

# British Bone Marrow Registry (BBMR)

## Donor Information



**British Bone  
Marrow Registry**

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# I've been found as a potential match – what does that mean?

Put simply, as a potential match you may have the chance to save someone's life, either here in the UK or somewhere else in the world! Read on to find out why and how...

## What is bone marrow?

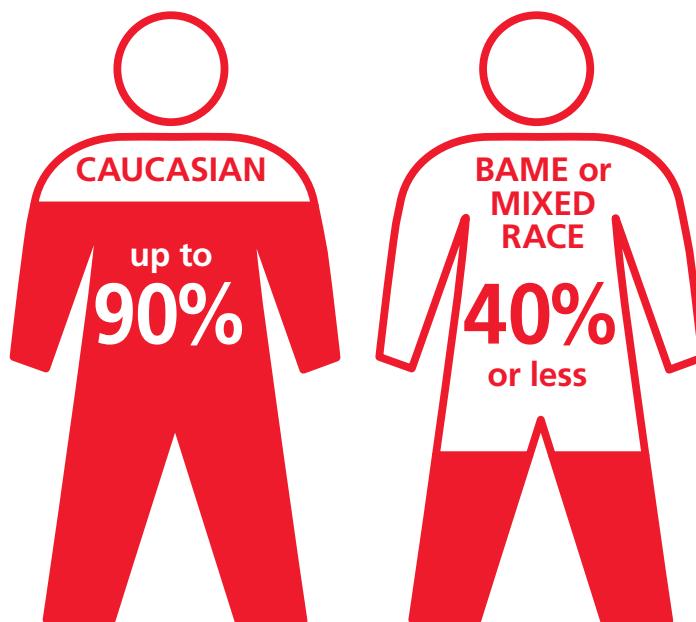
Bone marrow is a remarkable living factory. It's the soft, spongy tissue found at the centre of certain bones in your body where blood stem cells reside. Blood stem cells produce all your essential blood cells, such as red blood cells to carry oxygen and white blood cells to fight infection.

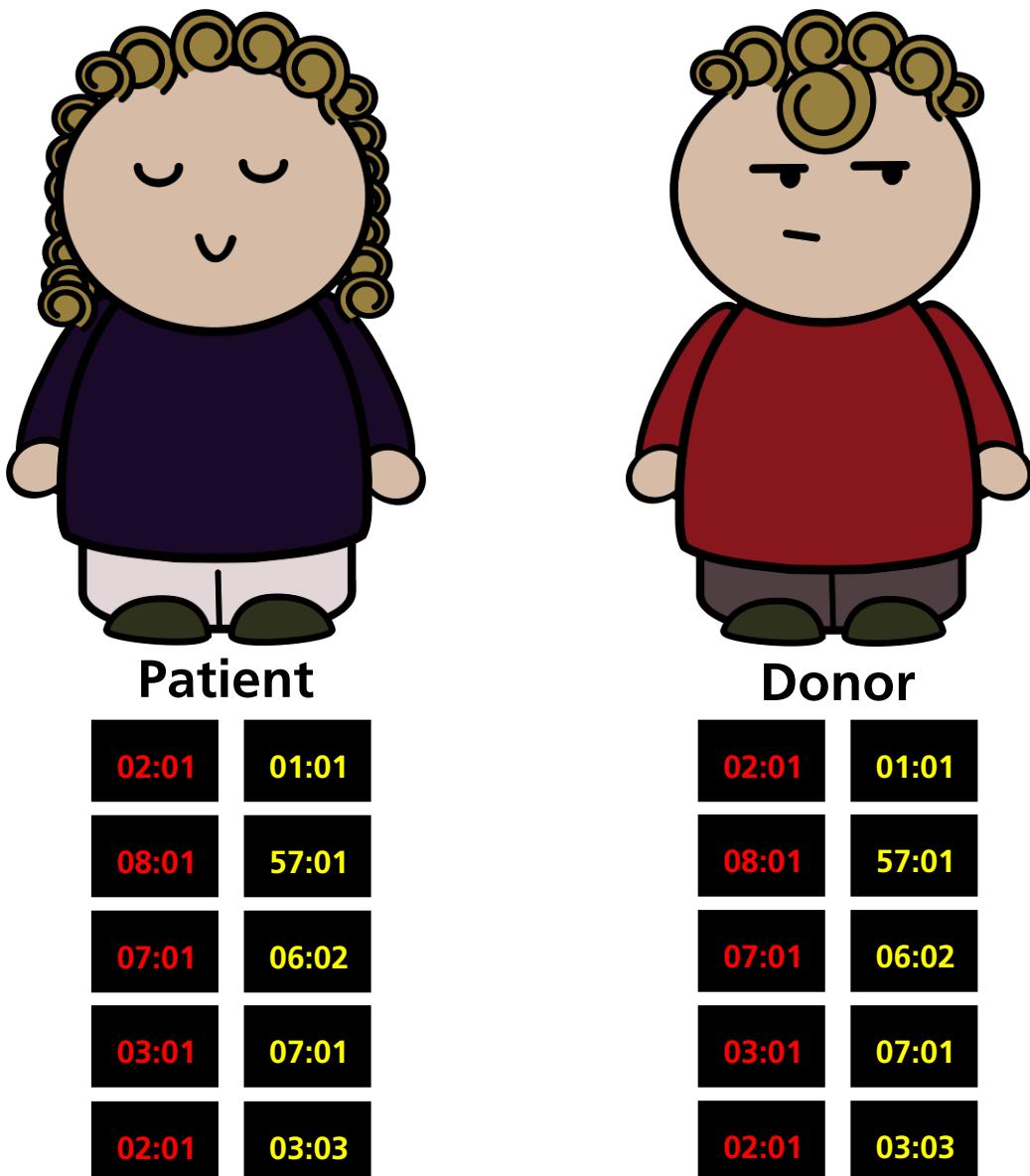
## Who needs bone marrow transplants?

