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| BT No.: 0585 | Ver. 4 |
| IRISH BLOOD TRANSFUSION SERVICE | |

TITLE: HAEMOCHROMATOSIS WELCOME PACK

Supersedes Version: Ver.3

Change Description:

- Revise BT - 0585 & 0587.
- Amend the information in the BT docs to reflect the changes outlined in CC 499/16.
- Add reference to Hep E testing to BT - 0585.

Reason for Change:

Reflect changes outlined in CC 499/16 in the HH documentation & to include a reference to Hep E testing.

Change order No.:

IBTS/CO/555/16

Referenced Procedures

N/A

SmartTrain Roles

N/A

SmartSolve Document Category

| Category | Mobile | Cryobiology | Website |
|-----------------|---------------|--------------------|----------------|
| Yes / No | No | No | Yes |

This BT is available from Nursing/Internet

BEFORE YOU BEGIN.....

WELCOME TO THE IBTS HAEMOCHROMATOSIS CLINIC.

DO YOU HAVE A PRESCRIPTION FORM FROM YOUR DOCTOR OR HAEMOCHROMATOSIS CLINIC NURSE?

IF YOU DON'T WE CANNOT TAKE BLOOD FROM YOU TODAY. PLEASE ASK YOUR DOCTOR OR NURSE FOR A PRESCRIPTION FORM, THEY WILL BE ABLE TO DOWNLOAD IT FROM [WWW.GIVEBLOOD .IE](http://WWW.GIVEBLOOD.IE). ONCE YOU HAVE A COMPLETED PRESCRIPTION FORM YOU CAN MAKE ANOTHER APPOINTMENT.

DO YOU WISH TO BE A BLOOD DONOR, OR WOULD YOU PREFER NOT TO HAVE YOUR BLOOD USED FOR TRANSFUSING OTHERS?

THIS IS ENTIRELY YOUR CHOICE, AND EITHER WAY IT DOESN'T MAKE ANY DIFFERENCE TO THE TREATMENT YOU WILL RECEIVE FROM THE IBTS AT THIS CLINIC

HOWEVER IF YOU DO WANT TO BE A BLOOD DONOR

THEN WE WILL ASK YOU THE FOLLOWING QUESTIONS - THE ANSWERS THAT YOU GIVE MAY AFFECT WHETHER YOU CAN BE A DONOR. REMEMBER, IF YOU'D PREFER NOT TO HAVE TO ANSWER THESE QUESTIONS, YOU DON'T HAVE TO. YOU DON'T NEED TO BECOME A BLOOD DONOR TO CONTINUE TO RECEIVE TREATMENT AT THIS CLINIC.

THERE ARE MANY MORE QUESTIONS THAT WE ASK BLOOD DONORS EVERY TIME THEY COME TO DONATE, BUT THESE ARE THE MOST IMPORTANT FOR YOU TO BE AWARE OF AT THIS POINT.

HAVE YOU EVER HAD A BLOOD TRANSFUSION IN THE PAST?

HAVE YOU LIVED IN THE UK (THIS INCLUDES NORTHERN IRELAND, THE ISLE OF MAN, AND THE CHANNEL ISLANDS) FOR A YEAR OR MORE - CUMULATIVELY - BETWEEN 1980 AND 1996?

HAVE YOU EVER INJECTED DRUGS - EVEN ONCE, EVEN MANY YEARS AGO?

HAVE YOU EVER WORKED AS A SEX WORKER?

ARE YOU DONATING BLOOD SO AS TO BE TESTED FOR HIV OR HEPATITIS OR SOME OTHER INFECTION?

MALES ONLY IN THE PAST 12 MONTHS HAVE YOU HAD ORAL OR ANAL SEX WITH ANOTHER MALE EVEN IF IT WAS SAFER SEX USING A CONDOM OR PRE-EXPOSURE PROPHYLAXIS (PREP)?

SO – IF YOU DO WANT TO BE A BLOOD DONOR, AND IF YOU'RE HAPPY TO ANSWER THE QUESTIONS IN THE PREVIOUS PARAGRAPH, PLEASE ANSWER **YES** WHEN THE REGISTRATION CLERK ASKS YOU IN A FEW MINUTES TIME IF YOU'D LIKE TO BE CONSIDERED AS A BLOOD DONOR. IF YOU DON'T WANT TO BE A BLOOD DONOR, OR IF YOU DON'T WANT TO ANSWER SOME OF THE QUESTIONS ABOVE, THEN PLEASE ANSWER **NO** WHEN YOU'RE ASKED IF YOU WOULD LIKE TO BE CONSIDERED AS A BLOOD DONOR.

