

You can save even more lives.

Join the British Bone Marrow Registry



**British Bone
Marrow Registry**

What is bone marrow?

Bone marrow is a remarkable factory. It's the soft, spongy tissue found at the centre of certain bones in your body where blood stem cells live. Blood stem cells produce all your essential blood cells, such as red blood cells to carry oxygen and white blood cells to fight infection.

Who needs bone marrow transplants?

There are some diseases, such as some forms of leukaemia, which stop the factory from working properly. For many such patients, the best option of a cure is receiving a bone marrow transplant.

Sarah's story

In May 2004, Sarah was looking forward to a summer wedding when she was rushed into hospital. Within just a few hours she was diagnosed with Leukaemia.

Following four rounds of chemotherapy, Sarah, a teacher and life-coach, was in remission, and in March 2005 she married Mark.

Sadly by Christmas of the same year the cancer had returned. Sarah was immediately booked in for further treatment, but her only hope for a full recovery was a stem cell transplant.

Sarah and her family campaigned tirelessly to highlight the shortage of stem cell donors from Black, Asian, Minority Ethnic (BAME) and mixed race heritage groups and eventually a match was found. In November 2006 Sarah received her life-saving transplant.

Now fully recovered Sarah is still working along with family and friends to encourage others to become donors. She says "I now appreciate life and live for the moment. If, due to our campaigning, one other life is saved, then the whole thing was worth it."



What are the odds of getting a match?

Chance of a match for Bone Marrow Transplant Patients



About one third of patients have a suitably matched brother or sister. But the remainder rely upon the generosity of a complete stranger to donate bone marrow or blood stem cells for them and finding a suitable donor can be really difficult. This is because the patient and donor need to have the same tissue type (known as a HLA type). There are many millions of potential tissue type combinations, which is why we always need more donors.

What is the British Bone Marrow Registry and who can join?

The British Bone Marrow Registry (BBMR) is part of NHS Blood and Transplant. We help patients find suitable stem cell matches by recruiting possible donors from our blood donors.

We are recruiting from two particular groups of blood donors:

1. Male caucasian donors aged 17-40
2. Black, Asian, Minority Ethnic or mixed race donors of either gender aged 17-40.

You also must be willing to donate to any patient in the UK or worldwide.

Why can only these donors join the BBMR?

We focus on these groups because:

- We know that patients do better with stem cells donated by younger male donors.
- There is a particular shortage of potential donors with Black, Asian, Minority Ethnic or mixed race heritage – so it is really important that we can recruit more donors to help patients from these communities.

Lack of donors from these ethnic backgrounds means patients from the same backgrounds have far less chance of getting a match than their Caucasian counterparts.

I'm in! How do I join?

To join the BBMR, please tell a member of staff before you give blood and complete the consent form at the back of this leaflet. They'll take one small extra blood sample from you when you give blood.

And if I'm a match?

If you are found to be a potential match, we will contact you to discuss the next steps. It is rare to be found as a match – the overwhelming majority of donors will never be contacted as a potential match – but every additional donor we register increases the chances that a lifesaving match can be made.