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 (or stem cell) transplant.

## 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 and why it's so amazing that you have been identified as a potential match for a patient in need.





To give the patient the best chance, we need to find an unrelated donor with the same HLA (Human Leukocyte Antigen) type. Your HLA type (also often referred to as your 'tissue type') defines a complex protein on the surface of many cells in your body: this acts in a sense like a barcode on your cells which your immune system constantly checks. The closer a HLA match the donor and patient are, the less likely that the patient's immune system will reject the new cells.

You can think of each antigen as the time on a digital clock. Current standards are to match ten antigens/clocks between patient and donor. In the example above, you can see that the patient and donor are fully matched at these 10 points of comparison.

The challenge is to find an unrelated donor with the same ten antigens/clocks. Even with over 27 million donors globally on registries like the BBMR, this is not always possible.

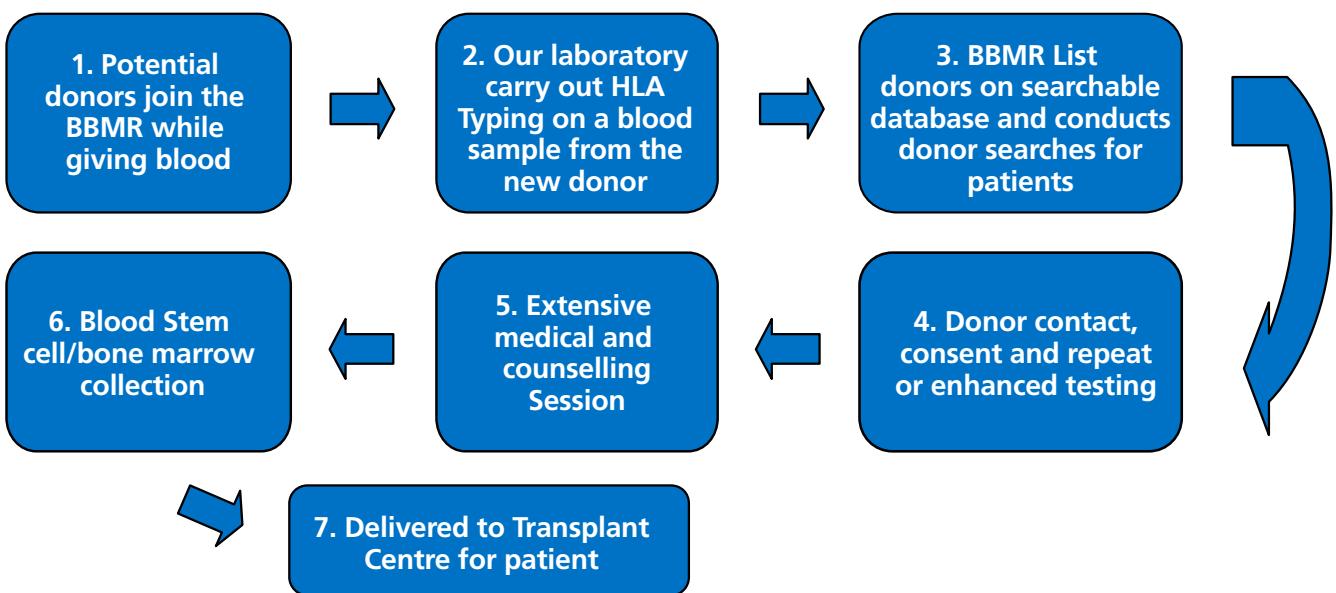
## Needle in a haystack

- BBMR is part of global networks to match potential bone marrow donors with patients in need. Worldwide there are over 27 million donors, yet that isn't enough to find a match for every patient in need.
- Looking at the BBMR as a whole, there is approximately a 1 in 240 chance that a donor will come up as a potential match in any given year.
- If a donor is found as a potential match for a patient, BBMR will contact them and ask for more blood samples to conduct further suitability tests.
- Following these suitability tests, there is approximately a 1 in 5 chance that a potentially matched donor will ultimately be asked to donate PBSC or Bone Marrow for a patient.

