



Bone Marrow & Peripheral Blood Stem Cell Donors' Booklet

Asia-Pacific Blood and Marrow Transplantation Group (APBMT)
Donor Safety Working Group

Table of Contents

Preface	1
1. How to use this booklet	2
2. Donor's (your) information	3
3. Contact information.....	4
a) Related donors (donation to family member).....	4
i) In case you need to contact the harvest facility	4
ii) In case the harvest facility needs to contact you	4
b) Unrelated donors (donation through the Blood and Marrow Donor Bank)	4
i) In case you need to contact the harvest facility	4
ii) In case the Marrow Donor Program Office or harvest facility needs to contact you	5
4. For the information of other medical personnel	6
5. Schedule for bone marrow donation.....	9
6. Schedule for peripheral blood stem cell donation	10
7. How to prepare for donation.....	11
8. Procedure of bone marrow donation	13
a) Precautions for autologous blood collection	13
i) Before collection	13
ii) On the day of collection	13
iii) After collection	13
b) How bone marrow is harvested.....	14
c) Possible complications of harvesting and anesthesia	15
d) Precautions after donation.....	15
e) Follow-up system and donor casualty insurance	15
9. Procedure of peripheral blood stem cell donation	16
a) How peripheral blood stem cell transplantation is done.....	16
b) G-CSF injection	16
i) Possible side effects associated with G-CSF injection	16
ii) Precautions during G-CSF injection on an outpatient basis.....	17
c) Precautions to be taken previous to/on the days of donation	18
d) Possible symptoms during donation.....	19
e) Precautions in everyday life after donation	19
i) Possible symptoms soon after donation.....	19
ii) Precautions soon after donation.....	19
iii) Precautions in the first month after donation.....	20
f) Follow-up system and donor casualty insurance	20

Preface

Bone marrow and peripheral blood stem cell transplantations are increasing each year as treatment methods that offer hope for a cure. These procedures have become essential for patients with difficult-to-treat diseases for which a complete cure by drugs or other means is unlikely.

Both bone marrow transplantation and peripheral blood stem cell transplantation require healthy donors and it is essential to maintain donor safety.

Asia-Pacific Blood and Marrow Transplantation Group (APBMT) and Donor Safety Working Group are committed to saving the lives of those who are struggling with difficult-to-treat diseases.

Asia-Pacific Blood and Marrow Transplantation Group (APBMT)
Donor Safety Working Group

1. How to use this booklet

- ◆ This booklet is to be provided to people who have decided to donate bone marrow or peripheral blood stem cells.
- ◆ When you receive this booklet, please read it completely and fill in your contact information as well as schedule for donation.
- ◆ As this booklet includes important information regarding bone marrow or peripheral blood stem cell donation, please read the contents carefully.
- ◆ Keep this booklet as both, a record of your donations and a health management tool.
- ◆ Every time you have a medical examination or health check-up at a medical institution, please show this booklet at the reception desk or to the doctor and tell them that you are/were a bone marrow or peripheral blood stem cell donor.
- ◆ This booklet contains important information related to your own health, so please be careful not to lose it. Please preserve this booklet with your health check-up records and other information you may have from before and after your bone marrow or peripheral blood stem cell donation.



2. Donor's (your) information

Name: _____

Address: _____

Telephone number: _____ () _____

Mobile phone number: _____ () _____

Blood type: ABO _____ Rh _____

Past medical history: _____

Do you have any allergies?: No Yes (Causes: _____)

Emergency contact information

Name: _____ (Relationship: _____)

Address: _____

Telephone number: _____ () _____

Mobile phone number: _____ () _____

3. Contact information

a) Related donors (donation to family member)

i) In case you need to contact the harvest facility

Please contact the doctor-in-charge mentioned below in case you notice anything different regarding your health either before or after bone marrow or peripheral blood stem cell donation.

