

New IBTS Hereditary Haemochromatosis Clinic Service

Free Phlebotomy Service available in

D'Olier Street Clinic – Dublin Telephone: 01 4745000

St Finbarr's IBTS Clinic – Cork Telephone: 021 4807400

Clinic opening hours and Prescription form and more details of the service
available

at www.giveblood.ie

The Irish Blood Transfusion Service (IBTS) is providing a free phlebotomy (venesection) service for people diagnosed with Hereditary Haemochromatosis in Ireland, **whether or not they are eligible or willing to be blood donors for transfusion purposes.**

Attendance is by appointment only and patients must have a definite diagnosis of Haemochromatosis and a signed prescription (available online at www.giveblood.ie) from their doctor or clinic nurse. Patients have the option of becoming blood donors if they meet the IBTS criteria set out in [www.giveblood](http://www.giveblood.ie) .i.e.

This service is available in Dublin and Cork and appointments can be made by contacting the Dublin or Cork clinic as outlined above. We hope eventually to extend it to other towns and cities. This service is a pilot project in the first instance. Continuation will depend on the success of the pilot in providing cost effective care to people with Haemochromatosis at the IBTS.

People who wish to use this service must get a prescription from their GP or hospital clinic on the IBTS form -. This prescription will be good for one year and for up to four phlebotomies within that year.

Information for general Practitioners, Hospital Consultants and Hemochromatosis Clinic Nurses/Nurse Practitioners.

- The service will consist of phlebotomy only and will be provided for patients who have a an IBTS prescription from their doctors which can be downloaded from [www.giveblood .ie](http://www.giveblood.ie)
- The treatment will be by appointment only in either Dublin or Cork.
- Patients that are not eligible to be blood donors as well as those that are eligible will be able to use this service.
- Patients must be a minimum of 18years of age – there is no upper age limit for referral.
- Phlebotomies will be at a maximum frequently of 4 per year with a minimum of 90 days between each phlebotomy.
- Patients must have undergone initial de-ironing as necessary and the plasma and ferritin levels must be lower 600ou/L before being referred to the IBTS.
- No blood tests are taken for iron status or other investigations.
- Patients must be fit enough to have a phlebotomy performed outside of a hospital clinic – a history of any of the following will prevent referral–
 - no serious heart or lung diseases,
 - no history of strokes or TIA's.
- Patients must have no complications of Haemochromatosis or other conditions that need follow up by their GP/Consultant more that once a year other than stable and straightforward conditions such as uncomplicated hypertension under therapeutic control diet controlled diabetes mellitus and or simple skin conditions.
- Patients that are positive for transfusion transmissible diseases such as HIV Hepatitis B or C, those that are known to be active drug users or sex workers cannot be referred. While we accept the risk that patients may transmit infections from accidental blood exposures the level of blood exposure risk in therapeutic phlebotomies warrants this degree of protection for the blood transfusion environment.
- Patients that do not tolerate phlebotomies of 470mls or those with difficult venous access are not suitable for referral as we do not have the capability to provide alternatives to 470ml phlebotomies on our clinics.
- The IBTS reserve the right to refuse treatment to patients that are disruptive or who act in any way that may be considered a threat the safety or supply of blood for transfusion. In addition patients that repeatedly do not attend for appointment will be referred back to their physician.

How will it work?

- 1.** Patients with HH who in the opinion of their own Doctor require phlebotomy get a prescription from their doctor on the downloadable IBTS prescription form for up to 4 X 470 mls phlebotomies per year.
The prescription can be renewed annually as required but a maximum of one years treatment is allowed per prescription.
- 2.** The patient makes an appointment with the IBTS for an initial visit to either the Dublin or Cork clinic.
- 3.** On the first visit the patient will have a therapeutic phlebotomy and an assessment for their willingness and eligibility to become a blood donor. If the patient is willing an interview will take place and testing for transfusion transmissible diseases along with blood group will be carried out in the same was a whole blood donor. If suitable and willing they will treated at the whole blood clinics in D'Olier Street Dublin and St Finbarr's Cork.
- 4.** If the patient does not want to become a blood donor or is not eligible then he/she can continue to attend the D'Olier St. or St Finbarr's HH clinic for treatment.
- 5.** All treatment is free regardless of insurance status or medical card status- we will not collect/require that information.
- 6.** On the first visit the patient who wishes to become a blood donor will have a Hb measurement. The cut off level for a therapeutic phlebotomy is 11.0 g/l. The Hb level required for donation for transfusion purposes for both men and women is higher by law - 13.5 g/l for men and 12.5 g/l for women.