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.

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!

## I've been found as a potential match – what happens next?



After you agreed to join BBMR while donating blood, a small blood sample was sent to our laboratory to carry out the HLA typing. This identified a number of markers which are used for matching patient and donors.

After this complex testing was complete, your details were added to our database and made available for anonymous searching. Every day we compare this anonymous information against many patients and if you are reading this it means that you have been found as a potential match for someone.

The next stage is to carry out further testing (typically, this repeats the HLA typing carried out when you joined BBMR, an essential quality control procedure). One of two types of testing can now take place:

**One** – We may ask for your permission to carry out more extensive HLA testing on a stored sample of your DNA, which we retained after you joined. There is not always sufficient sample in our laboratory, in which case we may contact you to ask for a sample of your saliva (from which we can extract DNA to carry out testing). If this relates to you, we will be in contact to discuss further.

**Two** – We will contact you to request some blood samples. We will ask you for two sets of samples, which will go to two different locations:

1. Set one will go to a laboratory for HLA confirmation. This is either to better define your HLA markers or confirm the original typing information.
2. Set two will be used for testing for infectious disease markers. This is the same testing that is carried out whenever you give blood, to ensure that you have no infections which could harm a patient.

Before we ask you to do this, we will ask you a number of questions about your health and your lifestyle. We need to be sure that donation would not pose a risk to your health or potentially harm the person receiving your donation. In addition, we ask you to complete a Donor Health Check form (this is the same form that you would have completed every time you donate blood) and to confirm your height and weight.

### **Why is my height and weight so important?**

We would never ask you to donate if we believed that this might harm you. There are established limits to the maximum Body Mass Index that are allowed for donor safety. Your Body Mass Index is calculated by using your height and weight. If your Body Mass Index is more than 33, we would ask you to get it confirmed outside of your home – this is because home scales can easily be used incorrectly whereas scales in, for example, a pharmacy will be independently calibrated. If you inadvertently understate your BMI, we would not know this is the case until you arrive at our facility for a medical assessment prior to donation – if we then found that you could not donate, this could cause significant problems for a patient as they would then need to continue or restart their search for a suitable donor.

Once we have carried out these steps, the patient's medical team will consider whether or not you are the best match for the patient. Because of the complexity of finding suitable matches, doctors will typically consider a number of donors (who may well be from a number of different countries).

If you are not found to be the best match, we will let you know.

If you are found to be the best match, we will ask you to attend a medical session.

This medical session will take place at one of our specialist donation centres. Owing to the specialist work they do, we only maintain a number of these across the UK, so we may ask you to travel. We will make suitable travel and, if necessary, accommodation arrangements.

At the medical session, the doctor will carry out a comprehensive medical check-up. This will include asking you a number of questions about your medical history, carry out a chest x-ray and an electrocardiogram to check that your heart is healthy and take blood samples for testing both that you are healthy and that you do not have any infectious diseases.

About a week after this medical, we will be in touch to confirm the outcome. If you are female, it is also important to avoid pregnancy after the medical as the risks become greater to the patient as they are prepared for a transplant, as you will not be able to receive G-CSF or donate if pregnant.

Assuming that all is well, we will issue a Donor Clearance form to the patient's hospital – this confirms that you are healthy to donate and that you have agreed to donate on the dates we have previously agreed with you.

At this point, it is really important that you do not change your mind and withdraw your consent to donate. At this time, the patient will start their preparatory regime, which includes them being administered chemotherapy drugs. If the donation does not go ahead, the patient may die.

Please see the two sections below which details the two methods of donation.

## **Donor Information for consent to PBSC (Peripheral Blood Stem Cell) Donation**

Blood stem cells are predominantly found in the bone marrow and only a small number circulate in the blood normally. Blood stem cells differ from other blood cells in that they are capable of dividing and renewing themselves as well as producing all the different types of blood cells such as red blood cells, white blood cells and platelets.

There are two possible ways of donating stem cells: peripheral blood stem cell collection and bone marrow donation. Usually, the doctors looking after the patient for whom you are a match will express a preference for the way you donate. However, there are sometimes medical reasons you may only be able to donate by one route or you may have a strong preference for one above the other. This information leaflet explains the most frequently used method, peripheral blood stem cell collection and a separate section below details bone marrow donation.

## Peripheral Blood Stem Cell (PBSC) Collection

There are two phases to this:

### 1. Medication to release stem cells into the bloodstream – G-CSF administration:

For the four days preceding the donation a nurse will inject you with a medication which vastly increases the number of stem cells in your circulating blood: G-CSF (Granulocyte-Colony Stimulating Factor). G-CSF is a protein which occurs naturally in the body and regulates the production of certain white blood cells called granulocytes. G-CSF induces blood stem cells to leave the bone marrow cavity and enter the blood – a process known as “mobilization”. Pharmaceutical companies can manufacture a synthetic form of G-CSF (e.g. lenograstim) which, if injected over 4-5 days, enables sufficient stem cells to be mobilized into the blood where they can be collected in the second phase of the donation procedure.

