

Ref: FOIA Reference 2021/22-316

Date: 24th September 2021

Email foi@uhnm.nhs.uk

Dear

I am writing to acknowledge receipt of your email dated 14th September 2021 requesting information under the Freedom of Information Act (2000) regarding Von Willebrand Disease.

As of 1st November 2014 University Hospitals of North Midlands NHS Trust (UHNM) manages two hospital sites – Royal Stoke University Hospital, and County Hospital (Stafford). Therefore the response below is for the two sites combined from that date where appropriate.

Q1 In the past 6 months (latest 6 months available) how many patients have received the following treatments (for any disease?)

- **Alphanate**
- **Berinert (Human C1-esterase inhibitor)**
- **Cinryze (Human C1-esterase inhibitor)**
- **Firazyr (Icatibant injection)**
- **Lorviqua (Lorlatinib)**
- **Ruconest (Recombinant human C1-esterase inhibitor)**
- **Takhzyro (Lanadelumab)**
- **Veyvondi (Vonicog alfa)**
- **Voncento**
- **Wilate**
- **Wilfact**

A1 Figures show number of patients receiving requested medications direct from pharmacy. Report is for March 21 – August 21 inclusive.

- Alphanate = 0
- Berinert (Human C1-esterase inhibitor) = 6
- Cinryze (Human C1-esterase inhibitor) = 7
- Firazyr (Icatibant injection) = 14
- Lorviqua (Lorlatinib) = 0
- Ruconest (Recombinant human C1-esterase inhibitor) = 0
- Takhzyro (Lanadelumab) = 7
- Veyvondi (Vonicog alfa) = 0
- Voncento = 0
- Wilate = 0
- Wilfact = 0

Q2 In the past 6 months (latest 6 months available) how many patients have received the following immunoglobulin treatments (for any disease?)

- **Cuvitru**
- **Gammanorm**
- **Gamunex**
- **Hizentra**
- **Hyqvia**
- **Intratect**
- **Kiovig**
- **Octagam**
- **Privigen**
- **Subgam**

A2 We are unable to provide the information you require in the requested format as to release this data could lead to the identification of the person(s) involved due to the low numbers involved, and would breach the Trusts obligations under Data Protection Act 2018. Accordingly, this aspect of your request is exempt from disclosure under the terms of Section 40(2) of the FOI Act. *Personal information*. However as the Trust is committed to openness and transparency we can band the numbers as being <5

This exemption is an absolute exemption and therefore no consideration of the public interest test is needed.

Figures show number of patients receiving requested medications direct from pharmacy. Report is for March 21 – August 21 inclusive.

- Cuvitru = <5
- Gammanorm = 11
- Gamunex = <5
- Hizentra = 19
- Hyqvia = 0
- Intratect = 25
- Kiovig = 6
- Octagam = 6
- Privigen = 48
- Subgam = 0

Q3 How many Von Willebrand Disease patients have been treated in the past 3 months with the following drugs?

- **Desmopressin**
- **Tranexamic Acid**

A3 We are unable to provide the information you require in the requested format as to release this data could lead to the identification of the person(s) involved due to the low numbers involved, and would breach the Trusts obligations under Data Protection Act 2018. Accordingly, this aspect of your request is exempt from disclosure under the terms of Section 40(2) of the FOI Act. *Personal information*. However as the Trust is committed to openness and transparency we can band the numbers as being <5

This exemption is an absolute exemption and therefore no consideration of the public interest test is needed

Data shows inpatients with the Von Willebrand Disease clinical coding. Does not necessarily mean this was the reason for their admission.

- Desmopressin = 0
- Tranexamic Acid = <5

*Please note that any individuals identified do not give consent for their personal data to be processed for the purposes of direct marketing.

UHNM NHS Trust is a public sector body and governed by EU law. FOI requestors should note that any new Trust requirements over the EU threshold will be subject to these regulations and will be advertised for open competition accordingly.

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An anonymised copy of this request can be found on the Trust's disclosure log, please note that all requests can be found at the following link: <http://www.uhnm.nhs.uk/aboutus/Statutory-Policies-and-Procedures/Pages/Freedom-of-Information-Disclosure-Log.aspx>

This letter confirms the completion of this request. A log of this request and a copy of this letter will be held by the Trust.

If you have any queries related to the response provided please in the first instance contact my office.

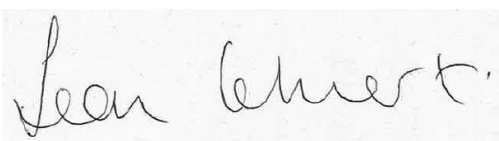
Should you have a complaint about the response or the handling of your request, please also contact my office to request a review of this. If having exhausted the Trust's FOIA complaints process you are still not satisfied, you are entitled to approach the Information Commissioner's Office (ICO) and request an assessment of the manner in which the Trust has managed your request.

The Information Commissioner may be contacted at:

Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF or via www.ico.org.uk.

If following review of the responses I can be of any further assistance please contact my secretary on 01782 671612.

Yours,





**University Hospitals
of North Midlands**
NHS Trust

Jean Lehnert
Data, Security & Protection Manager