YOU'LL BE GIVEN DIFFERENT FORMS TO COMPLETE DEPENDING ON THE ANSWER, BUT THE TREATMENT WILL BE THE SAME. IF YOU'RE PLANNING ON BEING A DONOR YOUR BLOOD WILL BE TESTED FOR THE STANDARD BLOOD DONOR TESTS, OTHERWISE THERE'S NO DIFFERENCE.

OF COURSE, WE WOULD LIKE EVERYONE WHO FEELS THAT THEY ARE ELIGIBLE TO DONATE SAFELY TO BECOME BLOOD DONORS. BUT WE REALISE TOO THAT THIS JUST DOESN'T SUIT EVERYONE, FOR MANY REASONS.

ONE MORE IMPORTANT POINT: WE HAVE ASKED DOCTORS NOT TO SEND PATIENTS TO THIS CLINIC WHO THEY KNOW HAVE HAD POSITIVE BLOOD TESTS FOR HIV, HEPATITIS B, OR HEPATITIS C IN THE PAST. THIS IS TO GIVE AN ADDITIONAL LEVEL OF SECURITY TO BLOOD DONATIONS IN IRELAND. IF YOU HAVE TESTED POSITIVE FOR ANY OF THESE IN THE PAST, PLEASE TELL ONE OF THE NURSES. BE ASSURED THAT WE WILL TREAT THE INFORMATION IN THE STRICTEST POSSIBLE CONFIDENCE.

INFORMATION FOR PEOPLE ATTENDING THE IBTS HAEMOCHROMATOSIS CLINIC
Please read this information carefully today. You will be asked to sign that you have read and understood the contents.

THE PHLEBOTOMY PROCESS

Registration

When you come to the haemochromatosis clinic you will be asked to register with the Irish Blood Transfusion Service (IBTS). We ask you for your name, address, date of birth, telephone numbers and e-mail address. This information is entered on the IBTS computerised database and is used by us to communicate with you (e.g. to send invitation letters / texts / e-mails to blood donor clinics if you wish to become a blood donor in the future).

Information related to you and your treatment is stored securely on the database. If you have given blood at the IBTS before and you are on our database, you will be asked to confirm that your details are correct.

Medical Screening

Each time you attend the clinic you will be asked a few questions around your general health to make sure that nothing has happened in the recent past that would make it unsafe for you to have a phlebotomy on this occasion. **We ask that you read the questionnaire and information provided thoroughly. All the information you give us will be treated in the strictest confidence.** You will be interviewed by a doctor or nurse in an area that provides as much privacy as the setting allows.

You will be asked to declare:

- that you read / listened to, understood and completed the health questionnaire (or health & lifestyle questionnaire if you're planning to be a blood donor in the future) and that all the information you provided is true and accurate to the best of your knowledge,
- If relevant, that you read / listened to and understood this information (the Phlebotomy Information),
- that you understood the nature of the phlebotomy process and the risks involved in undergoing a phlebotomy - see section entitled Possible Complications of phlebotomy,
- that you had an opportunity to ask questions and had satisfactory answers to any questions that you asked

and to give consent:

- to proceed with the phlebotomy process,
- **If you're going to be a blood donor in the future then on this phlebotomy we ask you to give consent**
for your blood to be tested for HIV, hepatitis and other infectious agents

and for a small sample of your blood to be stored - see section entitled Testing Blood Collected at Phlebotomy Clinics.

For medical or other reasons it may not be possible to perform a phlebotomy today. In these circumstances we will explain the reason(s) for our decision to you. In addition if you are considering becoming a blood donor in the future we may ask your permission to contact your General Practitioner (GP) for further details which will help us decide if you can become a blood donor in the future.

What if I Change My Mind?

If you decide you would rather not have a phlebotomy here today, you can change your mind and leave the clinic at any time. We will not put any pressure on you to undergo treatment. We simply ask that you return your questionnaire to a member of our staff.

Haemoglobin Testing

Haemoglobin (Hb) is a protein that contains iron and is found in red blood cells. It carries oxygen around the body and gives blood its red colour. Hb levels vary from person to person and men usually have higher levels than women. Hb levels are often slightly lower in the summer months.

If your Hb level does not meet the required level we will advise you how long you should wait before your next phlebotomy. We will also advise you if you should visit your GP.