**G-CSF Administration:** G-CSF is given by injections under the skin (a bit like insulin injections for diabetes) once a day for 4 days before your donation. They are usually given into the skin of the abdomen, thighs or upper arms by a homecare nurse who will visit you at home or at your workplace. The 4th set of injections may be administered at the designated collection centre.

**Possible side-effects of G-CSF:** the commonest side-effect is feeling like you have the flu with fatigue, a “muzzy” head and muscle or bone aches and pains. The latter are common in the back, pelvis and sternum (breastbone). Paracetamol usually relieves these symptoms. (You should avoid aspirin and aspirin-like medications during and for 2 weeks after G-CSF administration as such medicines can affect your blood cells (platelets)). You may experience swelling, redness or a tingling sensation at the injection site. Occasionally donors have nausea, vomiting, night sweats and difficulty in sleeping. All of these side-effects wear off very quickly after the last injection, usually within 48 hours.

More serious side-effects are very rare. As with any medicine, people can be allergic to G-CSF and occasionally allergic reactions are serious. The homecare nurse will remain with you for approximately one hour after the injections to ensure no complications occur. Nurses are trained in the management of rare reactions and carry the appropriate emergency kit for treating allergic problems. There is approximately a 1 in 5,000 to 1 in 10,000 (0.01%) risk of a splenic injury (pain and bleeding) and, to date, there have been a handful of cases worldwide in donors (both unrelated and related) undergoing G-CSF mobilization. Should you experience any unusual pain or tenderness in the upper left side of your abdomen just beneath your ribcage either while you are on the injections or within a week afterwards you should immediately contact the emergency telephone numbers you will have been provided with. You should avoid contact sports and excessive exercise whilst receiving the injections and for 2 weeks or so afterwards.

There are one or two case reports of lung and vascular complications after stem cell donation, but this is in the context of over 100,000 volunteer donors now having received G-CSF.

There is no evidence of any long-term harm caused by G-CSF injections. Studies following large numbers of donors have shown that the risk of developing leukaemia or cancer within several years after the use of G-CSF is not increased compared to donors not receiving G-CSF and the World Marrow Donor Association has made a statement to this effect to reassure donors. A number of donors have developed autoimmune disorders such as underactive thyroid glands and rheumatoid arthritis some years after receiving G-CSF but there is no evidence that these conditions occur more commonly than in the general population.

As with all injections, the same risks apply for when you have given blood; including possible bruising at the puncture site (hematoma). Hypodermic needles have also (rarely) been associated with nerve or tendon injury, infection and arterial puncture or laceration.

## **2. Collecting stem cells from the bloodstream – apheresis:**

On the fifth day you will be seen at the designated collection centre. A sterile needle is inserted into one vein in each arm and blood is removed from one arm and passed through the cell separator (apheresis) machine. The blood is centrifuged such that it separates into "layers" of its different components. The stem cells are separated and collected into a special bag and the remaining white blood cells, red blood cells, platelets and plasma (the liquid component of blood) are returned to you via the needle in your other arm. If you are already a platelet donor you will be familiar with this type of machine. The procedure lasts about 4-5 hours with an additional hour for the stem cells to be processed in a laboratory. You will lie on a special reclining bed or couch in a day care ward with a nurse in attendance throughout. Many donors find it helpful to have a companion with whom to pass the time. You may be asked back on the sixth day for a further donation, if the dose of cells obtained is not sufficient. This would necessitate a 5th injection of G-CSF and you would be asked to stay in a local hotel overnight.

At the pre-donation medical assessment donors are occasionally found to have veins that are not suitable for donation (e.g. they are too small) or, rarely, veins fail to work on the day of collection. If you fall into this category you will be asked to consider having a temporary catheter, known as a central line (or CVC), inserted into one of your larger veins (in the neck or groin) to make the procedure easier and more comfortable for you. Alternatively, if the assessment is at your pre-donation medical you may prefer to consider a bone marrow harvest. Fewer than 5% of our donors require a central line.

## PLACEMENT OF A CENTRAL LINE

If a central line is needed, a highly experienced anaesthetist/radiologist, appropriately qualified doctor or specialist nurse will place the central line. A local anaesthetic similar to that used by dentists is used to numb the skin at the insertion point. This is given through a small needle and may be uncomfortable for a few seconds and may cause some light bruising, but it should mean that the procedure itself is not painful. The line will only be in place for one or two days at the most. If the line needs to remain in place for a second day, you will be admitted to the hospital overnight between the two collections.

