



YOU ARE

A

**MATCH!**



# YOU ARE A [ MATCH! ]

Dear \_\_\_\_\_,

Thank you for signing up as a volunteer bone marrow donor and being part of **The Singapore Bone Marrow Donor Programme (BMDP)**. We are Singapore's only database of volunteer marrow unrelated donors.

The first step you took when you first signed up with us was to provide a tissue sample through a buccal swab – which was then tested to determine your tissue-type. This information together with your contact details were stored in our database.

Now, you have been identified as a possible match donor for a patient based on your tissue-type. This booklet is to help you understand the next steps of your journey, should you continue through to make this life-saving donation. Most importantly, do know that you are not alone and will be supported by a **Donor Centre Staff** who will keep you fully informed of the process and schedule.

Before you are finally selected as the best match for the patient to donate, more testing is required, and the steps are outlined in this booklet.

Once again, thank you. You may be on the way to save a life.

CEO & Team of BMDP



## STEP 1

### Verification Typing

To confirm that you are the best match for the patient



## STEP 2

### Donor Workup

To ascertain that you are physically fit for donation



## STEP 3

### Donation

Bone Marrow Collection or Peripheral Blood Stem Cell



## STEP 4

### Follow Up

Routine medical follow-ups after donation

## Who needs a Bone Marrow Transplant?

Bone marrow transplants are used to treat patients whose bone marrow is not producing the correct amount of various blood cells. More than 60 potentially fatal diseases, including several types of leukemia, are treated through bone marrow transplant. With no suitable family donor, the patient is referred to a register like the BMDP.

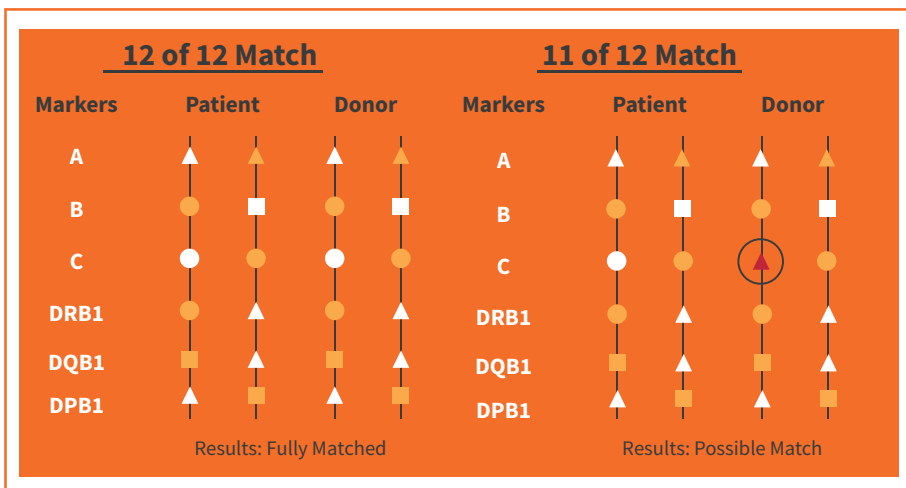
## Why is a match so important?

The cells that manages the body's immune system come from the bone marrow and therefore, a transplant essentially introduces a new immune system to the patient.

If the donor and the patient do not share the same genetic markers, the new white blood cells will attack the host body. These proteins – or markers – are called the Human Leukocyte Antigens (HLA) and are found on most of the body's cells.

The HLA proteins are important in matching patients and donors for a blood stem cell transplant.

- You have **2** sets of tissue-type markers, which are compared in the matching process. One set is inherited from your mother, the other from your father.
- When a transplant centre looks at the match level, it is looking at how alike the tissues of the patient and the donor are to each other.
- The transplant centres look at **up to 12** HLA antigens – **A, B, C, DRB1, DQB1, DPB1** – to select a donor. Ideally we are looking for a full match.



