INTEGRATED CARE PATHWAY FOR VENESECTION OF PATIENTS WITH HAEMOCHROMATOSIS OR POLYCYTHAEMIA

1. INTRODUCTION

This pathway is designed for patients diagnosed with haemochromatosis or polycythaemia requiring regular venesections as part of a supervised programme without the need to attend a clinic appointment with a consultant at each venesection episode. All staff members involved in administering this pathway must be familiar with the health board phlebotomy policy and must be trained and competency assessed in its use.

2. CRITERIA FOR PATIENT SELECTION

In order to access the pathway patients must have been diagnosed haemochromatosis or polycythaemia and the decision made by a consultant haematologist to start long term treatment with regular venesection. Patients must be mobile enough to transfer with minimal help. Patients will be referred, in writing, by a Haematology consultant to the nominated nurse in charge of the pathway (Gerontology Day Hospital (GDH) sister in Prince Philip Hospital. The referring physician is responsible for consenting the patient for long term venesection.

The referral letter must contain the following information:

- Diagnosis
- Confirmation of consent
- Ferritin and transferrin saturation results with target values in cases of iron overload
- Haematocrit (HCT) target in cases of polycythaemia,
- Haemoglobin (Hb) level, to monitor for anaemia
- Desired frequency of venesection or testing prior to venesection
- Contact telephone number for the patient or relative

3. RESPONSIBILITY OF THE NURSE IN CHARGE

The nurse in charge of the clinical area is responsible for ensuring referred patients meet the above criteria and the required information is provided. The referring doctor must be informed immediately if the patient cannot be accepted onto the pathway. An information sheet (appendix 1) must be completed for each patient and kept in a designated folder in the relevant clinical area with a copy being filed in the patient case notes.

The patient will be sent an appointment for venesection or a blood test arranged and results reviewed. The venesection procedure sheet must be completed for each episode.

4. HAEMOCHROMATOSIS / IRON OVERLOAD

Initial therapy

- Once weekly venesection of 450-500ml (equivalent to 450-500mg blood) until the serum ferritin concentration is <50 ng/ml and the TFsat is < 50%. Fortnightly venesection may be considered in frailer patients or those unable to attend weekly.
- The venesections will be performed by junior doctors or trained nurses in a designated clinical area (GDH clinic currently held on Tuesday mornings in PPH).
- Monitor the Hb at every visit for the first month and monthly thereafter. If anaemia develops refer the patient back for review in clinic as true iron overload may not be present
- Monitor serum ferritin monthly
- When ferritin is <50 ng/ml and TF sat <50% refer patient to the nurse led maintenance haemochromatosis pathway.

Maintenance pathway

- Monitor ferritin, TF sat and FBC 3 monthly
- Venesect to maintain ferritin <50 ng/ml and TF sat < 50%
- If the ferritin is above 200 ng/ml the patient may need 2 venesections performed a week apart
- Patients will not been seen routinely in Haematology clinics. Any patients with evidence of liver disease at diagnosis will be referred to a liver specialist for investigation and monitoring.
- Patients not attending for monitoring will be sent reminder letters and if no response obtained will be discharged to their GP.

5. PRIMARY POLYCYTHAEMIA

Venesection may be used as an alternative, an adjunct or prior to starting cytoreductive therapy.

Initial therapy (if required)

- At diagnosis, once weekly venesection (450-500 ml blood) until the HCT is < 0.45 to reduce the risk of thrombosis.
- Aspirin 75mg to be commenced

Maintenance therapy

- Monitor full blood count at the specified interval and if HCT > 0.45 but < 0.50 arrange for one venesection. If HCT > 0.50, arrange for two venesections at weekly intervals.

6. SECONDARY POLYCYTHAEMIA

Occasionally venesection is indicated for secondary causes of polycythaemia when other risk factors are present. The HCT target may differ according to the patient and will be indicated in the referral letter.

7. REFERENCES

1) Diagnosis and therapy of genetic haemochromatosis (review and 2017 update) BJH, 2018, 181.

2) Diagnosis and management of hemochromatosis. 2011. American Association for the study of liver diseases. Hepatology, 54
3)
4) European association for the study of the liver (EASL) 2010 guidelines for HFE haemochromatosis. Journal of Hepatology, 53

Appendix 1: Patient data sheet

Patient addressograph:	Date referred: Contact telephone number:
Diagnosis:	Referring Consultant:

	Date:
Consented for venesection:	
Venue for venesection:	
Target: ferritin transferrin sat HCT (delete as appropriate)	
Current: ferritin transferrin sat HCT (delete as appropriate)	
Current Hb	
Frequency of blood test	
Medical review arranged:	

Addressograph

Appendix 2: Procedure for Venesection: Polycythaemia

Procedure	Date	Date	Date
Access vein in ACF	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Venesected…..mls	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Bag disposal	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
200ml oral fluids	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Patient fainted/felt faint?	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Bloods taken	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
HCT			
Date of next appointment			
Signature			