**Possible complications of having a central line:** serious complications associated with the insertion of short-term central lines exist but are very rare. They include internal bleeding or air embolus (both extremely rare – less than 0.5%). Catheters that are placed in the neck can also result in a collapsed lung. This occurs in less than 4% of patients and is usually picked up on the chest X-ray that is performed as a check after the line is inserted: usually no treatment is needed. Other complications that might occur are local bleeding, infection at the insertion site (warmth, redness or tenderness over the skin) or in the blood stream (fever, malaise, nausea, vomiting) and blood clot formation. Occasionally, the line does not function properly or may become blocked: this is not a serious complication but may require replacement of the catheter.

The risks associated with central line insertion in healthy donors are low and you will be closely monitored by your clinical team. After you go home, you will be asked to report any symptoms such as pain at the insertion site or in your chest, difficulty in breathing or high temperature to the emergency telephone numbers you will have been provided with.

**Possible side-effects of apheresis:** as your blood enters the cell separator an anticoagulant (blood thinner) solution is added to stop it clotting in the machine. This can cause tingling in the lips, nose or fingers, a metallic taste in your mouth, nausea or a “shaky” vibrating sensation that may or may not be unpleasant. Such side-effects are caused by the solution temporarily lowering the blood calcium levels. It is important for you to let the nursing staff know if you are experiencing such symptoms as slowing the return blood flow rate or administering calcium can readily help to alleviate them. As with any blood donation some donors feel light-headed, sweaty or, very rarely faint as a result of lowered blood pressure. The procedure would be stopped, the bed tipped up and you would be given a cold drink until you felt better.

A small quantity of platelets may remain in the machine causing your overall platelet levels to drop minimally. We routinely check your blood count before and after the procedure to ensure that the levels remain safe. If your platelet count dropped more than usual you would be informed, and you might have an increased chance of bruising or bleeding after the procedure. We advise all donors

to avoid heavy lifting and contact sports and not to take aspirin or aspirin-like medicines during or shortly after the collection. Occasionally we cannot return the blood that is in the machine to you which means you will lose some red blood cells. The machine only holds a small amount of blood at any one time and this loss would not cause any problems.

Very rarely (less than 1 in 100 cases) mobilisation of stem cells into the bloodstream fails and insufficient cells can be collected for the transplant. In this unlikely event, you might be asked to undergo a bone marrow harvest if you are considered to be medically eligible for this procedure. You would be counselled about this separately and asked for your consent to proceed.

As apheresis is a procedure that uses a needle, the same risks apply for when you have given blood; including possible bruising at the puncture site (hematoma). Rarely, apheresis has been associated with nerve or tendon injury, infection and arterial puncture or laceration.

## AFTER CARE

If you experience any of the side-effects of apheresis, they will wear off very quickly after the procedure ends. The nursing and medical team will check that you have recovered sufficiently to travel back to your hotel or, if it is the last day of donation, back home. Any aches and pains caused by G-CSF usually subside within 24-48 hours of the last dose and your arms may be a bit bruised or sore where the needles were inserted for a couple of days. We do not recommend a particular time away from work to convalesce, but you may experience some initial fatigue which may be helped by taking a further 24-48 hours away from work or your normal duties.

Your recovery will be monitored by a BBMR stem cell co-ordinator who works in conjunction with the BBMR medical team and your general practitioner.

All donors are followed up for at least 10 years after donation and any serious conditions are reported into an anonymous central database so that any rare undiscovered side effects would come to light. Specifically, we will attempt to contact you 2-4 days, 14 days, 30 days then 1, 3, 5, 7 and 10 years after your donation to follow up on how you are doing.

To ensure you receive the best healthcare it is imperative that if you experience any serious ill health in between follow up phone calls; that you inform your GP and/or the BBMR promptly so that any relationship between the donation and later illness can be explored. It is highly unlikely ill health experienced after the first month following your donation will be associated with your stem cell collection. However, things we and your GP will want to hear about straight away include; any back or immune problems or if you receive a cancer diagnosis.

## **CONSENT**

The physician at the collection centre will talk through the donation procedure with you and answer any queries you have. When you are happy you will be asked to sign a form to document your consent to proceed with donation. It is essential that you satisfy yourself that you definitely wish to go ahead with the donation before the patient receives the chemotherapy they need to prepare for the transplant. This treatment usually begins 10-14 days before your donation. If you withdraw from donation after they have started this treatment, they may die from the lack of stem cells. You are therefore asked to consider the signing of the consent form as a morally binding and irrevocable decision.

## **FUTURE DONATIONS**

Occasionally, donors are asked to donate a second time for the same patient. This can either be a further donation of PBSCs or of bone marrow or of a different type of blood cell called lymphocytes (approximately 1 in 7 donors overall). We will only approach you if you have indicated to us that you would be willing to help the same patient again. You will be asked to fully consider the matter before proceeding.