## Why is a match so important?

Before we proceed to the details of the donation, please note that some medical conditions may affect your eligibility to donate. Therefore, do share with us if you have the following conditions below before we meet you for an information session:

- Ankylosing Spondylitis
- Cancer (excluding basal cell carcinoma of the skin)
- Diabetes (insulin dependent)
- Myasthenia Gravis
- Rheumatoid or psoriatic arthritis
- Systemic Lupus Erythematosus (SLE)
- Thalassemia
- Thyroid
- Crohn's Disease
- Celiac Disease
- Gout
- Guillian Barre Syndrome
- Henoch-Schonlein Purpura
- Idiopathic Thrombocytopenia Purpura
- Lichen Planus
- Lichen Sclerosus
- Kawasaki Syndrome
- Meniere's Syndrome
- Raynaud's Disease
- Reactive Arthritis (Reiter's Syndrome)
- Sarcoidosis
- Scleroderma
- Severe Eczema
- Severe Psoriasis
- Sickle Cell Anemia/ Sickle Cell Trait
- Thrombocytopenia
- Ulcerative Colitis
- Vitiligo
- G6PD

We would also like to know if you:

- Are under **45** kg
- Have a Body Mass Index (BMI) exceeding **35** [ weight(kg) / height(m<sup>2</sup>) ]
- Are pregnant or was pregnant in the past **9** months
- Have recently donated blood
- Have received vaccinations in the past **12** months
- Have done tattoos, acupuncture or body piercing the past **4** months

Please **DO NOT** do the following with immediate effect if you have intentions to proceed with the donation when confirmed as a match:

- Donate blood
- Tattoos, acupuncture or body piercing
- Vaccination - check with Donor Centre staff on types of vaccine
- Plan for pregnancy in the next **6** months



## STEP 1

### Verification Typing

You have been selected through an initial search of the database as a potential match and contacted by your Donor Centre Staff for an **information session**. This is an opportunity for you to ask questions regarding the donation. We strongly encourage you to involve your **family or significant others** for the information session so that they can fully understand and support you. We will also need you to run through the Medical Update & Consent Form that is sent together with this booklet to highlight any medical conditions you might have before the session.

During the session, you will be asked to update us on your current health status. For female donors, pregnancy or post pregnancy within 9 months will deem you ineligible. If you give **consent** to move forward for more testing, you will then be asked to provide a **buccal swab/blood samples** that will be used to verify your HLA typing. If you are under the legal age of 21 years, **parental consent** is required. We will also collect blood samples to verify your blood group and screen for the following infectious

- Human Immunodeficiency Virus (HIV)
- Hepatitis B
- Hepatitis C
- Human T-Lymphotropic Virus (HTLV)
- Syphilis
- Cytomegalovirus (CMV)

The outcome of the above testing will be shared with the patient's doctor and you will only be identified through a unique and anonymous donor ID. We might require more testing to be done if there are abnormality or ambiguity in the results.

Not all donors called for Verification Typing, will go on to donate due to various reasons, but it is important that you are ready for more testing and are willing to donate if chosen. Your commitment is important to the patient in need of a donor. We need your understanding that the patient would have to go through conditioning treatment to prepare for the transplant. If the donor pull out at this point, the consequences could potentially be very serious.

If you need further information prior to your decision, your Donor Centre Staff is available to answer any questions or concerns. You will also be given an option to speak with other donors so that you can make an informed decision to move on to the next stage.



## STEP 1

### Verification Typing

#### What Happens After Verification Typing?

The donor centre staff will let you know if you are the most suitable donor for the patient within the next 1 to 6 months. The date of the donation depends on the patient's treatment regime. If you are, we will schedule a donation date with you. Otherwise, you may be called for another patient in the future.

Please stay on the register and remain committed. Your **Verification Typing** result will be added to your existing tissue-typing.

If you are selected, we will call you to arrange a donation date based on the patient's treatment plan. A medical examination will be scheduled approximately 3-4 weeks before the donation.

**Please abstain from doing body piercing/tattoo/acupuncture/vaccinations and donating blood, before the donation takes place.**

Do keep us informed if you intent to travel in the next 6 months or are planning to receive vaccinations.



## STEP 2 Donor Workup

The Donor Workup refers to the various medical procedures that ensure you are fit and healthy if you are selected to donate.

The BMDP will appoint a qualified doctor to look after you, usually a haematologist, from one of our Collection Centres. Whenever possible, we will try to accommodate your preference of collection centre subject to availability.

The workup process consists of 2 stages that typically takes around 2 to 3 hours:

### Doctor Consultation & Donor Consent

Your appointed doctor will complete a donor health questionnaire and evaluate you and your family's medical history. At this time, more information will be shared about the donation process, including any potential risks and side effects, and questions you have will be answered. You are welcome to invite a family member or friend along to attend this session with you.

