

Leukemia / Bone Marrow Transplant (BMT) Program of British Columbia

Patient Education Manual







UNIVERSITY OF BRITISH COLUMBIA



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## L/BMT Patient Education Manual • Donor Module

## Introduction

We would like to help donors and their families learn about the stem cell and marrow donation process. With this information, we hope you will find the procedure less stressful and frightening. There are many caring and knowledgeable people on your health care team to help you through this experience. Please do not hesitate to speak to them!

## Important Numbers

Hematology Apheresis Unit Centennial Pavilion, 6<sup>th</sup> Floor, Vancouver General Hospital Nursing Unit: 604-875-4626 After hours: 604-875-4343 Ask to speak to the Donor Physician

Donor Physician - Leukemia/Bone Marrow Transplant Office: 604-875-4863 After hours: 604-875-4343

Ask to speak to the Donor Physician

## Introduction

## **Donor Selection Process**

## **Selection Criteria**

### Human Leukocyte Antigen – HLA

Human leukocyte antigen (HLA) typing is used to match patients and donor for blood and marrow transplant. HLA are proteins – or markers – found on most cells in the body. The body's immune system uses these markers to recognize which cells belong to the body and which do not.

A close match between the patient's HLA markers and the donor's can reduce the risk that the patient's body will attack the donor cells or that the donor cells will attack the patient's cells after the transplant.

### **HLA Matching**

A well-matched donor is important to the success of the transplant. There are many HLA markers. The best case scenario is that 10 out of 10 HLA markers will match. These requirements are based on research studies of transplant outcomes.

#### Other Factors in Determining a Match

To select the best possible donor or if there is more than one donor, the doctor will look at other factors such as the donor's age, gender, blood type, size, health, number of pregnancies in a female donor or whether the donor tests positive for a common virus called CMV. All of these factors are known to affect the transplant outcome. For example:

- 1. If a patient has more than one 10/10 match donor, a male or a female that has never been pregnant is preferred.
- 2. If multiple matches are available, the youngest donor will usually be selected after taking into consideration the donor's health and prior exposure to common viruses.

## **Testing & Procedures**

### **HLA-Match Testing**

HLA testing to determine whether individuals are a good match only requires blood tests to be done. A bone marrow biopsy is not required. At the testing stage, the potential donor does not have to come to Vancouver. Testing can be performed at the donor's closest laboratory, and the blood will be sent by courier to Vancouver. The BMT Coordinators will arrange this and the Leukemia/BMT Program will cover all courier and testing costs.

Potential donors, patients and families need to be aware that HLA test results may take up to three weeks to process. It is also important to note that the patient and donor may still be a good match, even if they do not share the same blood type. Blood type and HLA type are completely different.

### **Preliminary Tests for Donors**

All identified donors will need pre-collection diagnostic tests. These will include a screening blood test for hepatitis viruses and HIV (the AIDS virus), urine tests and a medical history and physical examination by a physician. For donors over 40 years of age, a chest X-ray and an electrocardiogram

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(ECG) are often done. Note that these tests can be done in the donor's home town as long as the results are in English. Donors do not need to come to Vancouver for pre-collection tests unless there are specific tests required.

For donors having a bone marrow harvest, an anaesthetist will also see the donor upon his/her arrival in Vancouver to review his/her medical history, conduct a physical examination and to discuss the method of anaesthesia. Anaesthetic is usually a general but freezing from the chest down (spinal anaesthetic) can also be used.

#### Stem Cell Collection or Bone Marrow Harvest Procedure

All stem cell collection or bone marrow harvest procedures must be done in Vancouver. So if a donor is found to be an HLA match and is asked to donate stem cells or bone marrow, he/she **must** come to Vancouver for the procedure. The Bone Marrow Transplant Coordinators' office will be in touch with the donor to arrange this. The donor's health care costs relating to the collection of bone marrow/stem cells will be covered by the Province of British Columbia (except in exceptional circumstances). Unfortunately, travel, accommodations and living expenses will not be covered. These will be the donor's responsibility. For more information, please contact the Bone Marrow Transplant Coordinators office at 604-875-4863.

## **Stem Cell Basics**

## What are stem cells?

Blood cells grow in the same way as other human cells. They develop in the bone marrow from a parent cell known as a stem cell. Stem cells are immature cells that can develop into all of the different types of blood cells: white blood cells, red blood cells and platelets. Stem cells are usually found inside the bone marrow spaces of large bones. They can also travel from one bone to another by way of the blood stream.

In a blood and marrow transplant, stem cells are harvested, either from the large bones or from the blood stream, and transplanted to the patient. Stem cells collected from the pelvic bone in the lower back are called bone marrow. Stem cells harvested from the blood in the veins are called peripheral blood progenitor cells. This is why blood and marrow transplants are often referred to as blood stem cell transplants. For simplicity, we will use the terms bone marrow and stem cells interchangeably in this booklet.

Your BMT doctor will discuss how stem cells will be collected from you.

