



GIG  
CYMRU  
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WALES

Bwrdd Iechyd Prifysgol  
Bae Abertawe  
Swansea Bay University  
Health Board

Cadeirydd/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: 8<sup>th</sup> October 2020  
Ein Cyf / Our Ref: 20-H-018

☎ 01639 648363

✉ FOIA.Requests@wales.nhs.uk



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

Dear [REDACTED],

I refer to your Freedom of Information Act Request acknowledged by ourselves on 7<sup>th</sup> August 2020. Your request sought information relating to Fabry and Gaucher's disease and Hunter's Syndrome.

Please note that we have provided the information for the period 01.04.20 to 30.06.20.

**1. Within your Health Board, how many patients currently have a diagnosis for;**

You clarified on 17<sup>th</sup> September 2020 that you are looking for numbers of patients admitted to hospital with one of the below diagnoses.

- a. Fabry Disease** - <5\* patients
- b. Gaucher Disease** – see above. Fabry and Gaucher Disease are coded using the same clinical code within our systems, therefore we cannot differentiate between the two.
- c. MPS II (Hunter Syndrome)** – 0 patients

**2. Of the patients above, how many have been newly diagnosed within the past 3 months for**

- a. Fabry Disease**
- b. Gaucher Disease**



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

### **c. MPS II (Hunter Syndrome)**

Swansea Bay Health Board does not hold this information. Diagnosis information would be held in patient notes within individual GP practices.

### **3. How many patients (including any patients whose treatment is on hold due to Covid-shielding) are being treated at this point in time with:**

You clarified on 6<sup>th</sup> September 2020 that you were looking for numbers of patients regardless of their 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**

**Any other treatment for Fabry disease [please state which treatments]**

**Any other treatment for Gaucher disease [please state which treatments]**

To obtain this information 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. Of the patients being treated for Fabry disease can you please provide the numbers of patients being treated through homecare?**

We do not have any patients on our Primary Care prescribing system receiving any of the above medications.

\*Where fewer than 5 has been indicated we are unable to provide you with the exact number of patients as due to the low numbers, there is a potential risk of identifying individuals if this was disclosed. We are therefore withholding this detail under Section 40(2) of the Freedom of Information Act 2000. This information is protected by the General Data Protection Regulation (GDPR) and Data Protection Act 2018 and its disclosure would be contrary to the data protection principles and constitute as unfair and unlawful processing in regard to Articles 5, 6, and 9 of GDPR. This exemption is absolute and therefore there is no requirement to apply the public interest test.



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**

