



GIG
CYMRU
NHS
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: 13th July 2020
Ein Cyf / Our Ref: 20-F-019

☎ 01639 648363
✉ FOIA.Requests@wales.nhs.uk

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

Dear

I refer to your Freedom of Information Act Request acknowledged by ourselves on 17th June 2020. Your request sought information relating to Smith-Magenis Syndrome.

1. Total population covered by the health authority

I can confirm that the information you are seeking is included on the Swansea Bay website at:

<https://sbuhb.nhs.wales/about-us/swansea-bay-uhb>

Under Section 21 of the Freedom of Information Act (information accessible by other means), we are not required to provide information in response to a request if the information is already reasonably accessible to you.

2. The total number of people diagnosed with Smith-Magenis syndrome within this population

3. Year of Birth

4. Male / Female

Testing for Smith-Magenis Syndrome is completed via a laboratory in Cardiff as part of the All Wales service. Therefore, the databases for both testing and test results are held by Cardiff and Vale Health Board.

However, although Cardiff & Vale Health Board carry out testing they would not hold the number of people 'diagnosed' with Smith-Magenis Syndrome within Swansea Bay Health Board, only the patients that were tested by their facility. The comprehensive data on diagnosis for Swansea Bay patients would be held within the individual patient's notes.



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

This information is therefore not held centrally and to obtain this information would involve a manual trawl and search of patient 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.

I hope this information is helpful. If you require anything further please contact us at 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.

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), 2nd Floor, Churchill House, Churchill Way, Cardiff, CF10 2HH. Telephone Number: 029 2067 8400.

Yours sincerely



Pam Wenger
Director of Corporate Governance