The phlebotomy

After the medical screening process, you will be shown to one of the phlebotomy beds. A pressure cuff will be put around your upper arm to make the veins more prominent and the area will be cleaned with antiseptic. A doctor, nurse or specially trained donor attendant will insert a needle that is attached to a blood bag. A new sterile blood bag is used for every phlebotomy. **It is never reused.** Your blood will flow through this needle into the blood bag that is kept out of sight below the level of the bed. You will be asked to open and close your hand to ensure smooth and consistent blood flow.

A member of staff will keep a close eye on you and on the blood bag to make sure that everything is going well. Most people fill the blood bag in 8 to 15 minutes. It holds 470 mls of blood (under a pint). If, for any reason, the blood flow is slow, it may be necessary to stop the phlebotomy early. **If you experience any pain or discomfort or feel unwell during the phlebotomy, you must tell our clinic staff immediately. In the interests of your comfort and safety the phlebotomy will be stopped.**

When the phlebotomy is completed, the needle will be carefully removed from your arm and a dressing applied. **We ask you to press firmly and directly on the needle site for at least 3 minutes after the needle is removed, keeping your arm straight. Please don't pick up your bags or put on your coat during this time. This is important in helping to prevent bruising.**

Resting

You will be advised to rest for a short period before going to the canteen area where you will be offered a drink and light refreshments. We advise that you remain in the clinic for at least 15 minutes after your phlebotomy to make sure that you are feeling well.

Possible Complications of phlebotomy

For the majority of people the process of phlebotomy is a very simple and trouble-free experience. However, problems sometimes arise during or after a phlebotomy. We outline some complications of phlebotomy here, so that if they occur, you will know what to do.

Let one of our staff know immediately if you feel faint or unwell during or after your phlebotomy or if you have pain, discomfort or altered sensation in your arm, hand or fingers, when the needle is inserted, during the phlebotomy or after the needle is removed. We will stop the phlebotomy immediately and will care for you until you feel better. We ask that you do not leave the clinic until we advise that it is safe for you to do so.

Bruising

Bruising may develop due to seepage of blood from the vein into the tissues of the arm. It can look very dramatic but is usually harmless. Bruising may appear some way from the phlebotomy site (on the back of the arm or near the wrist), may not start until a day or two after the phlebotomy and may change colour over a few days from blue-black to greenish yellow. Most bruises are not painful and fade within 7 to 10 days. Sometimes bruising may take a few weeks to disappear completely. If a bruise develops during the phlebotomy the procedure will be stopped. On occasion the bruising may worsen and become painful. Very occasionally a bruise may become infected and you may need treatment with antibiotics.

To minimise the risk of bruising, we ask you to tell us if you have pain or discomfort when the needle is inserted, during the phlebotomy or after it is removed. You must also press firmly on the needle site for at least 3 minutes after the needle is removed, keeping your arm straight. We ask all patients to limit the use of their phlebotomy arm for the first 15 minutes after phlebotomy and ideally to avoid using the arm for heavy work or exercise for the rest of the day.

If you do develop a bruise during or after phlebotomy we recommend that you avoid heavy lifting and strenuous exercise for at least a few days until the bruise is improving. For example, do not go to the gym or lift heavy shopping bags, as doing so could aggravate the bruising. However, normal gentle movements are very beneficial and should be continued. Cold compresses can be useful within the first 24 hours. Do not apply heat within the first 24 hours as this could make the bruising much worse.

If you experience any of the following after phlebotomy you should contact us in Dublin on 01 4322800 or Cork 021 4807400 or contact your GP:

- severe pain in your arm, hand or fingers

- numbness or persistent 'pins and needles' or altered sensation in your arm, hand or fingers,
- swelling that is large or increasing in size,
- change in colour (pale or blue colour)
- swelling of the hand or fingers,
- painful redness or inflammation.

Bleeding from the needle site

If this happens immediately after phlebotomy:

- lift your arm above your shoulder and press on the needle site,
- sit down and ask for assistance from our staff.

You can avoid bleeding by pressing firmly on the needle site after the needle is taken out and by limiting the use of your phlebotomy arm for 15 minutes after phlebotomy. Be careful when eating and drinking and when putting on your coat after phlebotomy.

Please leave the plaster in place until the next day. This is to prevent the phlebotomy site from becoming infected.

