Information for Donors with Haemochromatosis

Blood Donation and Genetic Haemochromatosis

The treatment of Genetic Haemochromatosis (GH) involves the removal of body iron stores by regular removal of blood (venesection). Blood donation is an acceptable alternative to venesection, and has the advantage of utilising the blood for NHS patients.

I have haemochromatosis, can I donate?

People with genetic haemochromatosis, who have finished intensive venesection (de-ironing phase) and/or are in the maintenance stage of their treatment, can be accepted as blood donors. However, GH patients must be able to meet all the donor selection criteria and be free from any organ or tissue damage as a result of iron overload.

Blood donors with GH and the specialist team who manages their condition are advised that they still remain under the care of their specialist for monitoring of the condition and the effects of venesection or blood donation.

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

What is the donor selection guidance or criteria?

The safety of blood is of paramount importance as it may be given to very vulnerable patients. The donation process, collection and processing of blood for distribution to patients is underpinned by legislation (Blood Safety & Quality Regulations, 2005) and best current practice (donor selection guidance). This ensures that donors are screened and excluded from donation for major illnesses, medication and lifestyle (including sexual behaviour and drug abuse) which may potentially be a transmission risk of blood borne infection (for example HIV, hepatitis or syphilis).

GH patients will therefore be subject to the same screening process as other blood donors, and genetic haemochromatosis does not pose any additional risks. Blood from GH patients is therefore perfectly safe for donation and use in patients.

How do I become a blood donor?

If you have 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.

What happens next?

A member of the Clinical Support Team will confirm the eligibility criteria for Haemochromatosis donors, ensuring that you are able to donate with a recent serum Ferritin level. Unfortunately, if there is any evidence of iron overload in key organs (liver, heart, pancreas) or chronic condition you will not be able to proceed.

Following telephone acceptance, please return the agreement letter back to CST as soon as possible to be able to book you 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?

All first time blood donors must be between the ages of 17 and their 66th birthday. If you are between 66 and 70, then you must have given blood (or had a venesection) successfully and without feeling unwell at least once before in the past. If you are over 70 then you may donate as long as you have donated blood (or had a venesection) successfully and without feeling unwell in the last 2 years. So, if you are over 66 please let us know the date you had your last venesection or donated blood.

If you are over 70 and have been advised to practice social distancing, you are still able to donate blood to maintain your iron levels within normal limits, as long as you do not have a designated medical condition requiring self-isolation.

How often can I donate blood?

NHSBT Blood donors may routinely donate at a minimum interval of 12 weeks. However, Haemochromatosis donors are able to donate more frequently based on their previous Ferritin levels. Most Haemochromatosis donors in maintenance phase will have a target Ferritin of 50 mcg/ml, with levels generally below 100 mcg/ml. For Haemochromatosis donors with higher levels, please see the recommended donation intervals in the table below:

Ferritin level (mcg/ml)	Donation Interval	Next Ferritin test	GP or specialist review
<100	12 weekly	6 months or year	annual
>100 < 200	10 weekly	6 months	Twice a year
>200 < 300	8 weekly	3 months	Twice a year
>300 < 450	6 weekly	3 months	3 monthly

What happens when I attend the Blood Donation Session

As with all blood donors you will be asked to complete and sign a Donor Health Check (DHC) questionnaire. If accepted, you will be able to give your donation on the day. On subsequent visits, you will follow a similar procedure as that of other regular donors.

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 DHC questionnaire each time they come to donate. During this 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 or by using the online service on www.blood.co.uk. If you have not linked your account after being accepted by our clinical team please go to already a donor section and select create an account. This will allow you to access your record online and be able to book future appointments

Monitoring of GH

As stated above, 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 being a blood donor, and helping to save and improve many lives through the selfless act of blood donation. In addition, we are pleased to be able help your condition by taking your blood and putting it to good use.

Thank you