

Date 05/12/2025
Your Ref
Our Ref 10818

Enquiries to Richard Mutch
Extension 35687
Direct Line 0131 465 5687
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Dear

FREEDOM OF INFORMATION – HEMOPHILIA A PATIENTS

I write in response to your request for information in relation to Hemophilia A patients.

Question:

- Please provide Hemophilia A patient numbers broken down by: age, disease severity and treatment regimen (PPx denotes use for prophylaxis and OD denotes use on demand). I have proposed a format below to capture the relevant information. If data is not available by age breakdown, then please provide aggregated total in the yellow highlighted column:

Answer:

July through September 2025	Age											
	0-12 years						13+					
	Mild		Moderate		Severe		Mild		Moderate		Severe	
	PPx	OD	PPx	OD	PPx	OD	PPx	OD	PPx	OD	PPx	OD
Hemlibra (emicizumab)	0	0	0	0	9	0	0	0	0	0	25	0
Altuvect (giiroctocogene fitelparvovec)	0	0	0	0	0	0	0	0	0	0	5<	0
Esperoct (turoctocog alfa pegol)	0	0	0	0	0	0	0	0	5<	5<	11	5<
Elocta (efmoroctocog alfa)	0	5<	0	0	0	0	0	0	0	0	0	5<
Advate (octocog alfa)	0	5<	0	0	0	5<	0	5<	0	5<	5<	6
Kovaltry (octocog alfa)	0	0	0	0	0	0	0	0	0	0	0	0

Headquarters
Mainpoint
102 West Port
Edinburgh EH3 9DN

Chair Professor John Connaghan CBE
Chief Executive Professor Caroline Hiscox
Lothian NHS Board is the common
name of Lothian Health Board

Iblis (octocog alfa)	0	0	0	0	0	0	0	0	0	0	0	0
Refacto AF (moroctocog alfa)	0	0	0	0	0	0	0	0	0	0	0	0
Xyntha (moroctocog alfa)	0	0	0	0	0	0	0	0	0	0	0	0
NovoEight (turoctocog alfa)	0	0	0	0	0	0	0	0	0	0	0	0
Nuwiq (simoctocog alfa)	0	0	0	0	0	0	0	0	0	0	0	0
Vihuma (simoctocog alfa)	0	0	0	0	0	0	0	0	0	0	0	0

Question:

Inhibitor patients

2. For Hemlibra-treated **Hemophilia A Inhibitor** patients, please indicate the number of patients by age group and dosing frequency for Q3'25 (July–September 2025). If data is not available by age breakdown then please provide aggregated total:

Answer:

Age group (Hemophilia A inhibitor patients)	Once weekly	Every 2 weeks	Every 4 weeks
0-12 years	0	5<	0
13+ years	5<	5<	5<
Total	5<	0	5<

Question:

Non-inhibitor patients

3. For Hemlibra-treated **Hemophilia A non-inhibitor** patients, please indicate the number of patients by age group and dosing frequency for Q3'25 (July–September 2025). If data is not available by age breakdown then please provide aggregated total:

Answer:

Age group (Hemophilia A non-inhibitor patients)	Once weekly	Every 2 weeks	Every 4 weeks
0-12 years	0	5<	0
13+ years	0	23	5<
Total	0	23	0

To protect the identity of the individuals involved any figure of 5 or less has not been shown in the tables above. Since we do not have their consent to release this data from their records, the information is exempt under section 38(1)(b) of the Freedom of Information (Scotland) Act i.e. to provide it would breach the Data Protection Act (2018).

I hope the information provided helped 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 www.itspublicknowledge.info/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 FOI Reviewer at the email address at the head 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/Pages/default.aspx>

Yours sincerely

ALISON MACDONALD
Executive Director, Nursing
Cc: Chief Executive