## How are stem cells collected?

There are two different methods to collect stem cells.

- 1. Peripheral Blood Stem Cell Collection. Stem cells can be collected from the blood. This procedure is called a peripheral blood stem cell collection. This technique does not require surgery. It does, however, involve a few more steps than a conventional bone marrow harvest. Prior to the collection, the donor is given a medication to promote the growth and release of stem cells from the bone into the blood. The stem cells are then collected using a special machine called a Cell Separator. This technique has dramatically increased in popularity over the last ten years. Stem cells are generally collected using this method here at the Leukemia/BMT Program of BC.
- 2. Bone Marrow Harvest. Stem cells can be collected directly from the bone marrow spaces, most often from the pelvic bones. Several puncture sites are made along the bone and the cells are removed using a needle. This procedure is known as a bone marrow harvest. This technique is used less often here at the Leukemia/ BMT Program of BC.

## **Peripheral Blood Stem Cell Collection – In Depth**

A peripheral blood stem cell collection generally follows the three steps below.

- I. Vein assessment
- 2. G-CSF administration
- 3. Actual collection of peripheral blood stem cells

## **Vein Assessment**

#### What to Expect

A vein assessment is necessary to ensure that the donor has strong veins with good blood flow for the blood stem cell collection procedure.

An appointment will be made for you to go to the Vancouver General Hospital Hematology Apheresis Unit, also referred to as the HAU. The HAU is located at the Krall Centre on the 6<sup>th</sup> floor of the Centennial Pavilion. On your first visit to the HAU, you will be given a tour of the unit. The process of stem cell collection will be explained and shown to you.

> A nurse will check your arm veins located in the elbow area to ensure that they can be used for the stem cell collection procedure. The Cell Separator machine needs a certain amount of blood flow in order to work properly. Therefore, a strong vein with good blood flow is needed.

> > If the veins are too small or delicate, the insertion of a temporary intravenous line called a "St Paul's Catheter" may be necessary. A St. Paul's Catheter is a small plastic tube that is placed into a large vein located in the side of the neck. Sometimes it is necessary (but rare) to place the St. Paul's Catheter in the large groin vein, which drains the blood from the legs. This tube allows the blood to be easily removed and returned to your body. If you require a St. Paul's Catheter, the nurse will make an appointment for you with the Angio-Radiology Department. The St. Paul's Catheter will be inserted the day before or the day of the stem cell collection. The catheter will be removed after the collections are completed.

The nurses and doctors at the HAU wish to make the collection experience as stress-free and comfortable as possible. Please let them know if there is anything they can do to assist you in this.

## **G-CSF Administration**

#### Frequently Asked Questions - FAQs

#### What is G-CSF?

G-CSF is a colony stimulating factor. Colony stimulating factors are naturally occurring special proteins in the human body that stimulate blood cell production and growth. G-CSF helps increase the number of stem cells in your blood stream.

These naturally occurring proteins can also be manufactured as a drug. The G-CSF used in our Program is Neupogen®. The generic name is filgrastim.

#### Why is G-CSF given?

In order to limit the number of times you have to undergo stem cell collection, the BMT doctor will try to move your stem cells out of your bone marrow and into your blood stream. This process is called **mobilization**. The G-CSF you will receive will encourage the growth of stem cells in your body and mobilize them into your blood stream for collection.

#### How will it help my sibling?

**Engraftment** is the process by which infused stem cells grow in the bone marrow and manufacture new blood cells. Engraftment is the indication that the new stem cells are working properly. Research has shown that stem cells that have been mobilized engraft faster than stem cells collected directly from

the bone marrow.

lf you are a donor, G-CSF will be administered at no cost to you.

#### How much does G-CSF (Neupogen®) cost?

If you are a donor, G-CSF will be administered at no cost to you.

#### How is G-CSF given?

G-CSF will be administered daily by injection through a tiny needle under the skin. Arrangements will be made for you to receive your injections either in the Hematology

Apheresis Unit, the Leukemia/BMT Daycare Unit or if you prefer you may arrange to have them given at your family doctor's office or walk-in clinic near your home.

Generally, you will take G-CSF for 4 days and there will be 2 stem cell collections.

#### What should I expect when injecting G-CSF?

When G-CSF is injected, you may feel a slight stinging sensation at the injection site. Sometimes, injecting into a larger surface area such as the abdomen or injecting the medication slower can reduce the stinging. If you experience some pain or redness at the injection site, it should go away soon. If it does not, contact

the Donor Physician at the Leukemia/BMT Program at 604-875-4863 or 604-875-4343 (24-hours).

Sometimes a "bump" occurs at the injection site. **Do not rub it.** The bump will often go away within a few hours. If the bump persists for more than a few hours, contact the Donor Physician at the Leukemia/BMT Program at 604-875-4863 or 604-875-4343 (24-hours).

A small amount of medication can sometimes leak out at the injection site when the needle is withdrawn. If it does, simply apply light pressure with an alcohol swab, but do not rub the area.