If you are under the age of 21, parental consent is necessary to proceed with the medical examination and consent for the donation. Therefore at least 1 parent must be present during this session.



Once you agree to proceed, you will be asked to sign a donor consent form, which confirms that you understand what will take place during the donation process, risks and side effects involved.

### Physical Examination

Next, you will be given a thorough medical examination to ensure you have no pre-existing medical conditions that could pose any risks to you or the patient. The following will be tested to determine your eligibility to donate:

- X-ray
- ECG
- Haematology (Blood) profile
- Renal (Kidney) profile
- Liver profile
- Infectious diseases
- G6PD
- Hemoglobin Electrophoresis (For PBSC method of donation only)

This is important as some diseases can be transmitted to a patient through donation and the results will help determine your eligibility. Meanwhile, you should take care of yourself and refrain from going to crowded places to avoid catching an infection.

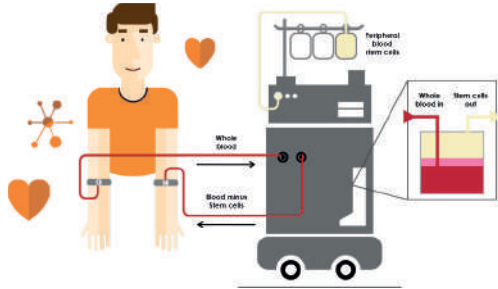
## **STEP 3** Donation

Once you have cleared the medical examination, you then proceed to donate via the bone marrow or Peripheral Blood Stem Cell (PBSC) Collection.

### **PBSC Donation**

PBSC Donation is the most common method of stem cell collection used almost **90%** of the time. It is a nonsurgical procedure to collect blood stem cells from the bloodstream.

To increase the number of blood stem cells in the bloodstream, you will receive daily injections of a hormone called **granulocyte-colony stimulating factor (G-CSF)** for **4** days prior the donation date and a **5th** injection on the day of your donation.



You will receive the injection on the first day at the collection centre and taught to self-administer for the next few days. During the first dose of injection, You will be kept under **observation** for any allergic reactions for **an hour**. If you are not comfortable with self-administration, you can visit a General Practitioner with a referral letter from the hospital to administer the injection for the subsequent days and costs incurred will be fully reimbursed.

You will reach the hospital in the morning on your donation day. Local **anesthesia** is administered in both arms before a sterile needle is inserted each arm. Your blood is collected from one arm and will pass through the **apheresis machine** that separates out the blood stem cells, and all the remaining blood is returned to you through the other arm. This process repeats continually for **5-8** hours and after which, the collected blood stem cells will be sent to the laboratory to determine if the target cell dose is achieved. In most cases, we were able to reach the target amount within a day. Occasionally, the donor will be required to repeat a second day donation if the target dose is not achieved. In rare cases where insufficient cells are collected over the **2** days, you may be asked to donate via bone marrow collection.

There are times when the veins on the donor's arms is assessed to be unsuitable for donation in which a **central line placement** may be required. This will be determined during the medical examination.





## STEP 3 Donation

**Side Effects and Recovery(PBSC):** You may experience headaches, bone, muscle aches, fever or soreness at the injection sites before the donation. These are side effects of the G-CSF injections and they usually subside shortly after the donation. Medication to manage the symptoms may be allowed under the instructions of a qualified doctor. During the donation, you may experience some discomfort such as dizziness, nausea, feeling cold or numbness and tingling feeling on your lips, nose or fingers. After the donation, you may have bruising and cramps on your arms. This will go off after a few hours or a few days after donation. Generally, donors are able to get back to routine work or study within the next few days.

### Bone Marrow Donation

A Bone Marrow donation is a surgical procedure that takes place in a hospital whilst under **general anesthesia**. You will be reviewed by the anesthetist before the procedure. You may be asked to check in the evening before the donation or on the morning of the procedure depending on the hospital practices. Regardless, you are required to fast **8-10** hours before the donation.

Under general anesthesia, the doctor will collect your liquid marrow via a needle from your pelvic bone (not the spine area) with your back face up. The procedure generally takes less than an hour. After the procedure, it is essential for you to stay overnight to allow the effects of the anesthesia to wear off and go home the following day.