## **Donor information for consent to Bone Marrow donation**

Blood stem cells are predominantly found in the bone marrow and only a small number circulate in the blood normally. Blood stem cells differ from other blood cells in that they are capable of dividing and renewing themselves as well as producing all the different types of blood cells such as red blood cells, white blood cells and platelets.

As mentioned previously, there are two possible ways of donating stem cells: peripheral blood stem cell collection and bone marrow donation. Usually, the doctors looking after the patient for whom you are a match will express a preference for the way you donate. However, there are sometimes medical reasons you may only be able to donate by one route or you may have a strong preference for one above the other. This section explains bone marrow donation or "harvest" compared to peripheral blood stem cell collection which was explained previously.

### **Bone Marrow Donation**

#### **THE GENERAL ANAESTHETIC:**

The main risk, although very small is that associated with the general anaesthetic. In a healthy patient having non-urgent surgery the risk of death is graded as "very rare" and is approximated at 1 in 100,000 (0.001%). As a healthy donor the risk is even lower as you will have had a medical assessment to detect any foreseeable risk factors prior to the donation process and you will be undergoing minor surgery. Serious complications of anaesthesia include life-threatening events such as cardiac, circulatory or respiratory complications as well as allergic reactions during and

immediately after anaesthesia. These are all rare. Minor complications include soreness/bruising in the back of the hand where a needle has been used to insert a thin plastic tube (cannula) into a vein to give you medications during the anaesthetic. You may have a sore throat from where a tube was inserted into your main airway to assist breathing and, very occasionally, teeth, caps, crowns or veneers can be damaged when the tube is put in. Some of the anaesthetic drugs given can cause nausea, vomiting, headaches or muscle pains all of which can be countered with basic medications during and after the procedure.

The anaesthetist will be with you during your donation and is highly trained in anaesthesia and the management of emergency situations. They will monitor your heart, blood pressure and oxygen levels until the end of the procedure when you will be taken to the recovery room where most people regain consciousness. Trained staff will be with you and continue to monitor your condition. Once the anaesthetic has worn off and you are considered to be stable you will be able to return to your hospital room.

### **THE HARVEST PROCEDURE:**

While you are under anaesthetic you will be laid on your stomach and the marrow cells will be collected using hollow needles and syringes placed in your pelvic bones on both sides (right and left iliac crests). No surgical incision or stitches are needed but several puncture holes will be made in the skin and then through the outer layer of the bone to the marrow cavities inside. A maximum of 1.5 litres of marrow and blood will be extracted (or less if you weigh less than 75 kg) and the procedure typically takes 30-60 minutes.

**Possible side-effects of the harvest:** you are likely to be sore and have bruising around the sites of the needle insertions and may have a dull ache and stiffness over your lower back. The hospital team are able to provide you with medication to ease this with a supply to take home if needed. It is normal to feel tired after the procedure and some of your red blood cells will have been removed at the harvest so you may be a bit anaemic. Sometimes donors are given iron supplements to help speed the return to normal of their blood counts and all will have a check blood test done, usually at their GP's, a few weeks after donation. Most donors achieve a reasonable recovery within 7-10 days. If you have a physical job or very active lifestyle, it may take a couple of weeks to return to your activity levels pre-donation.

Complications that may occur as a result of the procedure are infection (requiring antibiotic treatment) or injury at the needle insertion sites (including possible bruising at the puncture site (hematoma). Rarely, nerve or tendon injury, and arterial puncture or laceration). You may also experience a tingling or a numb sensation near the harvest site or buttocks or prolonged back pain as a result of possible bone, nerve or other tissue damage. This may occasionally require further medical treatment or some form of physical therapy such as physiotherapy. A very small number of donors (less than 1 in 300 or 0.3%) experience long-term back pain. A proportion of these people have had back problems prior to their donation, and it is important that you disclose any previous or current back problems to the doctor you see for medical assessment. You would usually not be allowed to donate bone marrow in such a circumstance.

## AFTER CARE

Your recovery will be monitored by a BBMR stem cell co-ordinator who works in conjunction with the BBMR medical team and your general practitioner. They will help arrange and check blood tests with your GP and make routine follow-up phone calls to you at set intervals following your donation.

## CONSENT

The physician at the collection centre will talk through the donation procedure with you and answer any queries you have. When you are happy you will be asked to sign a form to document your consent to proceed with donation. It is essential that you satisfy yourself that you definitely wish to go ahead with the donation before the patient receives the chemotherapy they need to prepare for the transplant. This treatment usually begins 10-14 days before your donation. If you withdraw from donation after the patient has started this treatment, they may die from the lack of stem cells. You are therefore asked to consider the signing of the consent form as a morally binding and irrevocable decision, although your right to withdraw of course still does remain.

## FUTURE DONATIONS

Occasionally, donors are asked to donate a second time for the same patient. This can either be a further donation of bone marrow or a donation of peripheral blood stem cells or of a different type of blood cell called lymphocytes. Approximately 1 in 7 donors are asked for a second donation. We will only approach you if you have indicated to us that you would be willing to help the same patient again. You will be asked to fully consider the matter before proceeding.

