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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: 22<sup>nd</sup> October 2019  
Ein Cyf / Our Ref: 19-J-010

☎ 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 8<sup>th</sup> October 2019. Your request sought information relating to Fabry and Gaucher's disease.

**Q1. How many NEW patients have been diagnosed for Fabry Disease in the past 3 months [latest 3 months available]?**

**Q2. How many NEW patients have been diagnosed for Gaucher's Disease in the past 3 months [latest 3 months available]?**

**Q3. How many NEW patients have been diagnosed for MPS II (Hunter Syndrome) in the past 3 months [latest 3 months available]?**

In regards to Q1, Q2 & Q3 – this information is not held centrally, and would require a manual trawl of patient records in order to obtain the figures 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.



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

**Q4. Please state the number of patients treated in the past 3 months [latest 3 months available] on each of the following treatments, regardless of diagnosis;**

**Replagal (agalsidase alpha) - 0**

**Fabrazyme (agalsidase beta) - 0**

**Galafold (migalastat) - 0**

**VPRIV (velaglucerase alfa) - 0**

**Cerezyme (imiglucerase) - 0**

**Cerdelga (eliglustat) - 0**

**Zavesca (miglustat) - 0**

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**

