease ONLY?

## Answer:

The information you have requested is detailed in the table below. I have not released numbers of 5 or fewer in the table, as this information could lead to the identification of the individuals involved. Since we do not have their consent to release their personal data, the information is exempt under section 38 of the Freedom of Information (Scotland) Act 2002 as to provide it would breach the principles of the Data Protection Act 2018.

Number of patients treated, NHS Lothian	Number of patients
Treatment	
Marstacimab for Haemophilia B ONLY	≤5
Gene therapy for Haemophilia B ONLY	≤5
Desmopressin for Von Willebrand Disease ONLY	≤5
Tranexamic Acid for Von Willebrand Disease ONLY	Information not held

## Question:

3. Of the patients that were treated with Veyvondi in the past 3 months, how many patients received treatment: Prophylactically; During surgery; On demand to treat bleeding episodes

## Answer:

The information you have requested is detailed in the table below. I have not released numbers of 5 or fewer in the table, as this information could lead to the identification of the individuals involved. Since we do not have their consent to release their personal data, the information is exempt under section 38 of the Freedom of Information (Scotland) Act 2002 as to provide it would breach the principles of the Data Protection Act 2018.

Treatment with Veyvoni, NHS Lothian	Number of patients
Treatment	
Prophylactically	≤5
During surgery	≤5
On demand to treat bleeding episodes	8

## Question:

4. Of the patients that were treated with Voncento in the past 3 months, how many patients received treatment: Prophylactically; During surgery; On demand to treat bleeding episodes.

## Answer:

The information you have requested is detailed in the table below. I have not released numbers of 5 or fewer in the table, as this information could lead to the identification of the individuals involved. Since we do not have their consent to release their personal data, the information is exempt under section 38 of the Freedom of Information (Scotland) Act 2002 as to provide it would breach the principles of the Data Protection Act 2018.

<b>Treatment with Voncento, NHS Lothian</b>		<b>Number of patients</b>
<b>Treatment</b>		
Prophylactically		≤5
During surgery		≤5
On demand to treat bleeding episodes		≤5

Question:

5. 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)

Answer:

The information you have requested is detailed in the table below:

<b>Treatment with Voncento, NHS Lothian</b>		<b>Number of patients</b>
<b>Treatment</b>		
Haemophilia B		36
Von Willebrand Disease		186
Von Willebrand Disease - paediatric patients (age 17 or under)		16

I hope the information provided helps with your request.

If you are unhappy with our response to your request, you do have the right to request us to review it. Your request should be made within 40 working days of receipt of this letter, and we will reply within 20 working days of receipt. If our decision is unchanged following a review and you remain dissatisfied with this, you then have the right to make a formal complaint to the Scottish Information Commissioner within 6 months of receipt of our review response. You can do this by using the Scottish Information Commissioner's Office online appeals service at <https://www.foi.scot/appeal>. If you remain dissatisfied with the Commissioner's response you then have the option to appeal to the Court of Session on a point of law.

If you require a review of our decision to be carried out, please write to the reviewer at the address at the top of this letter. The review will be undertaken by a Reviewer who was not involved in the original decision-making process.

FOI responses (subject to redaction of personal information) may appear on NHS Lothian's Freedom of Information website at: <https://org.nhslothian.scot/FOI>

Yours sincerely

**ALISON MACDONALD**  
**Executive Director of Nursing Midwifery and AHPs**  
Cc: Chief Executive