

Patient Information Leaflet

Blood Donation and Genetic Haemochromatosis (GH) at Northern Ireland Blood Transfusion Service (NIBTS)

The treatment of GH involves the reduction of iron stores in the body and this is achieved by regular removal of blood. This usually involves a period of de-ironing (venesection approximately every fortnight to achieve an iron (ferritin) level < 50 mcg/l) followed by maintenance treatment (venesection approximately 3-4 times per year) to maintain ferritin level < 50 mcg/l. The amount of blood removed on each occasion is similar to that donated by blood donors.

Blood from GH patients can be used for transfusion to patients. GH patients wishing to donate their blood can attend the Northern Ireland Blood Transfusion Service (NIBTS) instead of the hospital or GP clinic.

Which GH patients can become blood donors?

GH patients must meet the same selection rules as apply to other blood donors. These are strict and they are designed to ensure the blood is safe for the patients receiving it. In general patients must be fit and healthy with no major illnesses.

There are also certain rules about lifestyle including sexual behaviour or drug misuse, which can result in exclusion of blood donations. Please read and consider carefully the section below on lifestyle factors and blood donation:

Lifestyle Factors and Blood Donation

You must NEVER donate blood if:

- You think you need a test for HIV or Hepatitis
- you are HIV positive or HTLV positive

- you are a Hepatitis B or C carrier
- you have **ever** received money or drugs for sex
- you have **ever** injected yourself with drugs, even a long time ago or only once. This includes body-building drugs and injectable tanning agents.
You may be able to donate if a doctor prescribed the drugs. Please ask.

You must not give blood for at least 12 months after sex (even if you used a condom or other protective) with:

- a partner who is, or you think may be:
 - HIV positive or HTLV positive
 - a Hepatitis B or C carrier
- (if you are a man) another man. This includes anal and oral sex.
- (if you are a woman) a man who has ever had sex with another man, even if they used a condom or other protective
- a partner who has ever received money or drugs for sex
- a partner who ever injected, or been injected with drugs, even a long time ago. This includes bodybuilding drugs and injectable tanning agents. **You may be able to give if a doctor prescribed the drugs, so please ask.**
- a partner who has, or you think may have been sexually active in parts of the world where HIV/AIDS is very common. This includes most of Africa.
There are exceptions, so please ask.

Do not give blood for at least 12 months if you have misused drugs intranasally (snorted)

How do I donate my blood to the Blood Transfusion Service?

All GH patients must have an initial appointment with one of the doctors at the Blood Transfusion Headquarters (HQ) building at Belfast City Hospital to assess their suitability for the programme. GH patients accepted onto the

panel who require de-ironing venesection must attend NIBTS HQ in Belfast to donate blood. GH patients requiring maintenance venesection can either donate blood at NIBTS HQ or at their local community blood donation session.

If you wish to proceed we require a referral letter from your hospital consultant. The referral letter should be addressed to the Consultant in Transfusion Medicine at NIBTS. Details required in the referral letter include:

- Confirmation of GH diagnosis (genetic testing result)
- Confirmation of no end organ damage as a result of the GH e.g. no liver or cardiac disease
- Medical history
- Medication history
- Results of a recent iron profile
- Frequency of venesection requested i.e. once every fortnight; once every 3 months
- Confirmation that the hospital consultant will continue to oversee the care of their GH patient

If there is no obvious reason on the referral letter why you cannot be accepted as a blood donor we will write to you to make an appointment to see one of the doctors at NIBTS HQ. If for some reason the information provided by your hospital consultant prevents you from becoming a blood donor we will write back to your hospital consultant and inform them of this.

What happens when I attend the Blood Transfusion Service?

You will be interviewed and asked to complete and sign a healthcheck questionnaire. If accepted, you should be able to give your first donation that day. On subsequent visits to NIBTS you would follow a similar procedure to that used for a normal blood donor. If you are undergoing de-ironing you will need to have all of your venesections performed at NIBTS HQ. We encourage

you to make an appointment (between 9-5) for all your subsequent venesections.

If you are undergoing maintenance treatment you can if you prefer attend a local community donation session after your initial assessment in NIBTS HQ. If you wish to do this we will register you onto your preferred community session and you will then receive correspondence from our donor administration staff calling you to donate when they are next in that area.

There are a number of reasons why a donor is temporarily deferred including foreign travel, infection, surgery, and medical investigations. All donors are asked about these on the health check questionnaire each time they come to donate. As GH patients require venesection to treat their condition, a donation can be accepted from GH patients in these cases but marked for discard. This means the donation will not go forward for patient use. Obviously we would like to make as much of the blood from GH patients as possible available for patients so we ask that you attend for donation when you are well and think that you satisfy the selection criteria. Further information can be obtained on donor eligibility rules on our website: www.nibts.org.

How does blood donation differ from venesection in hospital?

As already stated overleaf, blood donation involves either attending the NIBTS HQ or a local community donation session. It also involves completion of a healthcheck questionnaire at each visit. Another important difference is that each blood donation will be tested for certain infections that can be transmitted by blood transfusion to patients. These include HIV, Hepatitis B, Hepatitis C, Hepatitis E, and Syphilis. In the event of a positive result for any of these tests you will be informed of the result and given appropriate advice.

Who will be responsible for my medical supervision?

Your hospital consultant or GP will still be responsible for your medical supervision and monitoring of your condition. They will also be responsible for

checking your iron levels. NIBTS does not perform iron studies. A finger pin prick test will be performed on each visit to ensure your Haemoglobin is satisfactory for donation.

What do I do next?

If you are interested in joining our NIBTS GH panel, please ask your hospital consultant or GP to send us a referral letter as detailed under section 'How do I donate my blood to the Blood Transfusion Service?' We will then be in touch with you regarding an appointment.

Further queries

If you require any further information you can contact NIBTS on 02890321414 and request to speak to a member of the medical team.