<ul style="list-style-type: none">● Harvest facility Name of the facility: _____ Address: _____ Telephone number: _____

<ul style="list-style-type: none">● Doctor-in-charge Name of the doctor: _____ Affiliation: _____ Contact information: _____
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ii) In case the harvest facility needs to contact you

The harvest facility may need to contact you immediately to inform you of the patient's condition or for some other reason. Please provide the doctor-in-charge with your contact information beforehand.

b) Unrelated donors (donation through the Blood and Marrow Donor Bank)

i) In case you need to contact the harvest facility

Please contact the doctor-in-charge or the Marrow Donor Program below if you notice anything different regarding your health before or after bone marrow or peripheral blood stem cell donation.

Please fill in this information yourself.

● Marrow Donor Program Office

Telephone number: _____

FAX number: _____

*When contact is necessary during nights or weekends, please contact the harvest facility.

● Coordinator

Name: _____

Telephone number: _____

● Harvest facility information

Name of the facility: _____

Address: _____

Telephone number: _____

● Doctor-in-charge

Name of the doctor: _____

Affiliation: _____

Contact information: _____

- ii) In case the Marrow Donor Program Office or harvest facility needs to contact you

The harvest facility may need to contact you immediately to inform you of the patient's condition or for some other reason. Please provide the doctor-in-charge /coordinator/ Marrow Donor Program Office with your contact information beforehand.

4. For the information of other medical personnel

This booklet is distributed to people who have decided to donate bone marrow or peripheral blood stem cells (PBSCs) to a related or unrelated patient. It contains records of donations. By showing this booklet to medical professionals whenever and wherever they get medical attention, donors can inform them that they have donated bone marrow or PBSCs.

Please utilize the information in this booklet to understand your patient's (donor's) health status, which could be useful for their examination and treatment.

What is Hematopoietic Stem Cell Transplantation?

- a) Hematopoietic stem cells, which form white blood cells, red blood cells, and blood platelets, are normally present in the bone marrow. However, a few hematopoietic stem cells are also found in the peripheral blood (the blood that circulates throughout the body). It has been observed that, when granulocyte-colony stimulating factor (G-CSF), an agent that facilitates an increase in the production of white blood cells, is injected into the body, the number of hematopoietic stem cells increases in the peripheral blood as well. Therefore, there are two sources to harvest PBSCs from the body: bone marrow and peripheral blood. Bone marrow transplant is a therapy in which hematopoietic stem cells taken from the donor's bone marrow are transplanted into the patient. Peripheral blood stem cell transplantation (also known as PBSCT) is a therapy in which hematopoietic stem cells harvested from the donor's peripheral blood are transplanted into the patient.
- b) Leukemia, aplastic anemia, and immunodeficiency disease cause abnormalities in the hematopoietic stem cells, thus hindering those cells from creating normal white blood cells. This leads to anemia and immunodeficiency.
- c) Bone marrow/PBSC transplants are therapies that replace diseased hematopoietic stem cells with healthy cells. Although some of these diseases can be cured using chemotherapy or immunosuppressants, several patients require a bone marrow or PBSC transplant. Major hematopoietic stem cell diseases include leukemia, myelodysplastic syndrome, malignant lymphoma, severe aplastic anemia, immunodeficiency, and some types of congenital metabolic disorders.

- d) Of all the hematopoietic stem cell allograft cases around the world, nearly 300,000 bone marrow/PBSC transplants have been conducted thus far between blood relatives and unrelated individuals.
- e) Those who donate healthy bone marrow aspirate are bone marrow donors, and those who donate hematopoietic stem cells are PBSC donors. The harvest methods greatly differ. The hematopoietic stem cells harvested from the donor are slowly injected into the patient's vein through the intravenous system over a period of several hours.
- f) Systemic radiation therapy and a large amount of anticancer drugs are given to the patient prior to the transplantation procedure for a period of one to two weeks. This destroys not only the diseased cells but also normal hematopoietic stem cells. This procedure is called transplantation conditioning (i.e. pretreatment). After the pretreatment, the number of white blood cells in the blood decreases significantly, thus causing the patient to lose resistance and become more prone to infection. For this reason, the patient must spend his/her time in a sterilized aseptic room, which maintains a flow of clean air without dust or bacteria.
- g) For the patient, timing of the transplantation is an important point to be considered and is carefully determined by observing the patient's disease status. It is also necessary to arrange for an aseptic room, which may have limited availability, as well as the schedules of facility staff.
- h) Even after transplantation, the patient could die during the early post-operative stage due to graft rejection, a graft-versus-host disease, whereby the transplanted lymphocytes attack the patient's body or due to a severe infection. Moreover, there is a chance that the patient's original disease such as leukemia may recur even though the donor's hematopoietic stem cells have been successfully transplanted and the patient has recovered. Therefore, it is not guaranteed that a patient will be cured after a bone marrow or PBSC transplant.
- i) Bone Marrow/PBSC Transplant (Bone Marrow Harvest) procedure:
Once anesthesia is given to the donor, an injection needle whose thickness is similar to that of a ballpoint pen filler is inserted into the donor's ilium (the pelvic bone) to aspirate the bone marrow.

