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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: 27th February 2020
Ein Cyf / Our Ref: 20-B-006

01639 [REDACTED]
FOIA.Requests@wales.nhs.uk

[REDACTED]
[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 5th February 2020. Your request sought information relating to Turner Syndrome.

Are you also able to confirm the number of women who are registered with a genetic condition called Turner Syndrome?

All testing for Turner Syndrome is done 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 women 'diagnosed' with Turner Syndrome. As the nature of Turner Syndrome is a varying range of symptoms, patients could be known to a number of different clinical departments (e.g. gynaecology, renal, cardiac etc.) and some patients may require no clinical intervention after diagnosis. 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



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

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

