

## 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 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 (with the exception of donation frequency). 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. Age thresholds are the same as for regular blood donors i.e. 17 minimum age; up to 66<sup>th</sup> birthday for first time donors; up to 70 years for a returning donor; and regular donors can continue to donate over 70. Minimum weight of 50kg. Further information on donor eligibility can be obtained on the NIBTS 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 be referred by their specialist to the medical team at NIBTS 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. Note the minimum donation interval at NIBTS HQ is 6 weekly. 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 to complete our online referral form (NIBTS also accepts referral letters from hospital consultants). The online referral form can be found on our website: <https://nibts.hscni.net/donating-blood/haemochromatosis/>

Details required on the online referral form /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 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 six weeks, once every three months
- Confirmation that the GH patient will be under the continuing care of a specialist 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 to make an appointment to donate. 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 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?

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You will be interviewed by session staff and asked to complete a Health Check questionnaire. If accepted, you should be able to give your first donation that day. If you are undergoing de-ironing, you will need to have all of your venesections performed at NIBTS HQ. If you are undergoing maintenance treatment you can, if you prefer, attend a local community donation session. 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. All donors are asked about these on the Health Check questionnaire each time they come to donate. We recommend that you confirm eligibility to donate each time prior to making a booking - please check the NIBTS website ([www.nibts.org](http://www.nibts.org)).

If a GH donor is permanently deferred from donation for whatever reason, venesection will then need to take place in the hospital setting.

## What happens if I have a query regarding my GH management as a donor at NIBTS?

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If you have any queries relating to the management of your GH, you should contact your specialist. As regards donation frequency, it is the responsibility of the specialist to set this out, and you as the patient/donor to adhere to this. NIBTS medical team will not give advice on frequency of donation, review iron profiles, or provide any patient management.

## What do I do next?

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If you are interested in joining our NIBTS GH panel, please ask your hospital consultant to either complete the online referral form or send a referral letter. We will be in touch with you after this is received and reviewed by NIBTS medical team.

Visit [www.nibts.org](http://www.nibts.org)

General Enquiries: 08085 534 666

Appointment Line: 08085 534 653

# Genetic Haemochromatosis & Blood Donation



## What you need to know...