Procedure	Date	Date	Date
Access vein in ACF	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Venesected….mls	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Bag disposal	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
200mls oral fluids	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Patient fainted/felt faint?	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Bloods taken	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
HCT			
Date of next appointment			
Signature			

Addressograph

Appendix 3: Procedure for Venesection: Haemochromatosis

Procedure	Date	Date	Date
Access vein in ACF	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Venesected .....mls	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Bag disposal	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
200ml oral fluids	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Patient fainted/felt faint?	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Bloods taken	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Ferritin			
Transferrin sat			
Date of next appointment			
Signature			

Procedure	Date	Date	Date
Access vein in ACF	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Venesected.....Volume	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Bag disposal	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
200ml oral fluids	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Patient fainted/felt faint?	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Bloods taken	Yes ☐ No ☐	Yes ☐ No ☐	Yes ☐ No ☐
Ferritin			
Transferrin sat			
Date of next appointment			
Signature			

Appendix 3: Patient letter first non attendance

Ext: 3049 Our ref: ERF/KE Date as postmark

Dear

You were due a blood test last month in order to monitor ferritin levels because of your underlying diagnosis of haemochromatosis. You do not appear to have had this test done to date. I would be grateful if you could attend for blood tests as soon as possible and ring the day hospital on 01554 783213 on Thursday or Friday afternoon the following day for the results.

Yours sincerely,

Dr. Rhian Fuge, MA, MRCP, FRCPath

CONSULTANT HAEMATOLOGIST

c.c. GP

Appendix 4: Patient letter repeat non attendance

Ext: 3049 Our ref: ERF/KE Date as postmark

Dear

Our records show that you have repeatedly failed to attend for blood tests to monitor iron levels in your blood. In people with haemochromatosis it is extremely important to keep a check on the iron levels to prevent serious damage to the liver, heart and other organs.

Please contact the day hospital on 01554 783213 to discuss ongoing monitoring. If we do not hear from you we will assume that you no longer wish to be under the care of Haematology for monitoring of your condition and we will discharge you back to the care of your GP.

Yours sincerely,

Dr. Rhian Fuge, MA, MRCP, FRCPath

CONSULTANT HAEMATOLOGIST

c.c. GP

Appendix 5: Patient blood transfusion letter

Ext: 3049 Our ref: ERF/KE Date as postmark

Dear

I am writing to inform you about a new development in Welsh Blood Service Policy whereby people with a diagnosis of haemochromatosis are now accepted as blood donors.

The usual age limits of up to 65 years for a new donor and up to 75 years for people who have previously donated still apply. People can donate every 3-4 months.

Our blood test monitoring service will remain unchanged and we will continue to offer venesection as before. However if you wish to donate blood which can be used for blood transfusions to patients, then you are now able to attend a Welsh Blood Service donor session which takes place in various locations across Carmarthenshire. More information can be found on the website www.welsh-blood.org.uk under the section headed “Giving Blood” or by the free phone helpline 0800 252266.

You may choose to either donate at any time convenient to yourself and as long as you attend for the monitoring blood tests as before, we can tell you if you need to come to us for any extra venesections. An alternative approach would be to await the blood test results and donate blood only if the iron tests are raised. Please note that donating blood is entirely voluntary and it is your personal choice whether you choose to give blood. We are unable to use the blood taken in the chemotherapy unit which will continue to be discarded and your treatment will continue along current lines if you do not wish to become a blood donor.

For any further details please contact the chemotherapy unit.

Yours sincerely,

Dr. Rhian Fuge, MA, MRCP, FRCPath

CONSULTANT HAEMATOLOGIST

Appendix 6: Patient maintenance pathway information

Haemochromatosis Maintenance Patient Information

As your iron levels have now reached satisfactory levels, the weekly venesections can be stopped.

We will continue to monitor the iron levels and will send out blood forms by post every 3-6 months and arrange a venesection if the ferritin is above 50.

Please have the blood test in the **pathology department** of Prince Philip Hospital (or Amman Valley Hospital) and

ring the Gerontology Day Hospital (01554 783213) FRIDAY between 2-4pm for your results.

You will be advised if you need a venesection which will be booked for a Tuesday morning clinic. You will be sent the blood forms for your next blood test when it is due.

There will be no routine Haematology clinic appointments; anyone with suspected liver disease at diagnosis will be referred to a liver specialist clinic for monitoring. If you miss 2 blood tests a reminder letter will be sent and if we do not hear from you we will discharge your care back to your GP.

If you wish to become a blood donor then please attend a Welsh Blood Service community donor session and, if you are eligible, by donating blood regularly you can reduce the number of hospital visits for venesections. We will continue to monitor the iron levels with the usual blood tests.