**Side Effects and Recovery(Bone Marrow):** You may feel some sore and stiffness in the lower back for a few days or longer, but you will be able to get back to routine work or study in a few days and full physical routine in a few weeks.

### End of donation

We strongly recommend a **family member/friend** to bring you home after the donation. Riding or driving on your own is not encouraged.



## STEP 4 Follow Up

After you have donated bone marrow or PBSC, your Donor Centre Staff will arrange for a follow up health check. Usually, this will be through a phone call after **1** week with **2** medical reviews by your doctor within a year. This is to ensure that your health has not been affected by the procedure even though most donors are back to work in a few days and resume their normal physical routine shortly after. Your donated cells will be completely replaced within **4-6** weeks in normal circumstances. If you feel unwell, please inform your donor centre staff and we will make the necessary arrangements for you to see the doctor earlier if necessary.

BMDP and your Donor Centre Staff care about your well-being and we are committed to supporting you throughout your journey. A social follow up via a phone call will be conducted annually up to 10 years from your donation.

### Subsequent Donation

After the donation, you will be reserved for **2** years for the patient you have donated to. In the event the patient requires a subsequent donation which could be in the form of a Bone Marrow/PBSC/Donor Lymphocyte Infusion (DLI) Collection, we will contact you to seek your interest and consent to donate. **DLI** is a form of therapy in which lymphocytes particularly T-Cell lymphocytes (a type of white blood cell) that is collected from the donor via **apheresis** to help the patient manage the disease better. The method is very similar to PBSC donation except that no G-CSF injections are required.

After **2** years, if you are still willing to be on the register, you will return to the public register to be available for other patients until you reach **60** years old.



## STEP 4 Follow Up

### Patient and Donor Communications

If you are identified as a match, the patient could be anywhere in the world. We will provide you some basic information such as their **gender, diagnosis** and if it's a **child or adult**.

After the donation, you may send and even receive messages such as greeting cards or letters but **no** information that can identify you will be shared. Identifying information includes name, nationality, age or even date of birth. The BMDP will facilitate any correspondence. If the patient is overseas, a foreign registry may be involved.

After 2 years, if both you and the patient are willing to establish contact, the BMDP will facilitate the exchange of contact information. However, do note that foreign registry may have a different policy on patient and donor contact and hence the arrangement may not be possible. We also appreciate that every individual is different, and it is acceptable not to initiate contact and to remain anonymous.

### Privacy

At the BMDP, we take privacy very seriously for both our donors and the patients that we are supporting. We do this to protect both parties from unwelcome attention or contact. This is especially important in a world where social media has made communication easy across the globe.

While you may be keen to share your news with your friends and associates, we do recommend that the following details should **NOT** be shared:

- Gender, disease and age group of the patient
- Exact dates and location of your appointments and donation
- Photos of stem cell bag with labels and information
- Anonymous letter and cards from patient

This is to protect your own interests to avoid unnecessary stress from the other involved parties.

# FREQUENTLY ASKED QUESTIONS

## *I've heard that donating bone marrow is very painful. Is this true?*

If you are donating by the bone marrow collection, you will be sleeping after general anesthesia is administered. Therefore, you will not feel anything. Most donors say they feel some discomfort or stiffness after the procedure and it usually takes a couple of days for the symptoms to subside.

## *Who determined the method of bone marrow donation?*

The best source of stem cell donation (Bone Marrow OR PBSC Collection) would be determined by the patient's medical condition. Transplant doctors may specify the preferred source of stem cells based on the needs of the patient, but ultimately the donor's choice or preferred method of donation will be respected. You will be asked to indicate your preference for Bone Marrow or PBSC collection during the information session.

## *What if I have any unavailable dates or planned work/holiday trips for the next 6 months?*

We will note your unavailable dates and try to facilitate the appointments around your schedule. If there are any changes to your calendar, do keep our staff informed. However, once a donation date has been fixed, we do not encourage any further changes to it as this will affect the patient transplant regime.

## *Can a donation happen on a weekend?*

We seek your understanding that the donation can only be scheduled on a week day when the full range of medical facilities are available.

## *Are there likely to be any long-term side effects on my health after making a donation?*

Most of our donors have returned to their normal routine after donating their bone marrow and none have feedbacked long-term side effects. Donated cells are fully restored within 4-6 weeks and there is a possibility that you may feel a little more tired than usual during this period, but this differs for each donor. Many of them report that they are back to normal within a few days.