* Bone marrow is a spongy hematogenous tissue present within the bone cavity and contains hematopoietic stem cells, which continuously produces red blood cells, white blood cells, and blood platelets that subsequently enter the blood stream. The bone marrow has no relation with the spinal cord (the nervous system).

- j) Bone Marrow/PBSC Transplant [PBSC Harvest] procedure:
G-CSF is injected hypodermically into the donor for a period of four to six consecutive days. On the 4th or 5th day after initiation of the injection, once the number of hematopoietic stem cells in the peripheral blood begins to increase, PBSCs are harvested using a blood component separator and then used for transplantation.



5. Schedule for bone marrow donation

Event	Date and time	Note
Preoperative check-up	Date (year/month/day): Time: AM/PM	
Autologous blood collection (1 st)	Date (year/month/day): Time: AM/PM	
Autologous blood collection (2 nd)	Date (year/month/day): Time: AM/PM	
Admission	Date (year/month/day): Time: AM/PM	
Bone marrow donation	Date (year/month/day): Time: AM/PM	
Planned discharge date	Date (year/month/day): Time: AM/PM	
Postoperative check-up	Date (year/month/day): Time: AM/PM	

6. Schedule for peripheral blood stem cell donation

Event	Date and time	Note
Preoperative check-up	Date (year/month/day): Time: AM/PM	
1 st G-CSF injection	Date (year/month/day): Time (1): AM/PM Time (2): AM/PM	
2 nd G-CSF injection	Date (year/month/day): Time (1): AM/PM Time (2): AM/PM	
3 rd G-CSF injection	Date (year/month/day): Time (1): AM/PM Time (2): AM/PM	
4 th G-CSF injection PBSC harvest Yes No	Date (year/month/day): Time: AM/PM	
5 th G-CSF injection PBSC harvest Yes No	Date (year/month/day): Time: AM/PM	
6 th G-CSF injection PBSC harvest Yes No	Date (year/month/day): Time: AM/PM	
Postoperative check-up	Date (year/month/day): Time: AM/PM	

7. How to prepare for donation

(For both related and unrelated donors of bone marrow and PBSCs)

Precautions regarding your daily life and health before donation:

- Please take the various precautions as informed by the harvest facility.
- Report any previous disease or symptoms as soon as possible. If you remember any conditions while undergoing treatment, that you have not previously reported, please contact your doctor as soon as possible. Note that doctors initiate preconditioning treatment to the patient approximately one week before the harvest. Please contact your doctor just to be safe if you feel something is wrong.
- Please contact your doctor if your health check-up reveals any abnormality.
- Take care not to catch a cold. Please contact your doctor as soon as possible if you are in poor physical condition.
- Get sufficient sleep. Don't forget to get adequate sleep and avoid overwork.
- Drinking alcohol can affect liver function. Avoid excessive drinking as well as overeating. Don't smoke before harvest!
- As bone marrow or PBSC donation is physically demanding, it is important to take sufficient nutrition.
- Women who are pregnant or breastfeeding are not allowed to donate. (Please do not take contraceptive pills for four weeks before donation.)
- Please do not donate blood before bone marrow or PBSC donation. You can donate blood only **six months after** donation if no abnormalities are detected in blood tests.
- Do not engage in activities causing muscle strain (weight training, physical activity that places a burden on muscles, etc.) for two weeks before donation as well as one week before the health check-up for donation. *Over-exercising may result in abnormal results from blood tests. In case you cannot avoid such activity, please consult your doctor.
- In order to monitor the donor's health status during donation, donors are asked to avoid nail art (nail polish, false fingernails, etc.) during donation.