## Things to keep in mind now until you donate

### Alcohol and illicit/recreational drug use

You should try to stop smoking, vaping or drinking any alcohol in the weeks before donation, as doing so will reduce your risk of developing any complications. Drinking alcohol or using illicit drugs in the days before your procedure must be avoided as doing so can increase the risk and severity of complications. For example, alcohol can interfere with the effectiveness of any anaesthesia. Drinking alcohol or using illicit/recreational drugs near the time of your procedure could also cloud your judgements or even increase risk to the patient by affecting the quality of the stem cells in the donation. Abstinence from alcohol and smoking is recommended until after you fully recover from your donation.

You should also ensure that you have good fluid intake the night and morning prior to your donation.

## Tattoos and body piercings

There is a very small risk of exposure to an infectious disease following a tattoo or piercing. For this reason, we would ask you to delay any tattoos or piercings until after you donate bone marrow or PBSC. If you have anything planned in the next few months, please let us know.

## What is the hepatitis E virus?

The hepatitis E virus (HEV) is found throughout the world in both humans and animals, especially pigs. There are several different variants of the hepatitis E virus; the one commonly found in the UK is called genotype 3. HEV can be present in pork products, shellfish and other meat; however, the risk to humans is extremely low if these are cooked thoroughly. HEV is not easily passed from person to person, but it can be passed on through blood transfusion or stem cell transplantation. Most people who become infected with HEV have no symptoms and the infection clears completely within a couple of months. It is thought that as many as 100,000 people in the UK are infected with HEV each year, the majority being caused by a dietary source, but less than 1 in 100 people become unwell as a result. HEV infection can be detected in patients or donors by a blood test however it is an expensive test.

## Why is HEV important?

HEV may pose a risk of harm to a patient whose immune system cannot clear the infection from the body, and the infection can then become persistent.

If a HEV infection is found or transmitted to a patient with reduced immunity, levels of the virus in the blood can be monitored and treatment given if required to prevent potential chronic inflammation of the liver. HEV symptoms in a stem cell patient recipient can also look like another disease called graft versus host disease adding further complications and potentially hampering treatment.

## Can HEV be prevented?

There is no vaccine for HEV at the moment. As testing for the virus is expensive and to protect your patient recipient from HEV infection, we kindly request that you follow the dietary advice below **from now until** we either inform you that you will not be donating or **after** you have donated your stem cells.

- When cooking pork and pork products (especially sausages) please ensure the meat is cooked thoroughly until juices run clear. This is especially important during barbecue season.
- Please avoid eating other raw or undercooked meat or shellfish.
- Please ensure you continue to wash your hands after going to the toilet.

## Frequently Asked Questions

### Apart from Hepatitis E; will I be tested for any other infectious diseases?

Yes, we will additionally test you for HIV, hepatitis C, B, Syphilis, Human T-lymphotropic virus type II, Cytomegalovirus, Epstein Barr virus, Toxoplasmosis and novel Coronavirus. Dependant on your past residential and/or travel history; you may also be tested for Malaria, West Nile virus, or Chagas.

### 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. For some patients and disease types, the patient's doctor will prefer the donor to donate by bone marrow retrieval, 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.

### Will you cover any expenses/loss of earnings?

Yes. BBMR will arrange for travel and accommodation travelling to and from our facility for medical assessment and the actual donation. Please keep any receipts for expenses such as food and refreshments to claim this back from us. We will also cover any loss of earnings – we will discuss the process with you should you be selected to donate.

### What if something goes wrong?

Should something out of the ordinary happen with your donation process and you are adversely affected; BBMR collection centres all have local arrangements to offer the best possible healthcare should something go wrong.

BBMR also operates a donor compensation policy with insurers.

### Will I be able to have contact/meet the recipient of my stem cells?

Possibly. It is a legal and ethical requirement that identity and location of both patient and donor are kept confidential.

However, a donor by mutual consent may exchange an anonymised greetings card or note through the BBMR office and the transplant centre in the immediate post donation period. If either party indicates at counselling that they do not wish to receive any form of communication or information their wishes must be absolutely respected. Some international registries do not allow any contact at all between donors and recipients, however.

It is BBMR policy that when 2 years have elapsed from the time of donation and when the following conditions are met it is acceptable for the donor and recipient to be given each other's details and be allowed direct contact and to meet, should they so wish.

- a) The donor has indicated in writing their agreement and desire to meet the recipient of their stem cells or other cellular product;
- b) The recipient has also indicated in writing their agreement and desire to meet the donor of their stem cells or other cellular product;
- c) It is considered extremely unlikely that a further donation of stem cells or other cellular therapy product will be required from the donor for that specific recipient and when the patient is physically and mentally well. It is usually the case in such circumstances that donors and their recipients have been exchanging anonymously cards and, or letters for some time and it should be obvious to the BBMR Medical Director that they are mutually agreeable to such a meeting.

