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## **Information for Donors with Haemochromatosis**

### **Blood Donation and Genetic Haemochromatosis**

The treatment of Genetic Haemochromatosis (GH) involves the removal of blood (venesection). The aim of this is to reduce the levels of iron in your body.

#### **I have haemochromatosis, can I donate?**

People with genetic haemochromatosis, who are nearing the end of the induction phase of treatment or in the maintenance phase of their treatment, can be accepted as blood donors. They must also be free from any organ damage because of iron overload.

Some newly diagnosed donors with genetic haemochromatosis who have normal ferritin levels may be accepted into the blood donation service without prior hospital venesection, once an appropriate donation interval has been determined by their specialist or GP.

Donor with carrier status can donate in accordance with the standard donation terms and intervals (12 and 16 weeks).

Blood donors with GH should remain under the care of their specialist for monitoring of the condition and the effects of giving blood.

NHSBT collects blood for the benefit of patients and healthcare and does not provide any form of monitoring or treatment based on the needs of an individual donor. The frequency of blood donation will be based on safety guidance and your serum iron (Ferritin) levels, as directed by your specialist.

#### **What other screening is involved to become a blood donor?**

The safety of blood is very important as it may be given to very vulnerable patients.

GH donors are therefore subject to the same screening process as other blood donors, as we cannot accept donors who have major illnesses or are taking certain medication. GH does not pose any additional risks; blood from GH donors is therefore perfectly safe for donation and use in patients.

Please inform session staff of any underlying health conditions, medication history, sexual health history and travel history as these are very important part of the screening process.

#### **How do I become a blood donor?**

If you have genetic haemochromatosis and would like to enrol as a blood donor, please call us on **0300 123 23 23** for registration and further advice. Further guidance on blood donation can be found on [www.blood.co.uk](http://www.blood.co.uk).

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## What happens next?

A member of the Clinical Support Team will confirm it is safe for you to donate. Unfortunately, if there is any evidence of iron overload in your organs or any other conditions which affects recipient or your own safety you will not be able to proceed.

Following telephone acceptance, please return the enclosed letter to the Clinical Support Team as soon as possible. You will then be able to book your appointments in advance by calling the helpline number **0300 123 23 23**.

You are also able to book appointments online at the recommended donation intervals (6,8, 10 or 12 weekly).

## What are your age limits?

Typically, blood donors must be between the ages of 17 and their 66<sup>th</sup> birthday. If you are between 66 and 70, then you must have given blood (or had a venesection) without feeling unwell at least once in the past. If you are over 70 then you may donate if you have donated blood (or had a venesection) without feeling unwell in the last 2 years.

## How often can I donate blood?

Donors with GH can donate more frequently than other blood donors based on their Ferritin levels and the advice of their specialist. The minimum donation interval for blood donors with GH is six weeks which includes any additional venesections arranged at the hospital.

## What happens when I attend the Blood Donation Session?

As with all blood donors you will be asked to complete and sign a Donation Safety Check (DSC) questionnaire. If accepted, you will be able to give your donation on the day. There are several reasons why a donor is temporarily deferred, including foreign travel, infection, surgery and medical investigations. All donors are asked about these on the Donation Safety Check questionnaire each time they come to donate. During any deferral period, we would recommend to re-book with your specialist team for venesection as and when required.

## How do I book further donation appointments?

In view of the limited number of appointment slots at each session, it is wise to book several appointments in advance at your recommended donation intervals. You can do this via the helpline number **0300 123 23 23**, or by using the online service on [www.blood.co.uk](http://www.blood.co.uk). If you have not created an online account after being accepted by our clinical team, please click on the "Where to donate" option and in the "Already a donor" box select "Create an account". This will allow you to access your record online and be able to book future appointments. If you have not been able to find a suitable appointment using either of these methods, please call our **dedicated GH donor appointment line: 0300 303 2732**.

## Monitoring of GH

It is very important to have continued access to the specialist team looking after your condition in the hospital. NHSBT is unable to monitor iron (Ferritin) levels or other aspects of your condition.

## Finally, ...

We want to thank you for your interest in being a blood donor. In addition, we are pleased to be able to help your condition by taking your blood and putting it to good use.

## Thank you