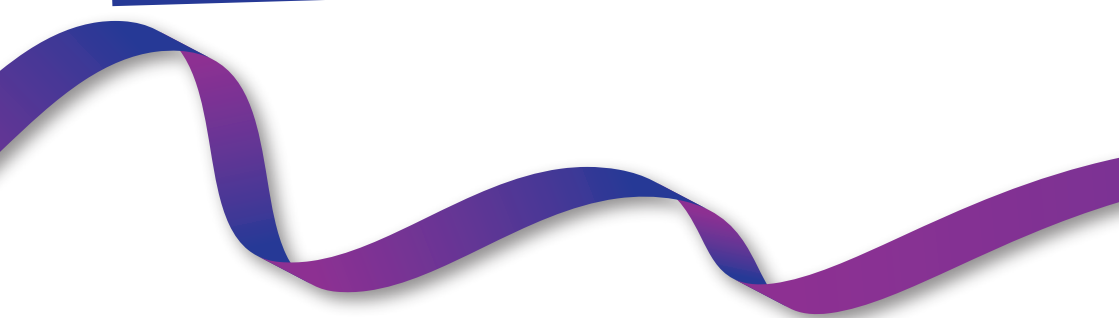
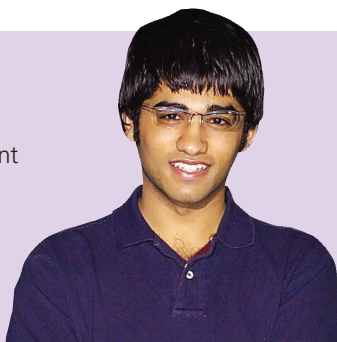
Humans have a really clever inbuilt system to help protect you from attack. Many cells in your body have a complex protein on the surface which acts as an identification marker (this is your tissue or HLA type). If your immune system notices any changes in this marker, it will go on the attack. This is great for helping to keep you safe from infections, but not so great if you require a bone marrow transplant. We need to find donors with the same HLA type so that the transplant isn't rejected.

So, if you are a potential match, we will do further tests on your blood to confirm how good a match you are. Then, it's time to donate!

Hamzah's story

Within just a month of joining the BBMR, Hamzah was found to be a match for a recipient and donated life-saving bone marrow.

He says: "I would do it again, and I would encourage more people from ethnic communities to register."



Many people do not realise – There are two potential ways to donate:

1. Blood stem cells from your peripheral blood stream

Blood stem cells live in your bone marrow and can produce any type of cell needed.

You will be given a special drug for the four days before you donate. This drug encourages blood stem cells to move from your bone marrow into your blood stream.

On the fifth day you will visit one of our blood centres to donate your stem cells. We collect the stem cells using a cell-separator machine (also known as an apheresis machine). The machine draws blood out of one arm, extracts the stem cells, then returns the remaining blood to your other arm. This is the same machine used for collecting platelets. We might ask you to return again the following day if we don't quite collect enough blood stem cells from you. Donors typically return to normal activity a day or two after the donation.

2. Bone marrow retrieval

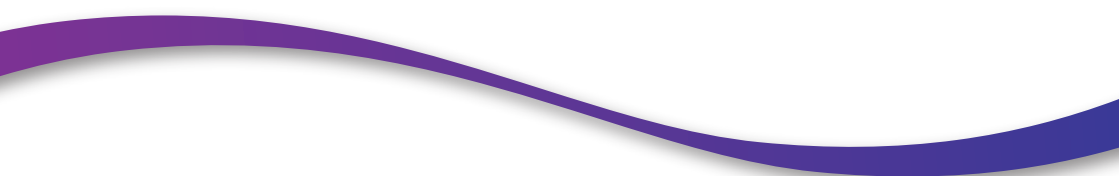
This involves the removal of bone marrow from your hip bones. This is done using a needle and syringe under a general anaesthetic in a hospital. Although it's not a surgical procedure, there will be marks on the skin made by the needle. As there may be some discomfort around this area, you will need to stay in hospital for up to 48 hours after the donation and have a period of recovery at home for up to five days.

The majority of donations (85%) are made by collecting blood stem cells from the peripheral blood stream, but we would ask potential donors to consider both donation methods before joining the BBMR.

After donation

We will fully support you before, during and after the donation. One of our coordinators will guide you through the donation process. We will cover any loss of earning or expenses during the donation period.

Both donation methods are very safe. However, no medical procedure is entirely without risk. Both methods may involve some temporary discomfort and any small risks involved will be fully explained during your meetings with our staff.



FAQs

I'm already registered with another registry – should I join BBMR too?

No – we work really closely with other registries in the UK – so if you have already registered with one, please do not register with another.

Who will see information about me?

