Reference:	FOI.10901.23
Subject:	Genetic Haemochromatosis
Date of Request:	7 February 2023

Requested:

a. 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.

b. 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 trust.

c. A copy of your protocol and/or patient pathway applicable to the care of people with genetic haemochromatosis.

d. The date that your protocol/patient pathway for genetic haemochromatosis was last reviewed or revised.

e. A copy of your clinical protocol(s) for therapeutic venesection.

f. The date that your protocol(s) for therapeutic venesection were last reviewed or revised.

Response:

a. Hywel Dda University Health Board (UHB) confirms that there were two hundred and thirty nine (239) patients recorded on the UHB's Welsh Patient Administration System (WPAS), with a diagnosis of genetic haemochromatosis, during the calendar year 1 January 2022 to 31 December 2022.

Please note:- This is a count of unique patients rather than a count of hospital admissions.

b. The UHB confirms that the average time from first referral to the patient's first appointment is one hundred and six (106) days, during the calendar year 1 January 2022 to 31 December 2022.

Please note:- Clinical condition recording on WPAS is in the process of being rolled out for certain specialties; therefore, the number provided above, for outpatient referrals, may be lower than actually referred.

c. – f. The UHB provides a copy of its Haemochromatosis and Polycythaemia Venesection pathway, which is currently under review, at Attachment 1.