

New IBTS Hereditary Haemochromatosis Clinic Service

Free Phlebotomy Service

Dublin - D'Olier Street Clinic

Cork - St Finbarrs IBTS Clinic

Every Wednesday 10.00-11.20 a.m.

Every Monday 12.30 - 14.30 p.m.
(excluding Public Holidays)

Opened August 2013

Opened January 2014

Prescription form and more details of the service available at www.giveblood.ie

Irish Blood Transfusion Service has introduced a new free Phlebotomy Clinic for people diagnosed with Hereditary Haemochromatosis. The new Cork clinic, opened in January 2014 and complements the service available at our Dublin D'Olier Street Clinic.

Attendance is by appointment only and patients must have a definite diagnosis of hereditary haemochromatosis and a signed prescription from their doctor or clinic nurse. Patients do not need to become blood donors but can if they wish. Other criteria applies – see below for more information.

When will the service start?

The phlebotomy service for Cork will begin on 20th January 2014 . We are currently taking bookings for phlebotomy in Cork from January onwards. Patients can call 021-4807400 to make an appointment. The phlebotomy service in Dublin is already up and running , and appointments can be made at 01 4745000.

Will the service extend to other regions?

We will do our best to get it running in Limerick, Galway and the North East within a year. We have to work out the real costs in areas where we do not have a current fixed clinic, based on the experience of the clinics in Dublin and Cork, and ensure a robust funding model.

Thank you for your help in promoting this service. Patient information Leaflets and clinic promotion posters for display are included with this letter.

If you have any further questions, please call or text Dr William Murphy on 087 2319442, or (preferably) email him on nmd@indigo.ie.

Information for General Practitioners, Hospital Consultants, and Haemochromatosis Clinic Nurses/Nurse Practitioners

- A new IBTS phlebotomy service will be available from January 2014 in Cork to complement the existing service in Dublin. This is conceived as a two year pilot project in the first instance. Continuation beyond two years will depend on the success of the pilot in providing cost effective care to people with haemochromatosis at the IBTS.
- The service will consist of phlebotomy only, and will be provided for patients who have a prescription from their doctors on the downloadable IBTS prescription form, available from www.giveblood.ie.
- People who are **not eligible to be blood donors** as well as people **who are eligible** will be able to use this service.
- Phlebotomies will be at a maximum frequency of 4 per year with a minimum of 90 days between phlebotomies.
- We will not take blood samples for iron status or other investigations.
- Patients must have undergone initial de-ironing as necessary, and the plasma ferritin level must be lower than 600 µg/L before referral to the IBTS.
- Patients must be fit enough to have phlebotomy performed outside of a hospital clinic, e.g. no serious heart or lung diseases or 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 than once a year, other than stable and straightforward conditions such as uncomplicated hypertension under therapeutic control, diet-controlled diabetes mellitus, simple skin disorders or similar.
- Patients must be older than 18 years, but there is no upper age limit.
- The treatment will be by appointment only at the clinics in d'Olier Street in Dublin and St Finbarr's Hospital in Cork.
- We ask you not to send us patients who are known to be positive for transfusion transmissible diseases (HIV, hepatitis B or hepatitis C), or who are known active drug users or sex workers. 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 transfusion environment.
- We also ask you not to send us patients who have difficult venous access for phlebotomy or who do not tolerate 470 ml phlebotomies – we do not have the capability to provide alternatives to full 470 ml phlebotomies in our clinics.

- We reserve the right to refuse treatment to patients who are disruptive or who act in any way that may be considered a threat to safety or supply of blood for transfusion. In addition we will refer repeatedly non-attending patients back to the referring physician.

How will it work?

1. People with hereditary haemochromatosis, 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 470ml phlebotomies per year.
The prescription can be renewed annually as required, but a maximum of one year's treatment is allowed per prescription.
2. The patient makes an appointment with the IBTS for an initial visit to one of the two clinics – Dublin & Cork. The maximum waiting for the first visit will be three months, and should be a lot shorter than that.
3. At the first visit the patient gets a therapeutic phlebotomy, and is assessed for willingness and eligibility to become a blood donor.
If willing and eligible, the patient undergoes a donor interview, and is tested for transfusion transmissible diseases, and for blood group, in the same way as all donors.
The donor is thereafter treated at the blood donor sessions at D'Olier Street and St Finbarr's.
4. If the patient doesn't want to be a blood donor, or isn't eligible to be one, then he or she can continue to come to the d'Olier Street/St Finbarr's haemochromatosis clinics for treatment.
5. All treatment is free, regardless of insurance status or medical card status – we will not collect that information.
6. At each attendance we will check your patient's haemoglobin level in the finger pulp vessels. The cut off level for therapeutic phlebotomy is 110 g/L; for donation for transfusion purposes it is higher by law – 135 g/L for men and 125g/L for women. Finger pulp haemoglobin levels can vary from venous levels for several reasons – some physiological, some artefactual, but they serve our purposes well for the most

part. If we have to repeatedly reject your patient because of low levels we will ask them to return to you for further management.

What if.....

My patient doesn't want to travel to Cork – can't he or she 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. This is not to impugn the integrity of any individual, but the literature is compelling that even apparently small incentives undermine the overall safety of blood transfusion over time.

My patient has HIV, Hep C or Hep B?

We ask that you do not refer these patients to us. We won't be checking the virus status in patients who don't 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 has sex with men, but doesn't want to discuss it with or tell the IBTS?

That's fine. As long as your patient opts to have therapeutic phlebotomies only, and indicates that he doesn't want to be considered for donation for transfusion purposes, he is under no obligation to discuss the reasons for his choice with us. We can expect that there will be some resentment expressed by some men over our exclusion-from-donation policy, but as things stand that policy remains in force.

My patient has poor veins?

We will not be able to use alternative approaches, such as needle and syringe, or paediatric collection devices, or red cell apheresis devices, at least for the time being. So if your patient isn't going to be suitable for phlebotomy using the standard blood donation equipment (16 gauge needle and 470 ml pack), we ask you not to send them to us.

My patient doesn't tolerate full volume phlebotomies?

Same as above.

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

They shouldn't. The practice of surreptitiously using the IBTS for treatment of haemochromatosis to avoid inconvenience or costs 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 transfusions. 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 four times a year when their serum ferritin is within the physiological range and provided they are free from other reasons for deferral. This isn't a perfect solution, and this new policy goes 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, or, being male having previously had sex with men.

The IBTS has well worked out protocols to deal with information like this 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 doesn't need to have a venesection more than a couple of times per year?

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

My patient needs more than 4 phlebotomies per year.

We will only provide up to a maximum of four 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 without impacting on their treatment at the IBTS clinics.

Communications 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 record 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 advise donors who develop problems after blood donation – faints, bruising, pain in the arm. This service will also be available to patients with haemochromatosis, but we will not otherwise be in a position to provide advice and service about the management of their haemochromatosis. This will remain the responsibility of their own doctor.

Similarly, we will not provide a telephone follow-up service, or a separate reporting 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, 24/7/365, for urgent matters.

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