Because of the complexity of finding suitably matched donors, approved patient registries both in the UK and in other countries are able to anonymously search for potential donors registered with us. We will only ever share essential information about you that is needed for matching to a patient. Please be assured that only NHS Blood and Transplant staff will have access to your personal information.

Do I get to meet any patient I help?

It is a legal and ethical requirement that identity and location of both patient and donor are kept confidential. Two years after donation, if both the patient and donor agree, we will allow personal details to be shared but you should note that this is a rare occurrence and that it may be subject to legal and policy decisions outside of our control.

How long will I be on the register for?

Unless you ask us to remove your details, you will remain on the BBMR until your 60th birthday. Because you might be found to be a potential match to a patient at any time before then, it is important we have up to date contact details for you. As your blood donation and BBMR records are linked, anytime you update your contact details with our blood donation colleagues this information will come to us. But, if you stop donating blood, please do remember to update your contact details by calling our **Donor Line on 0300 123 23 23**.

How does the type of Bone Marrow/Stem Cell donation get decided?

For most patients, the best method of donation is for these blood stem cells to be collected from the donor's peripheral blood stream (see page 4). For some patients and disease types, the patient's doctor will prefer the donor to donate by bone marrow retrieval (see page 4), as this method of donation will contain both the blood stem cells needed to produce new cells as well as mature cells to help fight infections in particular. We will discuss with you any preference from the patient's doctor but of course, as donation is voluntary, the final decision will rest with you.

How do I get more information?

If you have any further questions, please contact our Donor Line on **0300 123 23 23** or visit **www.bbmr.co.uk**.



Personal details

Please print clearly in black using block capitals

Title: Mr/Mrs/Ms/Miss/Other _____

First Names _____

Last name _____

Date of birth (DD/MM/YYYY) _____

Address _____

_____ Postcode _____

Home phone number _____

Mobile number _____

Email address _____

Place where you usually donate _____

Are you a member of any other UK Bone Marrow Registry?

E.g. *Anthony Nolan Trust* Yes ☐ No ☐ (Please tick one only)

Ethnicity codes

To which ethnic group do you consider that you belong?

☐ **A** White British

☐ **B** White Irish

☐ **C** Other White background

☐ **T** Gypsy/Irish Traveller

☐ **D** Mixed White & Black Caribbean

☐ **E** Mixed White & Black African

☐ **F** Mixed White & Asian

☐ **G** Other mixed background

☐ **H** Asian-Indian

☐ **J** Asian-Pakistani

☐ **K** Asian-Bangladeshi

☐ **L** Other Asian background

☐ **M** Black-Caribbean

☐ **N** Black-African

☐ **P** Other Black background

☐ **R** Chinese

☐ **S** Any other group

☐ **Z** Not disclosed

Bone Marrow Registration and Consent

To be completed by the donor and handed to a member of staff

I have read the information on this document and I agree that:

1. A sample will be taken by NHS Blood and Transplant (NHSBT) and tested to tissue-type my DNA and I agree for my details to be held on the British Bone Marrow Registry (BBMR).
2. My sample will be stored for up to 30 years to enable further tissue-typing for a potential match.
3. I may be contacted by NHSBT staff to update contact details, to inform if I am a match for a patient, to request additional blood samples or to enquire about participation in ethically approved research projects.
4. The residual blood/DNA from my sample can be used for ethically approved, anonymous research projects.

Signature _____

Name _____ Date _____

For NHSBT Collection Staff use

Date sample taken (DD/MM/YY)

Donor ID number (if available)

Pulse ID number (if available)

Donation number barcode
(if available)

For NHSBT H&I Laboratory Staff use

BBMR secondary sample ID

Problem

Date repeat sample requested (DD/MM/YY) _____

Date repeat sample taken (DD/MM/YY) _____

Data Protection

All information and data processed by NHS Blood and Transplant is in accordance with the provisions of the Data Protection Act 1998.

NHS Blood and Transplant is a special health authority within the NHS.