

Guide to Conversation with Your Parents

We encourage you to involve your parents in the conversation. Talking with your parents about stem cell donation can be challenging as they may be concerned for your safety. Listen to their concerns and share with them the facts as they may have heard myths or may not have a good understanding of stem cell donation. If you are below 21 years of age, parental consent is required to proceed with the donation.

The questions below are some commonly asked questions from parents of potential donors like you. You may use the information below to start a discussion to achieve the support you need during your life-saving journey!

Donation Basics and Facts

Q: Why did you join?

- I joined the Bone Marrow Donor Programme (BMDP), Singapore only register of volunteer bone marrow donors. BMDP matched potential volunteer donors like me with patients diagnosed with blood-related disease such as Leukaemia, Lymphoma and Myeloma.
- For patient with these diseases, bone marrow transplant may be the best treatment option that could save their life.

Q: Why do you want to donate?

- I decided to join the registry and pledged to help save the life of any patient in need of bone marrow transplant. I can help give a patient a second chance at life and hopefully more time with their family.
- I made promise to patients and their families and I want to follow through with my commitment.
- 70% of patients do not find a match within their own family. They depend on unrelated donors like me. I would want someone to help us if we were in the same situation.
- Matching a patient is more complex than simply matching blood types. I could be the only person on the registry that can help this specific patient. Generally, patient needs a donor who is of a close genetic match based on their human leukocyte antigen (HLA). Therefore, the urgent need to help find donor who inherit these markers are someone more likely to share the same ethnic background as the patient.

Conversation tip: Tell your parents specifically where and why you joined the registry in the first place. Share with them your motivation and how much it means to you. The best answer to this question is your personal encounter and motivation for donating.

Q: Are you sure this organisation is legitimate?

- The Bone Marrow Donor Programme is an Institution of a Public Character regulated by the Ministry of Health and governed by the Commissioner of Charities.
- They are a not-for-profit organisation that relies on public funding.
- BMDP was established in 1993 to provide hope for patients with leukaemia and other blood-related disorders.
- They are connected to an international network – World Marrow Donor Association (WMDA) and they facilitate transplants both locally and internationally.

Q: How does a bone marrow transplant work?

- Firstly, a patient who need a bone marrow transplant undergoes treatments to destroy their diseased bone marrow.
- Then, the donor's healthy blood-forming stem cells are given to the patient, where they can begin to function and multiply, replacing the patient's entire blood and immune system, giving them the second chance in life.

Stage 1: Information Session & Verification Typing

An information session will be conducted to help donor and family members to have a better understanding of the donation journey and commitment required. If I consent to proceed, a cheek swab and/or blood sample will be taken to confirm I am the best match for the patient.

Stage 2: Donor Work-Up

A doctor consultation with a full medical check-up will be conducted to ensure that I am medically fit to donate, and I do not have any condition that can pass on to the patient. My consent will be taken again to proceed.

Stage 3: Donation

Donation: Peripheral Blood Stem Cell (PBSC) or Bone Marrow Method.

Stage 4: Follow-Up

Routine medical follow-ups and social follow-up calls by BMDP staff.

Conversation tip: Invite your parents to join the information session with you so they can ask any questions they have to our donor management representative. If you are under 21 years, it is mandatory for your parents to be present in appointments.

Q: What is involved in donation?

- There are **two methods of donation**: Peripheral Blood Stem Cell (PBCS) and Bone Marrow collection. I get to choose the method of donation.
- For PBSC donation (Method 1), it is a nonsurgical procedure and normally performed in an outpatient setting in the hospital and takes between 5-8 hours.
 - a) I will be given Granulocyte-Colony Stimulation Factor (G-CSF) injections for five days leading up to the donation. These injections help to increase the number of blood-forming cells in my blood stream.
 - b) On the fifth day of G-CSF injection, blood stem cells will be collected via the blood stream; two needle plucks are inserted, one at each arm, blood will pass through the machine which separates only the blood stem cells. Remaining blood components such as red blood cells, white blood cells and platelets will return from the other arm.
- For bone marrow donation collection (Method 2), it is a surgical procedure and take place in a hospital operating room for about 50 minutes.
 - a) While under general anesthesia, liquid fluid marrow will be extracted from both sides of the pelvic bone. During the procedure, I will feel no discomfort. Upon observation, I will be discharged the following or subsequent day.
- For both methods, my body will naturally replace the donated stem cells within 4-6 weeks.

Health Concerns

Q: What about your health? Is it safe?

- The Bone Marrow Donor Programme take all the necessary precautions to safeguard the well-being of all donors in this lifesaving journey.
- There are many stages and steps involved in the donation process to assure donating is safe for me. These steps include completing a health history questionnaire, blood tests and physical examination prior to the donation.
- A donor management representative will accompany and follow up with me throughout the donation journey.

Conversation tip: You can always invite your parents to appointments and speak with the doctor for more detailed information on health concerns, side effects and risks. If you are under 21 years, it is mandatory for them to be present.

Q: What are the side effects and risks associate with GCSF-Injection and PBSC donation (Method 1)?

- During the five days of G-CSF injections, I may experience headaches, bone, muscles aches, fever or soreness at the injection site before the donation. These side effects of the G-CSF injections usually subside shortly after the donation.
- During the donation, I may experience some discomfort such as dizziness, nausea, feeling cold or numbness and tingling sensation on my lips, nose or fingers.
- After donation, I may have bruising and cramps on my arms. This will go off a few days after the donation.
- Generally, donors can return to routine work or study within the next few days post-donation.

Conversation tip: Donor management representative will follow up with you until you report a full recovery. Meanwhile, you can talk to your parents and discuss about daily tasks/chores and determine how it can be arranged.

Q: What are the side effects and risks associate with marrow donation (Method 2)?

- Due to the use of general anesthesia, side effects experiences may include sore throat, nausea and vomiting.
- After the procedure, I may feel some sore and stiffness in the lower back for a few days or longer. I will be able to get back to routine work or study in a few days and full physical routine in a few weeks.

Q: How does donating impact fertility and future pregnancy?

- Donation does not impact my fertility to have children.
- For female donors: If I choose to proceed with the donation process, I need to put my pregnancy plans on hold, as I will not be allowed to donate if I become pregnant during any stage of the process.

Time and Cost

Q: How will the donation process affect your study/work schedule?

- I may have to take some time off from school/work that includes information session, appointments for physical examination and actual donation. All these stages are mandatory to ensure that the donation is safe for me and the patient. Below is an estimate of how much time I will take from work:

Stage 1: Information Session & Verification Typing – 1-2 hours

Stage 2: Donor Work-Up – 4-5 hours

Stage 3: Donation – 1-4 days

Stage 4: Follow-Up – 1-2 hours

- Medical leave (MC) will be provided for all visits (Stage 2 and 4) to the hospital in preparation for the donation and post donation.
- Hospitalisation leave (HL) will be provided for the donation (Stage 3).
- I can request for BMDP to provide a letter to my school/employer to inform them about my participation in the programme.

Conversation tip: Share with your donor management representative about your schedule and they can help you draft a plan where you can share with your parents to put them at ease.

Q: Is this going to cost us anything?

- All medical expenses related to the donation will be covered by BMDP.
- Travel expenses incurred will also be reimbursed.
- Loss of income will not be compensated.

Q: Are you covered under insurance?

- BMDP covers donors for the extremely rare event of coma, disablement or death related to the donation.
- Should I require any medical attention for any condition related to the donation, all medical costs will be covered by BMDP.

Q: Can I accompany you for the donation?

Yes, I am encouraged to bring one companion along for the donation journey. Expenses will be covered for me and one companion.