



## NATL 445 02



### GENETIC HAEMOCHROMATOSIS ( GH ) Referrals Frequently asked Questions

#### **How do GH Specialists refer patients to SNBTS for blood donation ?**

The Genetic Haemochromatosis referral form for routine blood donation and information about making a referral can be found at <https://www.nss.nhs.scot/blood-tissues-and-cells/snbts-transfusion-team/genetic-haemochromatosis/>.

We have designed the referral form to include the essential information required to decide on a patient's eligibility to donate. Missing information makes it hard for us to make a decision without needing to contact the referrer or patient for more information causing delay.

#### **What is the process following a GH referral to SNBTS?**

Following receipt of the referral form by email we aim for a 12 week turn around. Referrals with incomplete information may take longer to process. Our admin team will liaise with the referrer if more information is needed. Once a GH donor has been approved, they will receive a letter advising them of this and explaining how to book an appointment. Referrers will also receive a copy of the letter via email confirming this. Timing of appointments will be dependent on the patient's preference and availability of sessions at their preferred centre.

#### **Why do SNBTS not use the CHI number in correspondence?**

SNBTS uses systems that do not link to other NHS Scotland records. Blood donors have a unique donor identification number which is different from the CHI number used for patients. However, if a CHI number is provided on the referral form, we are happy to try to include it in any subsequent correspondence.

#### **What is the age range for accepting GH patients for donation?**

Donors must be 17 years or older. Donors who are above the usual acceptable age for donation i.e. donors who have not previously donated blood and have had their 66<sup>th</sup> birthday, or donors who have previously donated and have had their 72nd birthday and have not donated in the last 2 years, **can be accepted at the discretion of the donor clinical support team**, provided they have been venesected without event in a clinical setting.

#### **What are the haemoglobin acceptance ranges for donors including those with GH?**

***Haemoglobin: 125-165 g/L (female), 135-180 g/L (male)***

If a GH patient has recently completed induction, please consider whether their haemoglobin is likely to meet the threshold on the day of donation. Our session staff have protocols to follow and cannot accept donors with a haemoglobin below these levels. Your patient could be deferred for 6 or 12 months depending on the result.



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#### **Which medications affect eligibility to donate?**

Although it is safe to donate blood whilst on certain medications, there are some drugs which may pose a risk to the recipient if they are exposed to this at the time of blood transfusion. Some examples include Finasteride and Carbimazole. This is why it is important where possible, to list all the medications taken by your patient including over-the-counter medications and those prescribed privately. Please also consider why your patient is taking a particular medication as this may highlight another medical condition for which they would not be eligible to donate.

#### **Where can I find out information about Donor Eligibility Criteria?**

All potential donors need to meet the same eligibility criteria before being able to donate blood. This is the same for GH donors and no exceptions can be made other than with age (see Q2). Donors can be turned down on blood safety or donor safety grounds.

GH patients with an underlying medical condition who are ineligible to donate on donor safety grounds may need close monitoring during therapeutic venesection. This is best provided in a clinical setting rather than a blood donation session.

UK donor selection criteria can be viewed at <https://www.transfusionguidelines.org>. Go to 'Donor Selection Guidelines: Whole Blood and Components' and select 'A-Z search'. This link can also be found at the bottom of the GH referral form.

#### **Is there a way to contact SNBTS directly to check an eligibility query before a referral is made?**

Yes referrers can contact our admin team on 0131 314 5520 (Mon-Friday 9am-3pm) and leave a message for one of the Donor Medical Team to call you back, or email our medical inbox directly at [nss.snbtsdcst@nhs.scot](mailto:nss.snbtsdcst@nhs.scot). Please continue to use our admin email when making any referrals [nss.snbtsdcstadmin@nhs.scot](mailto:nss.snbtsdcstadmin@nhs.scot).

#### **Can SNBTS accept GH patients for donation more frequently than every 12 weeks?**

Not at the current time. Unfortunately, our IT system cannot be set up to allow this to occur safely and without additional complexity at session for our staff.

#### **Do SNBTS let hospital specialists know each time a venesection is performed?**

At present our IT system is not able to provide this information automatically and we do not have the resources for our session or administration staff to do this. It is the responsibility of the GH donor to inform their specialist of the frequency of donation.



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#### **What reasons do GH patient give for not donating blood when they have been accepted by SNBTS?**

Based on a recent survey\* the most common reasons for non-attendance were

- **Patients found attending blood donation sessions inconvenient (16/40).**

Reasons included location, opening times, travel or travel costs.

SNBTS offers appointments across Scotland both in our donor centres in Edinburgh, Glasgow, Dundee, Aberdeen and Inverness and community collections. Our website has a postcode search option for next available appointments [www.scotblood.co.uk](http://www.scotblood.co.uk). Parking facilities will vary according to location. At present travel costs cannot be reimbursed.

- **Patient preferred to be venesected in hospital (7/40).**

Before referral GH patients should have the opportunity to discuss their preference for site of venesection and whether they wish to be a blood donor. Accessibility of blood donation sessions for the donor, as well as their personal preferences, should be taken into account.

- **Patient didn't think they were eligible (4/40).**

Reasons given were 'not in maintenance' or 'haemoglobin low or borderline'.

Patients should be referred once they are approaching or ideally at maintenance phase and their haemoglobin level is within the acceptable range for blood donation.

***Haemoglobin: 125-165g/L (female), 135- 180g/L (male)***

\*Survey sent to 220 GH patients who had been referred, accepted by SNBTS but had not attended a blood donation session (October 2024) 40 responders.