- Please consult a doctor before taking any treatment. Results from blood tests may be affected by certain medicines. Please consult a doctor not only when taking medicine prescribed at another hospital, but also when taking herbal or over-the-counter medicines.



8. Procedure of bone marrow donation

(For both related and unrelated donors)

a) Precautions for autologous blood collection

i) Before collection

- Abstain from alcohol and get sufficient sleep on the night before blood collection.

ii) On the day of collection

- Do not skip breakfast.
- To prevent traffic accidents, do not come to the hospital by motorcycle or scooter.

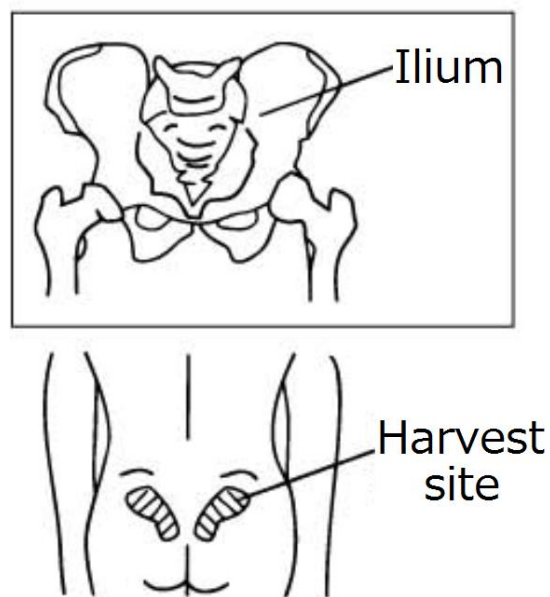
iii) After collection

- Apply pressure to the blood collection site, but do not rub.
- Drink water after blood collection to prevent dehydration.
- If you feel dizzy or lightheaded, lie down with your feet at a level higher than that of your head.
(If you are in the hospital, ask a hospital staff member to call the doctor in charge of the blood collection.)
- If any symptoms continue, please contact the doctor in charge of the blood collection, even if you are no longer in the hospital.
- Even if you do not feel unwell and have no physical problems after blood collection, please take a complete rest on the day of blood collection.
- If you are concerned about internal bleeding, swelling, pain, etc., please contact the doctor in charge of the blood collection.
- Try to eat iron-rich food (liver, soy beans, egg yolk, *hijiki* [brown algae], spinach, etc.)
- On the day of the blood collection, avoid heavy exercise and long baths.
- It is okay to take a shower with warm water. Remove the wet adhesive plaster (bandage).

If you have been prescribed an iron supplement, take the supplement just the way your doctor advises you to. When you take an iron supplement, your stool may become dark. There is no need for concern. However, please contact the doctor in charge of the blood collection if you have continuous loss of appetite or nausea.

b) How bone marrow is harvested

- Bone marrow is harvested under general anesthesia, in principle. After the preparations for anesthesia, a tube for the mechanical ventilator (tracheal tube) is inserted through your throat. A narrow tube (catheter) may be inserted into your urethra to direct urine out of the body.
- Bone marrow is harvested from your ilium (pelvic bone) while you lay face-down. A bone marrow needle (about the size of the core of a ballpoint pen) is inserted through the skin and several milliliters of marrow are drawn into a syringe at one time.



- The total amount of harvested bone marrow is fixed such that it does not cause any strain to the donor. The ability to produce blood is not influenced by bone marrow harvest.
- The harvest procedure takes approximately 2 to 4 hours from entering to leaving the operating room.

c) Possible complications of harvesting and anesthesia

Temporary	Blood pressure reduction, arrhythmia
After the harvest	Hematoma in the retroperitoneum or iliolumbar section Serum hepatitis C
Long-term	Pain or numbness in the harvest site
Others	Malignant hyperthermia, front tooth damage, needle breakage, urethral injury, thrombosis, laryngeal granuloma, pulmonary fat embolism

Cited from the “Explanatory Booklet for Prospective Bone Marrow Donors” (Japan Marrow Donor Program)

d) Precautions after donation

- Follow the instructions of the doctor-in-charge, regarding all aspects of your daily life after donation, including showering, bathing, as well as returning to work.
- Keep the puncture sites clean, for up to a week after bone marrow donation.
- Avoid strenuous exercise such as participating in a marathon or swimming for one week after donation.

e) Follow-up system and donor casualty insurance

The follow-up system after donation and donor accident insurance may vary across countries/regions. Please ask your doctor-in-charge about these matters in your country/region/institute.

