

**Aim:** To provide guidance for the management of patients with hereditary haemochromatosis (HHC) and virtual clinic

**Scope:** This SOP applies to hepatology nurse specialists, associate nurse specialists and physician associate practitioner

Version: 1

Date: 20/10/2015

Revision Due: 03/2019

Authors: Michelle Padgett

#### Referral

- Referral made to Hepatology nursing team from Consultant Hepatologists
- Where possible patient is introduced to Hepatology nurses in consultant clinic
- Perform Fibroscan as per Fibroscan SOP
- Explain management of Haemochromatosis and venesection procedure to patient, advise good fluid intake and substantial meal is eaten prior. Patient may wish to have an escort home initially. Book patient to return for venesection

#### Preparation for venesection

- Copy of most recent Hepatology clinic letter and patient stickers to be provided by admin staff in folder
- Confirm HFE gene and medical plan for patient in consultant hepatologist clinic letter. Ensure USS, Fibroscan and full liver screen including iron studies have been performed +/- liver biopsy/ECHO.
- Advise patient to inform other family members about need for screening
- Provide verbal and written information about HHC, symptoms and management plan, including likely period of weekly attendance until Ferritin at 50ug/L and transferrin saturation below 45%. Give Haemochromatosis society leaflet
- Give diet and lifestyle advice
- Review medical history and current medications
- Explain procedure to patient, allow patient to discuss any concerns
- Ensure patient has eaten and patient is clinically well to have venesection performed. Record blood pressure.
- Remove 250-300 mls at first venesection, titrating up to 500 mls the following week if initial volume tolerated by patient
- Record post venesection blood pressure, allow adequate time for recovery prior to patient discharge
- Write letter to GP on EPRO informing that venesection programme has commenced
- Add patient to Haemochromatosis database found on: G drive/Hepatology/Hepatology nurses/HHC clinic/HHC patients
- Add patient to Hep6vir for on-going monitoring once de-ironing achieved. Give information on blood donation service
- Add patient with liver cirrhosis to the stable cirrhosis clinics 6 months after venesection instead of Hep6vir for continued monitoring, bloods will be performed in clinic and venesection booked when required.

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Equipment required for venesection procedure

- Well lit room with ventilation and privacy curtain
  - Examination couch and pillow
  - Stethoscope and sphygmomanometer
  - Blood taking equipment and venesection bag. Aim to sample FBC, LFT's, Ferritin and iron studies every 4 weeks or sooner if clinically indicated.
  - Scales to weigh venesection collection bag
  - Water jug and disposable cups
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#### Clinic set up/frequency

- Clinic to be run by experienced Hepatology Clinical/Associate Nurse Specialist
- Patients referred from Nurse led clinic or Consultant clinic with diagnosis of Hereditary Haemochromatosis for the purpose of providing on going review of potential iron overload and prevention of this by inviting patient to have venesection performed. Interval for virtual clinic monitoring determined by previous iron studies blood results

#### Virtual Clinic Process

- Clinic list for Hep6Vir printed by admin staff for the present month and one following.
- Clinic letters checked to correctly identify the patient, the relevant history and medication.
- Blood tests checked for FBC, LFT,U+E ,Bone Profile (+INR for cirrhotic patients), Ferritin, Transferrin saturation and serum iron
- USS interval checked and requested as necessary for HCC surveillance in patients with cirrhosis (refer to HHC patient database)
- Patients with blood tests outside of expected range : Ferritin greater than 100 ug/L +/- transferrin saturation above 45% should be invited to have venesection performed
- Patients with blood tests within satisfactory parameters to be added to Hep6Vir list as determined by most recent blood results
- Dictate letter for patient and GP via EPRO.
- Correctly identify patients for forthcoming month on Hep6Vir using clinical letters on EPRO
- Send covering letter (found Hepatology nurses share drive) and blood test request via ICE to patient to be completed by the last week of the month.