

Ref: FOIA Reference 2019/20-342

Royal Stoke University Hospital
Quality, Safety and Compliance Department
Newcastle Road
Stoke-on-Trent
Staffordshire
ST4 6QG

Date: 14th October 2019

Email foi@uhn.nhs.uk

Dear

I am writing in response to your email dated 13th September 2019 requesting information under the Freedom of Information Act (2000) regarding hereditary angioedema.

On the same day we contacted you via email as we required clarification on what you meant by “treat”? Were you referring to inpatients or outpatients?

On 24th September 2019 you replied via email with the following:

“Treat in reference to questions is in or out patient with a drug, eg HAE with Berinert”

On 4th October 2019 we contacted you via email as we required further clarification on the following: what do you mean by TPO?

On 7th October 2019 you replied via email with the following:

“A TPO is a Thrombopoietin receptor agonist, such as Eltrombopag and Romiplostim”

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 Does your Trust treat hereditary angioedema HAE? [Yes/No]

A1 Yes

Q2 In the last 6 months, how many patients with hereditary angioedema (HAE) have been treated with?

- Berint
- Cinryze
- Firazyr
- Ruconest
- Takhzyro
- Tranexamic acid
- Other

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. Please see below:

- Berint = <5
- Cinryze = <5
- Firazyr = <5
- Ruconest = <5
- Takhzyro - 0
- Tranexamic acid - 0
- Other – n/a

Q3 Does your Trust treat Immune thrombocytopenia purpura ITP? [Yes/No]

A3 Yes

Q4 Over the past 6 months, how many patients with persistent / chronic* Immune thrombocytopenia purpura [ITP] have you treated [include all treatments such as steroids, splenectomy, immune globulins, Rituximab and TPOs]?

A4 Over the past 6 months fifteen (15) patients with persistent / chronic* Immune thrombocytopenia purpura [ITP] have been treated [include all treatments such as steroids, splenectomy, immune globulins, Rituximab and TPOs]

Q5 Over the past 6 months, how many patients with persistent / chronic* Immune thrombocytopenia purpura [ITP] were new to treatment with the following;

- **Eltrombopag [Revolade]**
- **Romiplostim [Nplate]**

A5 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 number as being <5.

Q6 At what line of treatment would you currently use a TPO in an ITP patient: 4th line, 3rd line, 2nd line or 1st line?

A6 At UHNM we usually use 3rd line but in some cases, 2nd line where there are no alternatives. In all cases we comply with NICE guidance.

Q7 Over the past 6 months, how many patients have you treated with the following conditions and treatments. If none, please state none.

	Total patients	Eltrombopag [Revolade]	Romiplostim [Nplate]
Immune thrombocytopenia purpura [ITP]			
Chronic hepatitis C virus (HCV) infection for the treatment of thrombocytopenia, where the			

degree of thrombocytopenia is the main factor preventing the initiation or limiting the ability to maintain optimal interferon-based therapy			
Acquired severe aplastic anaemia (SAA) who were either refractory to prior immunosuppressive therapy or heavily pre-treated and are unsuitable for haematopoietic stem cell transplantation			
Chemotherapy induced thrombocytopenia (CIT)			
Myelodysplastic syndromes (MDS)			

A7 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. Please see below:

	Total patients	Eltrombopag [Revolade]	Romiplostim [Nplate]
Immune thrombocytopenia purpura [ITP]	6	<5	<5
Chronic hepatitis C virus (HCV) infection for the treatment of thrombocytopenia, where the degree of thrombocytopenia is the main factor preventing the initiation or limiting the ability to maintain optimal interferon-based therapy	0	0	0
Acquired severe aplastic anaemia (SAA) who were either refractory to prior immunosuppressive therapy or heavily pre-treated and are unsuitable for haematopoietic stem cell transplantation	0	0	0
Chemotherapy induced thrombocytopenia (CIT)	0	0	0
Myelodysplastic syndromes (MDS)	<5	<5	<5

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

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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.

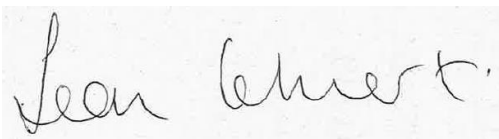
Should you have a complaint about the response or the handling of your request, please also contact my office to request a review of this. If having exhausted the Trust's FOIA complaints process you are still not satisfied, you are entitled to approach the Information Commissioner's Office (ICO) and 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 676474.

Yours,



Jean Lehnert
Information Governance Manager