9. Procedure of peripheral blood stem cell donation

(For both, related and unrelated donors)

a) How peripheral blood stem cell transplantation is done

- To harvest a sufficient amount of hematopoietic stem cells from peripheral blood (blood flowing in the body), G-CSF (an agent that increases white blood cells [WBC]) is injected subcutaneously for 4 to 6 days.
- PBSCs are harvested on the 4th or 5th day after the start of G-CSF injection (the timing for starting harvest differs depending on the donor's WBC count). On the day of harvest, PBSC harvest is conducted after approximately 3 to 4 hours of subcutaneous G-CSF injection.
- Thick veins in your arms (or one arm) are punctured with the injection needles for blood collection and reinfusion.
- In case a thick vein cannot be found on the day of harvest, a flexible tube called a catheter is inserted into a femoral vein (the area of the groin; this is called femoral vein access). This method may cause bleeding or infection. If these complications occur, appropriate measures should be taken.
- Peripheral blood stem cells are harvested using a blood component separator (about 3–4 hours). The donor cannot move either arm during the procedure.
- When a sufficient amount of PBSCs are harvested in the first attempt (4th or 5th day of G-CSF injection), you will leave the hospital after confirming no adverse effect on your physical condition. If the amount of PBSCs in the first attempt is insufficient, G-CSF will be injected again the following day and a second harvest will be attempted.

b) G-CSF injection

i) Possible side effects associated with G-CSF injection

Side effects during and soon after administration of G-CSF	Temporary	<u>Low back pain, bone pain, back pain, joint pain, muscle pain, headache*</u> ; blood pressure reduction, rash, erythema, nausea, vomiting, fever, fatigue, loss of appetite, palpitations
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		liver dysfunction, elevated uric acid, kidney dysfunction (elevated serum creatinine)
	Serious side effects	Shock possibly due to allergy to G-CSF, interstitial pneumonia, angina attack, cerebrovascular disorder, spleen rupture, acute iritis, exacerbation of gouty arthritis or other inflammation
Long-term side effects	<u>Long-term safety (several decades or more) has not been confirmed, and scientific data are currently being collected.</u> One case was reported in which a related donor developed acute myeloid leukemia about one year after donating peripheral blood stem cells and died (February 2003). However, from subsequent surveys in Japan and other countries, it is thought that the concern of increased risk of leukemia with injection of G-CSF can be excluded.	

*Cited from “Guidelines for Peripheral Blood Stem Cell Mobilization and Collection from Healthy Donors for Allogeneic Peripheral Blood Stem Cell Transplantation (Japan Society for Hematopoietic Stem Cell Transplantation, Japan Society of Transfusion Medicine and Cell Therapy)”

*Pain from temporary side effects disappears with pain medication.

ii) Precautions during G-CSF injection on an outpatient basis

The following side effects may occur during G-CSF administration. Please watch your health closely.

- **Fever**
- **Rash**
- **Palpitations**
- **Chest pain**
- **Leg swelling**
- **Low back pain**
- **Bone pain**
- **Joint pain**
- **Headache**
- **Loss of appetite**
- **Nausea/vomiting**
- **Fatigue**
- **Lightheadedness**
- **Difficulty sleeping**

Severe side effects are rare, but please carry this booklet with you while receiving G-CSF injections on an outpatient basis, and check whether you have the following symptoms. In the event that one of these symptoms occurs, contact the harvest facility. In urgent cases, seek emergency medical care. At that time, you (the donor) or a family member should show this booklet to the medical personnel and inform them that you are receiving G-CSF injection.

