Bwrdd Iechyd Prifysgol Bae Abertawe
Swansea Bay University Health Board

Cadeirydd/Chair: **Emma Woollett**
Prif Weithredwr/Chief Executive: **Mark Hackett**

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



**Cais Rhyddid Gwybodaeth / Freedom of Information request**
**Ein Cyf / Our Ref: 23-B-014**

**You asked:**

1. **For the period 1st January 2022 to 31st December 2022 (or the most recent 12 month period available), the number of patients diagnosed with genetic haemochromatosis under your care.**
   To obtain this information would involve a manual trawl and search of paper 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 and The Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulation 2004 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.

2. **For the period 1st January 2022 to 31st December 2022 (or the most recent 12 month period available), the average time in days from first referral from primary care to the patient's first appointment within your Health Board.**
   To obtain this information would involve a manual trawl and search of paper 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 and The Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulation 2004 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. **A copy of your protocol and/or patient pathway applicable to the care of people with genetic haemochromatosis.**
   I can confirm that the Health Board does not have its own specific protocol. However, it follows the British Society for Haematology (BSH) guidelines for genetic haemochromatosis. You can find this here - https://b-s-h.org.uk/guidelines/guidelines/diagnosis-and-therapy-of-genetic-haemochromatosis-review-and-2017-update

4. **The date that your protocol/patient pathway for genetic haemochromatosis was last reviewed or revised.**
   Please see question 3

5. **A copy of your clinical protocol(s) for therapeutic venesection.**
   Please see question 3

6. **The date that your protocol(s) for therapeutic venesection were last reviewed or revised.**
   Please see question 3