

# 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. All of our donation centres are in the UK.

## **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?

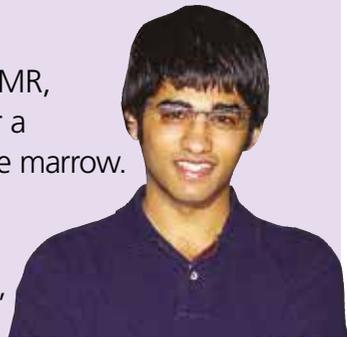
If you are found to be a potential match, we will contact you to discuss the next steps. It is rare to be found as a match – the overwhelming majority of donors will never be contacted as a potential match – but every additional donor we register increases the chances that a life-saving match can be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

### 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."



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!

## **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 collect quite 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 earnings 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 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 visiting [www.bbmr.co.uk](http://www.bbmr.co.uk) or 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 6). For some patients and disease types, the patient's doctor will prefer the donor to donate by bone marrow retrieval (see page 7), 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.

## What type of research will my data and samples be used for?

Occasionally, your data or the samples (including the DNA left over after tissue-typing) you provide to us when you first join the registry could be used in one of our research interest areas including: diagnosis, transplantation, disease pathology, donor motivation, donor health and wellbeing, donor epidemiology (e.g. the incidence and distribution of different HLA types in different areas of the UK), the relationship between ethnicity and HLA type, donation-related transmissible infections, donor and recipient matching, immunology (e.g. the relationships between antigens, antibodies and cell receptors) and novel 'alleles' (a variant form of a given gene). The research we might perform would be approved by a recognised independent research ethics committee and ensure your anonymity. The research might involve collaborators outside NHSBT but would not involve animals.

## 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](http://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* Yes  No  (Please tick one only)

## Ethnicity codes

To which ethnic group do you consider that you belong?

- |   |  |
|---|--|
| <input type="checkbox"/> <b>A</b> White British                 | <input type="checkbox"/> <b>J</b> Asian-Pakistani        |
| <input type="checkbox"/> <b>B</b> White Irish                   | <input type="checkbox"/> <b>K</b> Asian-Bangladeshi      |
| <input type="checkbox"/> <b>C</b> Other White background        | <input type="checkbox"/> <b>L</b> Other Asian background |
| <input type="checkbox"/> <b>T</b> Gypsy/Irish Traveller         | <input type="checkbox"/> <b>M</b> Black-Caribbean        |
| <input type="checkbox"/> <b>D</b> Mixed White & Black Caribbean | <input type="checkbox"/> <b>N</b> Black-African          |
| <input type="checkbox"/> <b>E</b> Mixed White & Black African   | <input type="checkbox"/> <b>P</b> Other Black background |
| <input type="checkbox"/> <b>F</b> Mixed White & Asian           | <input type="checkbox"/> <b>R</b> Chinese                |
| <input type="checkbox"/> <b>G</b> Other mixed background        | <input type="checkbox"/> <b>S</b> Any other group        |
| <input type="checkbox"/> <b>H</b> Asian-Indian                  | <input type="checkbox"/> <b>W</b> Arab                   |
|   | <input type="checkbox"/> <b>Z</b> 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 in 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). I also agree that BBMR may process and share pseudonymised\* information with other relevant organisations, both in the UK and worldwide when performing its task or in the public interest and for the provision of healthcare.
2. My sample/DNA will be stored indefinitely to enable further tissue-typing (including DNA sequencing) 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, pseudonymous\* research projects connected with transplantation, disorders or the functioning of, the human body. This research will not involve the use of animals.
5. I give permission for the anonymised or pseudonymised\* data generated by me being a blood donor and part of the British Bone Marrow Registry to be used by NHSBT to conduct research to improve scientific knowledge about the stem cell donor population and the possible health effects of stem cell donation.

\*Pseudonymisation is defined within the General Data Protection Regulations as "the processing of personal data in such a way that the data can no longer be attributed to a specific data subject without the use of additional information, as long as such additional information is kept separately and subject to technical and organisational measures to ensure non-attribution to an identified or identifiable individual" (Article 4(3b)) i.e. we would ensure your anonymity and any shared data will no longer identify you.

Please be aware that signing below and providing a sample does not guarantee that you will join the BBMR registry. This is because sometimes there are technical problems for example; testing failures meaning we are unable to tissue-type your DNA or health information provided makes you ineligible to join the registry. We may also decide to prioritise the processing of samples from some registrants over others to ensure BBMR has the broadest mix of new donors. We will write to you with your donor card to confirm once you have been added to the registry. You have the right to withdraw your membership of the BBMR registry at any time and can do so by contacting us on 0300 123 23 23. Likewise, you can withdraw your consent from us holding your samples/DNA for research at any time.

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 provided to BBMR/NHSBT is used in accordance with the General Data Protection Regulation (GDPR) and all other relevant privacy and data protection laws. To find out more about your privacy rights please visit our website [www.nhsbt.nhs.uk](http://www.nhsbt.nhs.uk) or call us on 0300 123 23 23.

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