Fainting / Feeling faint, weak or light-headed

Some patients feel faint during or after phlebotomy. This may be due to anxiety, fatigue, dehydration or loss of blood volume. It is important that you relax and drink plenty of cold, non-alcoholic liquids before and after phlebotomy. **If you feel faint, weak or light-headed during or after your phlebotomy please let one of our staff know immediately.**

Reducing the risk of fainting

Before phlebotomy we advise that you:

- get a good night's sleep,
- drink plenty of cold, non-alcoholic liquids in the 24 hours before phlebotomy - especially in warm weather,
- drink half a litre of water at the clinic in the 30 minutes just before phlebotomy - this will help to prevent fainting,
- eat savoury food and /or salty snacks the night before phlebotomy and at the clinic
- eat something substantial in the 3 hours before the phlebotomy,
- tell us if you have low blood pressure or feel faint or dizzy when you stand up suddenly,
- let us know if you are very anxious so that we can help you feel at ease.

During phlebotomy we advise that you:

- wear loose, comfortable clothing
- tense your buttock muscles for 5 seconds, then relax
- repeat 3 times every minute during and immediately after your phlebotomy - while you remain on the phlebotomy couch
- do not stand up too quickly - a member of staff will escort you to the refreshment area

After phlebotomy we advise that you:

- stay in our clinic for at least 15 minutes after phlebotomy,
- have some light refreshments in our canteen during this time,
- do not smoke for at least an hour,
- drink plenty of non-alcoholic liquids,
- avoid alcoholic drinks for at least 6 hours,
- do not have a hot bath or shower on the day of the phlebotomy,
- do not use a sauna or steam room on the day of the phlebotomy,
- avoid standing for long periods especially in poorly ventilated areas - such as standing in a long queue or on crowded public transport
- avoid strenuous exercise until the next day - such as jogging, running, swimming or going to the gym,
- avoid any activity that may present a hazard to you or others if you were to become weak or light-headed.

If you are involved in a hazardous occupation or hobby such as operating heavy machinery or mountaineering, you should defer the activity until the next day or sometimes longer. Please check with us, so that we can advise you appropriately if this applies to you.

If you feel faint after leaving the clinic you should sit or lie down straight away (on the ground if necessary) to avoid falling and injuring yourself:

- put your head between your knees for a few minutes,
- lie down if you need to, raise your feet and rest them on a chair if you can,
- stay sitting or lying for approximately 30 minutes or until you feel well again,
- whilst sitting or lying down tense your buttock muscles for 5 seconds, then relax and repeat this every 1 - 2 minutes,
- make sure that when you get up you do so slowly,
- if you still feel faint, lie down again
- have a cold non-alcoholic drink when you feel well enough to do so,
- do not drive for at least 6 hours after you have recovered because there is a risk that you may faint again whilst you are driving,
- if you feel faint whilst driving, slow down and stop the car as soon as it is safe to do so. Remain in the car and lay your seat as flat as possible. It is recommended that you do not get out of the car as fainting beside a road can be hazardous. Do **not** attempt to drive again. Call 999 for an ambulance.

If you lose consciousness (pass out) after phlebotomy please contact us on the above numbers for further advice as soon as possible.

Uncommon risks of phlebotomy

Nerve Injury / Nerve irritation / Pain

Please tell us immediately if you have pain, discomfort or altered sensation in your arm, hand or fingers, when the needle is inserted, during the phlebotomy or after the needle is removed.

Very infrequently, insertion or removal of the needle may cause irritation or injury of a nerve in your arm. Pain, discomfort or altered sensation in your arm, hand or fingers may indicate that a nerve has been injured. These symptoms may also occur if a collection of blood under the skin (bruise) is pressing on a nerve. Tell us immediately if you have any of these symptoms and we will stop the phlebotomy and give you appropriate advice. If these symptoms occur after you have left the clinic, you should contact us at the National Blood Centre on 01 4322800 or the Munster Regional Transfusion Centre on 021 4807400, or contact your GP.

Tendon Injury / Pain

On rare occasions a needle may come into contact with a tendon and cause a sharp pain when the needle is inserted. **Tell us immediately if you experience any pain or discomfort when the needle is inserted and we will stop the phlebotomy.**

Arterial Puncture

Rarely, the needle may inadvertently be inserted into an artery. If this happens the needle will be removed immediately and you will be given immediate treatment and appropriate advice.

