



GIG  
CYMRU  
NHS  
WALES

Bwrdd Iechyd Prifysgol  
Bae Abertawe  
Swansea Bay University  
Health Board

Cadeirydd Dros Dro/ Interim Chair: **Emma Woollett**  
Prif Weithredwr/Chief Executive: **Tracy Myhill**

**gofalu am ein gilydd, cydweithio, gwella bob amser**  
**caring for each other, working together, always improving**

Rydym yn croesawu gohebiaeth yn y Gymraeg ac yn y Saesneg. We welcome correspondence in Welsh or English.

Dyddiad/Date: 10<sup>th</sup> October 2019  
Ein Cyf / Our Ref: 19-I-018

01639 648363

FOIA.Requests@wales.nhs.uk

[REDACTED]

Corporate Services  
Headquarters  
1 Talbot Gateway  
Baglan  
Port Talbot, SA12 7BR

[REDACTED]

I refer to your Freedom of Information Act Request acknowledged by ourselves on 17<sup>th</sup> September 2019. Your request sought information relating to hereditary angioedema and immune thrombocytopenia purpura.

**1. In the last 6 months, how many patients with Hereditary angioedema (HAE) have been treated with the following medication**

- **Berint** – not held by the Health Board\*
- **Cinryze** – not held by the Health Board\*
- **Firazyr** – this is supplied as stock item to A&E, unable to quantify patient numbers
- **Ruconest** – not held by the Health Board.
- **Takhzyro** - 0
- **Tranexamic acid** – this is a common stock item for multiple indications, unable to quantify patient numbers.
- **Other**

The information above has been supplied by our pharmacy team, as we do not hold information centrally by condition. To obtain information by condition would involve a manual trawl and search of records which we have estimated would significantly exceed the 18 hours limit set down by the FOI Act as the reasonable limit. Section 12 of the FOI Act provides that we are not obliged to spend in excess of 18 hours in any sixty day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time.

\*Where we have stated not held, this treatment is supplied by the Welsh Blood Service:  
[www.welsh-blood.org.uk](http://www.welsh-blood.org.uk)



Pencadlys BIP Bae Abertawe, Un Porthfa Talbot, Port Talbot, SA12 7BR / Swansea Bay UHB Headquarters, One Talbot Gateway, Port Talbot, SA12 7BR

Bwrdd Iechyd Prifysgol Bae Abertawe yw enw gweithredu Bwrdd Iechyd Lleol Prifysgol Bae Abertawe  
Swansea Bay University Health Board is the operational name of Swansea Bay University Local Health Board

**2. 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]?**

Please note that we do not hold this information centrally. To obtain information by condition would involve a manual trawl and search of records which we have estimated would significantly exceed the 18 hours limit set down by the FOI Act as the reasonable limit. Section 12 of the FOI Act provides that we are not obliged to spend in excess of 18 hours in any sixty day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time.

**3. 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]**

**\*Patient has ITP for over 6 months and does not respond to standard active treatments**

Please note that we do not hold this information centrally. To obtain information by condition would involve a manual trawl and search of records which we have estimated would significantly exceed the 18 hours limit set down by the FOI Act as the reasonable limit. Section 12 of the FOI Act provides that we are not obliged to spend in excess of 18 hours in any sixty day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time.

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

Please note that we do not hold information centrally by condition. To obtain information by condition would involve a manual trawl and search of records which we have estimated would significantly exceed the 18 hours limit set down by the FOI Act as the reasonable limit. Section 12 of the FOI Act provides that we are not obliged to spend in excess of 18 hours in any sixty day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time.

The numbers prescribed from our pharmacy department are:

Eltrombopag - 11

Romiplostim - <5

	<b>Eltrombopag [Revolade]</b>	<b>Romiplostim [Nplate]</b>
--	-----------------------------------	---------------------------------



<b>Immune thrombocytopenia purpura [ITP]</b>	Not held centrally	Not held centrally
<b>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</b>	Not held centrally	Not held centrally
<b>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</b>	Not held centrally	Not held centrally
<b>Chemotherapy induced thrombocytopenia (CIT)</b>	Not held centrally	Not held centrally
<b>Myelodysplastic syndromes (MDS)</b>	Not held centrally	Not held centrally

I hope this information is helpful. If you require anything further please contact us at [FOIA.Requests@wales.nhs.uk](mailto:FOIA.Requests@wales.nhs.uk).

Under the terms of the Health Board's Freedom of Information policy, individuals seeking access to recorded information held by the Health Board are entitled to request internal review of the handling of their requests. If you would like to complain about the Health Board's handling of your request please contact me directly at the address below or register your complaint via [FOIA.Requests@wales.nhs.uk](mailto:FOIA.Requests@wales.nhs.uk).

If after Internal Review you remain dissatisfied you are also entitled to refer the matter to the information commissioner at the Information Commissioner's Office (Wales), 2<sup>nd</sup> Floor, Churchill House, Churchill Way, Cardiff, CF10 2HH. Telephone Number: 029 2067 8400.



Yours sincerely



Pam Wenger  
**Director of Corporate Governance**