## *Am I covered by insurance?*

BMDP covers our donors for the extremely rare event of coma, disablement or death related to the bone marrow/PBSC donation for a year following the work up. Should you require any medical attention for any condition related to the blood stem cell donation, all medical cost will be covered by BMDP.

# FREQUENTLY ASKED QUESTIONS

## *Do I have to pay for any of the tests and other costs?*

Out of pocket expenses incurred related to the donation will be reimbursed including travel and extra visits to the clinic in preparation for the donation. Loss of income will not be compensated. However, medical leave will be provided for all visits to hospital in preparation for the donation regime. Hospitalisation leave will be granted during the donation and post donation, subject to the doctor's assessment. We strongly encourage the donor to avoid driving and to commute via cab/private hire.

If you are required to inform your employer in writing, BMDP can provide a letter at the workup stage detailing the dates you will be involved for the donation.

## *Can I say "No"?*

You have the right to withdraw from donation at any time. But please remember that this can have serious implications for the patient leading to the transplant especially if the patient has started preparation for the transplant.

There are reasons for saying "no", including illness, the risk involved or even fear. While the BMDP respects the decision of the matched donor, uncommitted donors give false hope to patients waiting to have a transplant. Once a donor gives his or her consent, the patient begins pre-transplant treatment. When a donor decides to pull out at any stage after the endorsement, the patient will most likely die without a transplant as his or her own bone marrow would have been wiped out in readiness for the new donor cells to be introduced. The BMDP hopes that you will be committed to your participation as a bone marrow donor and we will do everything to make sure that you are fully informed and supported throughout the procedure.

## *I'm a Muslim. Am I allowed to donate?*

Yes, you are allowed to be a donor. In Singapore, the Islamic Religious Council has issued a Fatwa under the Administration of Muslim Law Act (Chapter 3, Section 32), giving approval for all Muslims to be bone marrow donors and help save the lives of patients who need a transplant.

## *What if I'm underweight/very light? Can I still proceed with the donation?*

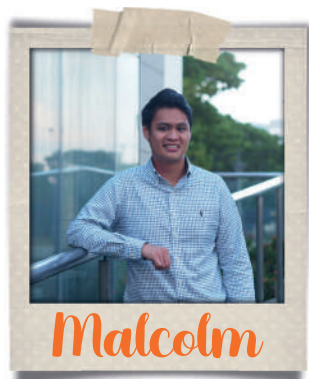
Ideally donors should be above 45kg and not exceeding a Body Mass Index (BMI) of 35 [ weight(kg)/height(m<sup>2</sup>) ] for a bone marrow donation and 40 for Peripheral Blood Stem Cell Donation.

**More details and FAQ at [www.BMDP.org](http://www.BMDP.org)**

# DONORS' VOICES

When I found out that it is rare for patients to find a matching donor, I realised how important it is for everyone to sign up to increase the chances of survival for patients. I couldn't imagine my recipient's expression when he/she received the good news that a match has been found.

There was no pain during the donation process, and I felt proud of myself when I saw my stem cells collected in a bag. I really feel good about it.



There were a lot of misconceptions around bone marrow donation. People asked if I was donating an organ or a part of me that is irreplaceable. In fact, my mother was initially quite fearful for me to proceed with the donation. However, when I clarified that I was donating my blood stem cells to potentially save someone's life and that these stem cells would be regenerated within weeks, her next reply was "What are you waiting for?"

It was truly a fulfilling and meaningful experience - to be able to make a difference in someone's life.

I have a daughter. And when I was informed that I was donating my blood stem cells to a child in need of a bone marrow transplant, my heart instantly sank. I could only imagine the emotional distress and pain that both the parents and child were going through.

The donation experience through the PBSC method was worthwhile. It even motivated me to create more awareness within the community to help improve the chances of other patients in finding a donor match.



# A LETTER FROM THE HEART

Dear Donor,

I would like to take this opportunity to thank you for your kindness and generosity to donate your bone marrow.

Your selfless act humbles me. I can't believe that a complete stranger would take the time and go through the discomfort of donating their stem cells to me.

All of my family would like to say thank you, as well you have given me an opportunity to be with all of them. I can only say thank you, thank you so much again.

Sincerely,

Your Bone Marrow Recipient



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