Fast / irregular pulse or tightness in the chest

Very rarely a patient may develop a faster than normal or irregular pulse or a sensation of tightness in the chest, during or after a phlebotomy. This is not necessarily caused by the phlebotomy. **If this happens during the phlebotomy, tell us immediately.**

Serious Complications resulting in injury or hospitalisation

We perform around 150,000 phlebotomies of blood every year. About once or twice a year a donor may need to be admitted to hospital as a result of a complication of phlebotomy. This could occur if for example a donor faints and bangs his / her head resulting in an injury.

Serious injuries can occur if a donor or patient faints after he / she has left the clinic. This is called a '**delayed faint.**' **The risk of a delayed faint will be greatly reduced by following the steps outlined above to reduce the risk of fainting.** If you have a problem after phlebotomy and need to seek urgent attention from a doctor or hospital, please let us know as soon as possible as we would like to hear the outcome. We are also required to record the incident and other less serious incidents and report them with your details to our insurance company.

If you become unwell after phlebotomy

If you become unwell or develop any illness after the phlebotomy, and that you feel is caused by the phlebotomy - such as pain in the arm where the phlebotomy was performed, or fainting, please talk to a doctor at the National Blood Centre on 01 4322800 or the Munster Regional Transfusion Centre on 021 4807400 as soon as possible. There is a doctor on call 24 hours a day who will advise you. However if you are unwell because of some cause other than the phlebotomy please call your own doctor.

Please do **not** e-mail us or leave a message on our Infoline as these are not manned 24/7.

Testing Blood collected at the phlebotomy clinic

We do not collect any samples for testing at the phlebotomy clinic, except to check if you are eligible to become a blood donor at your future phlebotomies, and then only if you specifically agree to that. In particular, we do not check your ferritin levels. Your own doctor will check these from time to time as s/he considers appropriate for your care.

Only if you wish to be considered as a blood donor:

1. Certain tests will be performed on your blood. Currently the mandatory tests are those for HIV, hepatitis B, hepatitis C, hepatitis E & HTLV (a virus carried in the blood) and syphilis.
1. If your blood gives a positive result for any of these tests your donation will be discarded and you will not be eligible to donate again. We will write and inform you and ask that you attend for further confirmatory tests and advice.
2. The IBTS is legally bound to inform the Public Health Service if your tests confirm that you are positive for HIV, hepatitis B, hepatitis C, hepatitis E or syphilis. We are obliged to forward your personal details including your name and address and the results of your blood tests.
3. Your blood is also tested to determine your blood group. In addition supplementary tests may be carried out on selected donations for example to meet the special needs of certain patients such as babies. These extra tests include more detailed blood grouping, a test for sickle cell trait and, very occasionally, tests for other relevant proteins in the blood. We will notify you of any results that may affect your health. The range of blood tests carried out by the IBTS is under regular review and other tests may be introduced in the future. We freeze a small sample of your blood and retain it indefinitely. This is done in case it becomes necessary to carry out additional tests at a later date.
4. **False Positive Reactions on our Screening Tests**
We have to carry out a range of screening tests on each donation. In a small percentage of donors, the donor's blood gives a false positive reaction on our tests. This means that although the screening test is reactive, additional testing shows that the result is not of any significance for the donor's health. You will be informed of such false reactions if they occur. While there are no health implications for the donor we are unable to use the blood for patients.

Data Protection

The IBTS holds patient details, treatment details and test results (where applicable) on a secure computerised database. This database is used by the IBTS to communicate with donors and patients and to record their donation or treatment details, including all blood sample test results. It is also used for the proper and necessary administration of the IBTS. All the information held is treated in the strictest confidence.

This information may also be used for research in order to improve our knowledge about the patient population, and for clinical audit, to assess and improve the quality of our service. Wherever possible, all such information will be anonymised.

All information and data that is processed by the IBTS is in accordance with the provisions of the Data Protection Acts. You have a right of access to your records. However, the IBTS is legally bound under the relevant European Union Directives that relate to blood transfusion services, to maintain your records, including the health and lifestyle questionnaires that you completed when you donated, on file for a minimum of 30 years. If you want to access your records, contact Donor Services, Dublin on 01 4322800 or Cork on 021 4807400.

Further General Information

If you have a question at any time you can phone our Infoline on 1850 731 137. This is open Monday to Friday from 9 a.m. to 5 p.m. You can also visit our website on www.giveblood.ie or email us at contactus@ibts.ie. Details of our clinics are available on our website.

If you need any information or have a query while you are at the clinic please speak with a member of our clinic staff.