Symptoms	1 st day	2 nd day	3 rd day	4 th day
• Breathing difficulty				
• Severe chest pain				
• Fever of 39°C or higher				
• Rash over the entire body				
• Intense dizziness or light-headedness				
• Severe fatigue which makes it difficult to go about daily life				
• Severe pain and swelling at the injection site				
• Severe pain (low back pain, bone pain, headache, joint pain, etc.) such that you cannot sleep even after taking a painkiller				
• Feeling unwell and not being able to take in food				
• Vomiting 2 or more times a day				

c) Precautions to be taken previous to/on the days of donation

- On the night before donation, please abstain from alcohol and get sufficient sleep.
- On the day of donation, be sure not to skip breakfast (avoid fatty food from the evening of the previous day before to the morning of the day in order to prevent increase in blood fat).
- To prevent traffic accidents, do not come to the hospital by motorcycle or scooter.
- People who are nervous or anxious, feeling a strong sense of hunger, or wearing tight clothing (such as tight underwear, belt, corsets, controlling undergarments, bodysuits, and so on) may get sick during the donation.
- Please wear loose-fitting clothes that can be easily taken off and put on to regulate your body temperature.
- You will be attached to the machine for 3 to 4 hours during the donation, so please go to the restroom just before the donation begins.

d) Possible symptoms during donation

Symptoms that may occur while PBSCs are being withdrawn	General fatigue, <u>numbness of the hands and feet, numbness around the mouth,*</u> dizziness, nausea, vomiting and decreased blood pressure associated with the vasovagal reflex
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*An anticoagulant is added to prevent clotting of collected peripheral blood. Numbness of your hands, feet or around the mouth appears by the effect of this agent. If these symptoms appear, please inform your doctor or a nurse immediately. Symptoms will be relieved with the use of a calcium preparation.

e) Precautions in everyday life after donation

i) Possible symptoms soon after donation

Symptoms that may occur soon after donation	Swelling of the puncture site Thrombocytopenia (bleeding tendency may be seen)*
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*Thrombocytopenia (platelet depletion) occurs when platelets are collected at the same time during peripheral blood stem cell harvest. If the platelet count is below the reference value after the harvest, the platelet component will be separated from the harvested peripheral blood and returned to the body by drip infusion.

ii) Precautions soon after donation

- Apply pressure to the harvest site but do not rub. Follow your doctor's directions.
- After the donation, do not lift heavy loads or put excessive strain on your arm.
- The puncture site may become blue and swollen. This will disappear within one to three weeks. If you have any particular concern, please consult your doctor-in-charge.
- Follow your doctor's instructions regarding returning to your daily life activities and work.
- To prevent dehydration, drink sufficient water after the donation. Try to have an adequate diet and go to bed early.
- Avoid smoking soon after the donation.
- Follow the advice of your doctor regarding showering and bathing.
- Avoid strenuous exercise such as participating in a marathon or swimming for one week after the donation.
- If pain persists or you do not feel well, contact your doctor-in-charge as soon as possible.

iii) Precautions in the first month after donation

The following side effects may occur during the first month after PBSC donation. Please watch your health closely.

- **Headache**
- **Chest pain**
- **Bleeding tendency**
- **Swelling of legs**
- **Fever**
- **Symptoms of anemia (light-headedness, dizziness)**

Please check whether you have the following symptoms. Contact the harvest facility if you have any of these symptoms. In urgent cases, seek emergency medical care. At that time, you (the donor) or a family member should show this booklet to the medical personnel, and inform them that you have donated PBSCs.

Symptoms	1 st week after donation	2 nd week after donation	3 rd week after donation	4 th week after donation
• Severe headache that does not improve even with pain medication				
• Severe chest pain				
• If you bleed easily and it is difficult to stop				
• Fever of 39°C without symptoms of a cold				
• Severe dizziness or light-headedness				
• Severe pain and swelling at the puncture site				
• Feeling unwell and not being able to take in any food				

f) Follow-up system and donor casualty insurance

The follow-up system after donation and donor accident insurance may differ across countries/regions. Please ask your doctor-in-charge about these matters in your country/region/institute.

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