What if

My patient does not want to travel to Cork or Dublin can they go to a local blood donation clinic?

Not at this point. Otherwise your patient has a real financial incentive (the cost and inconvenience of travel) to withhold information that would result in being rejected at the local blood donation clinic although they would be welcome at the Dublin Cork clinics for treatment.

My patient has HIV, Hep B or Hep C?

We ask that you do not refer these patients to us. We won't be checking the virus status in patients who do not want to donate for transfusion purposes and while we all accept the risk that patients may transmit infections from accidental blood exposures the level of blood exposure risk in therapeutic phlebotomies warrants this extra degree of protection for the blood donation environment.

My patient is a man who had sex with another man in the last 12 months but does not want to discuss it with or tell the IBTS?

A decision on the patient's eligibility will be based on the IBTS Medical Guidelines, if the patient does not want to discuss this that's fine. Your patient will be eligible to have therapeutic donations only and indicates that he does not want to be considered for blood donation for transfusion purposes he is under no obligation to discuss the reasons for his choice.

My patient has poor veins?

We are not in a position to use any alternative methods such as a needle and syringe or paediatric collection devices or red cell apheresis devices at present. So if your patient cannot tolerate the standard blood donation equipment (16 gauge needle & 470 ml pack) we ask that you do not refer them to the IBTS.

My patient does not tolerate full volume phlebotomies?

As above.

My patient has been going to blood donor clinics using the IBTS for treatment of HH without mentioning that they have Haemochromatosis?

They shouldn't. The practice of surreptitiously using the IBTS for treatment of Haemochromatosis to avoid the inconvenience or cost undermines the principle of donating entirely for altruistic reasons. Donating for altruistic reasons only is firmly established as providing the maximum safety for patients needing transfusion. Concealing a non- altruistic motive and abetting that practice is deceitful and potentially dangerous. Medical practitioners should never support such practice.

However if a current blood donor is found to have Haemochromatosis we allow them to continue donating up to 4 times a year when their serum ferritin is within physiological range and provided they are free from other reasons for deferral. This is not a perfect solution and this service provides some way towards addressing the issues around this.

This service may well reveal that some people have in the past donated blood for treatment of Haemochromatosis but have withheld important information that would have prevented them from being donors, for example living in the UK between 1980 and 1996.

The IBTS has established protocols to deal with information emerging some time after donations have been given. The recipients of previous donations are followed up appropriately while the donor's anonymity is protected.

My patient does not need to have a venesections more that a couple of times a year?

We will provide as many phlebotomies as you prescribe up to a maximum of 4 per annum.

My patient needs more than 4 phlebotomies per year?

We will only provide up to a maximum of 4 per year with a minimum of 90 days between phlebotomies. We cannot easily and cheaply apply a different set of standards at this point. However the patient may have phlebotomies at other clinics in the intervening periods if necessary with out impacting on their treatment at the IBTS clinics.

Communication and Data Management

All interactions with patients and donors will be logged on the IBTS computer and all records will be maintained in accordance with all relevant legislation.

There will be no paper records kept at the IBTS. The prescription form will be annotated with a record of the success or otherwise of each phlebotomy event and returned to the patient for their safekeeping.

The IBTS provides an after donation service to advice donors who develop problems after blood donation – faints, bruising, pain in the arm. This service will also be available to patients with Haemochromatosis. The IBTS are not in a position to provide advice and service about the management of patients/donors Haemochromatosis. This will remain the responsibility of their own doctor.

Similarly we will not provide a telephone follow up service or a separate report service for doctors who have provided prescriptions for patients – the costs for this are too high for us. We will reply to correspondence within our usual timeframes and duty medical staff are available at all times for urgent matters.