If the recipient was in another country; it might be the policy of their local registry has more onerous conditions than this or even forbid donor/recipient contact. It is customary between stem cell registries in such cases, that the more stringent contact rules of either one of the registries involved apply.

## **Will I be reimbursed for any expenses and loss of earnings?**

Expenses you as a BBMR donor incur can be reimbursed for. You will be given a form to record your expenses. Please bear in mind that:

- Only receipted items can be claimed for in regard to subsistence and travel related expenses (so please keep all receipts from donation related transactions where BBMR have not paid up front on your behalf – for submission to us at BBMR).
- Receipts must be submitted to BBMR with an accompanying 'expenses claim form'
- An expense claims can take up to two weeks to be paid.
- All claims will be paid directly into your nominated bank account(s) (please note you may be asked to nominate both a business and a personal bank account if you are self-employed) via direct transfer.

These guidelines refer specifically to the time before, during and after donation to accommodate the normal expected recovery period post donation, this will normally be 1-7 days' post donation for PBSC and 1-14 days\* for bone marrow harvest

\*In the unlikely event of any post-donation complications resulting in longer periods of recovery and any expenses incurred as a result, we are required to follow separate processes as required by our donor insurance providers and the Department of Work and Pensions.

## **Hotels**

Your donor centre contact will make all Hotel arrangements for you (and your companion if you have one). Typically, the reservation will include a daily £25 meal allowance at the hotel – where this cannot be organised, your BBMR Stem Cell Coordinator will let you know the arrangements. A limit of £25 per day (each) may be claimed by you and your companion (if you have one). Please be aware that we will not pay for any alcohol, however.

## **Train, Coach and Taxi journeys**

Train and coach tickets will be arranged by BBMR staff and either; tickets will be posted to you or a reference number allowing ticket collection at a station will be provided.

Taxi journeys will be reimbursed for journeys such as between train station and hotel, and hotel and donation facility. Typically, BBMR will ask for the donor to pay for the journey and request a receipt from the driver for reimbursement.

## **Travelling by own car**

Milometer readings must be taken from start and finish of each individual journey, which should be recorded on the reverse of the reimbursement claim form. Current reimbursement rates are 24p per mile. BBMR will reimburse you for parking costs involved in your donation (such as parking at or near your hotel and parking at or near your donation facility) when receipts are provided.

## **Expenses of Companion**

BBMR recommends that donors consider bringing a companion to accompany them during the donation process. BBMR will reimburse a companion's essential travel, accommodation, subsistence and loss of earnings as per these guidelines. BBMR will only reimburse costs for one companion.

## **Loss of Earnings**

Self-employed, hourly paid, zero-hours contract-workers, or where employers do not make up the difference between sick pay and normal pay, can claim loss of earnings to be reimbursed by BBMR.

### **(i) Employed**

A notional 25% will be deducted for Income tax and National Insurance (you will be paid net).

Please ensure you get a letter from your payroll department on headed paper to confirm the gross amount of lost earnings or provide a copy of your most recent pay slip.

## **(ii) Self-employed Trader**

The self-employed/sole trader should give independent, evidenced confirmation of loss of earnings from their accountant on the accountant's company headed paper. If no accountant is employed; evidence of a monthly average over a 12-month period can be used to calculate a claim. You may choose to be paid for loss of earnings net or gross.

If you choose to be paid net, loss of earnings will be paid into your nominated personal bank account.

If you chose to be paid gross; you will be asked to provide your 10-digit UTR ('Unique Taxpayer Reference') number and also to sign a statement of intention to declare the income to HMRC and pay the relevant tax and NI contributions through the self-assessment process. The gross loss of earnings payment can be made to either a nominated business or personal bank account.

Other expenses (e.g. travel, subsistence) will be paid to your personal account unless there is evidence that the business bore the costs initially.

## **(iii) Self-employed by your own Ltd Company**

The self-employed (via Ltd Company) should give independent, evidenced confirmation of loss of earnings from an accountant on the accountant's company headed paper. If no accountant is employed; evidence of a monthly average over a 12-month period can be used to calculate a claim.

Your loss of earning will be paid gross to your business' account; you will be asked to provide evidence of the nominated business bank account, plus the name, trading address and registered company number of the Ltd company.

BBMR will reimburse the gross amount for loss of earnings into a nominated business account with other expenses (e.g. travel, subsistence) being paid into your nominated personal bank account

## **Other**

Any other potential expenses, not mentioned in this document, should be discussed with your BBMR Stem Cell Coordinator to enquire as to whether they will be paid.

## **Any more questions?**

You can ask any questions you have of your Stem Cell Coordinator contact at BBMR. You can call us on 0117 912 5729 or email us at [bbmr@nhsbt.nhs.uk](mailto:bbmr@nhsbt.nhs.uk). We're open 8am to 6pm weekdays.

