

## What is Genetic Haemochromatosis?

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**Genetic Haemochromatosis** (GH) is caused by a faulty gene that affects how the iron is absorbed from your diet. This can lead to iron overload. You are at risk of developing the condition if both of your parents have the faulty gene and you inherit one copy from each of them. If you inherit only one copy, you are a carrier, and should not be at risk of iron overload due to GH.

## Blood donation and Genetic Haemochromatosis

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The treatment of Genetic Haemochromatosis (GH) involves the reduction of iron stores in the body and this is achieved by regular removal of blood (venesection). This usually involves a period of de-ironing (venesection approximately every fortnight) followed by maintenance treatment (venesection approximately 3-4 times per year). 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.

By carrying out venesection with NIBTS, the iron-rich blood taken can be donated to patients requiring blood transfusion, rather than being discarded as when venesected in hospital.

## Which GH patients can become blood donors?

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

Further information can be obtained on donor eligibility rules on our website: [www.nibts.org](http://www.nibts.org).

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

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All GH patients must have an initial appointment with one of the doctors at the Blood Transfusion Headquarters (HQ) building at City Hospital site to assess their suitability for the programme. GH patients accepted onto the panel who require de-ironing venesection must attend NIBTS HQ to donate blood. GH patients requiring maintenance venesection can either donate at NIBTS HQ or at their local community blood donation session.

If you wish to proceed please ask your hospital consultant or GP to complete our online referral form. This can be found on our website: <https://nibts.hscni.net/donating-blood/haemochromatosis/>

Details required on the online referral form 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 and details of any medication
- Results of a recent iron profile (please note if your iron levels are particularly high i.e. ferritin > 1000 ug/l you will need to be assessed by a liver specialist before we can consider accepting you onto our panel)
- Frequency of venesection requested i.e. once every fortnight, once every three months
- Confirmation that the GH patient will be under the continuing care of a physician who will check iron levels and are able to offer alternative venesection facilities whenever, for any reason, the donor does not meet all other criteria in UK Donor Selection Guidelines.

If you appear to meet the eligibility criteria you will receive a letter inviting you for an appointment at NIBTS HQ. If some information provided by your referring doctor prevents you from becoming a blood donor, your doctor will inform you of this.

## Who will be responsible for my medical supervision?

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Your hospital consultant or GP will 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-prick test will be performed on each visit to ensure your haemoglobin is satisfactory for donation.

## What happens when I attend the Blood Transfusion Service?

You will be interviewed and asked to complete a Health Check 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 of a regular blood donor. If you are undergoing de-ironing, you will need to have all of your venesections performed at NIBTS HQ. All donations are by appointment only, however we recommend donors attending for venesection attend from 9am-5pm. This will facilitate a medical review of your file prior to your attendance, and also ensure a doctor is available should any medical queries relating to your GH arise at the time of donation.

If you are undergoing maintenance treatment you can, if you prefer, attend a local community donation session after your initial assessment in NIBTS HQ. Again, all donations are by appointment only, so call 08085 534 653 to book. 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 book an appointment when we are next in your area.

There are a number of reasons why a donor is temporarily deferred, including foreign travel, infection, surgery, medical investigations or other

reasons: in these cases a donation can be accepted from GH patients but will be marked for discard.

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, this means the donation will not go forward for patient use if not otherwise suitable.

Obviously we would like to make available to patients as much of the blood from GH donors as possible 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](http://www.nibts.org).

### What do I do next?

If you are interested in joining our NIBTS GH panel, please ask your hospital consultant or GP to either complete the online referral form or send a referral form as previously detailed, and we will be in touch with you regarding an appointment.

**General Enquiries: 08085 534 666**

**Appointment Line: 08085 534 653**

**Medical Enquiries: 08085 534 669**

**Website: [www.nibts.org](http://www.nibts.org)**

# Genetic Haemochromatosis & Blood Donation



## What you need to know...