Other drugs may interact with G-CSF. It is important that you tell the doctor if you are taking any other medications. This includes over-the-counter drugs, naturopath/herbal remedies, vitamins, teas, etc. Inform your doctor even if you only take these occasionally.

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#### What are the side effects of G-CSF?

Generally, G-CSF is well tolerated. Some donors have experienced discomfort that is usually reported as headache and/or aching in the bones, most often in the back and hips. If you feel discomfort, please contact the Donor Physician for advice on how best to relieve it. Be sure to tell the Donor Physician if you experience any symptoms that concern you while you are taking G-CSF. The Donor Physician can be reached at 604-875-4863 or 604-875-4343 (24-hours).

Never take a medication for a side effect, or for anything else, unless your nurse or doctor recommends it.

## The Collection of Peripheral Blood Stem Cells

#### What to Expect

Your stem cells will most likely be collected by a procedure called **apheresis** (a-fair-ee-sis). Two ends of tubing will connect you to a cell separator machine during the collection. Your blood will flow out of one arm, inside the tubing, to the machine where it will spin your blood around at high speed. The spinning separates the different components of the blood into layers based on their weight. The stem cell layer will then be collected and the remaining blood will be returned to you via the other arm. The blood always stays inside the tubing set. The tubing and needles are sterile. They are used only once and then discarded.

You will be attached to the cell separator machine for 4–6 hours for each collection. There will be nurses and technicians present for the entire time. During the procedure it is necessary for you to stay in bed. Each bed area has a television set to help you pass the time. You may also have a friend stay with you.

#### Side Effects During the Apheresis Procedure

The apheresis procedure is safe. However, there are some side effects you may experience and should be aware of:

- If you have an IV (intravenous) needle in the inside elbow region of your arm(s) you
  will need to keep your arm(s) straight during the procedure. Sometimes this can
  be uncomfortable. Please let the nurses know so that they can assist you in getting
  as comfortable as possible.
- The flow of blood from your veins can sometimes be slow and variable. In this case, the nurses may ask you to squeeze your hands to increase blood flow, change your arm position, or the nurses may adjust the lines or machine. Occasionally a needle will have to be replaced in order to get better blood flow.

 Changes in blood volume may make some people feel dizzy or light-headed. You should tell the nurses immediately if you feel anything like this.

• An anticoagulant (anti-clotting) drug is mixed with your blood as it enters the machine to keep it from clotting during the procedure. This may cause a sour taste in your mouth. The anticoagulant can also lower your blood calcium and you may experience lightheadedness, nausea, muscle cramping, and/or a tingling feeling around the lips, hands or feet. You should tell the nurses immediately if you feel any

of these symptoms. Oral or intravenous calcium will bring quick relief of these side effects.

• You may start to feel cold during the procedure. If you feel chilled, please let the nurses know. They can give you extra blankets and heating pads to keep you warm and comfortable.

## **Frequency of Stem Cell Collections**

The goal is to collect enough cells for one transplants. The BMT physician will have discussed this with you prior to the collection. The targeted cell collection is usually achieved in 1 to 2 days. Occasionally a third day of collecting is required. The number of stem cell collections needed largely depends on the patient's weight and the donor's response to the G-CSF and the apheresis procedure.

Immediately after the apheresis procedure is completed, specimens are obtained from the bag of collected

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You

stem cells. These are sent as soon as possible to a special lab where the sample will be studied and the actual stem cell count will be determined. Results of this analysis will usually be completed by 4:00 pm that same day. Once the actual count is known and reviewed by the doctor, you will be notified as to whether more stem cell collections are needed on subsequent days.

## Processing the Stem Cell Collection

#### Freezing

In some cases, the transplant will not take place right away. In order to preserve the stem cells, they will need to be frozen. This process is called cryopreservation. Shortly after the stem cells are collected, they are sent to a special lab called the Clinical Cell Therapy Lab. There, the stem cells will be concentrated and a preservative will be added to protect the cells from the freezing process. They will then be stored in a special freezing vault until the time of transplant.

#### Refrigeration

Sometimes, the stem cells will be transplanted shortly after they are collected. In this case, the stem cells will be refrigerated and given within I to 2 days of the collection.

## When to Call the Doctor

If you have any symptoms that worry you or if you are concerned with any aspect of the stem cell collection, do not hesitate to contact the Donor Physician.

If the following signs and symptoms occur, contact the Donor Physician immediately:

- Have a fever of 38°C (100°F) or higher
- Have chills
- Develop a rash or symptoms of an allergic reaction
- · Pain when urinating
- Are bleeding, or have a problem such as a lump, swelling or bruising at the injection site that doesn't go away

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• Are bleeding, or have a problem such as a lump, swelling or bruising at the injection site that doesn't go away

• Notice anything unusual about your condition

The Donor Physician can be reached at 604-875-4863 or 604-875-4343 (24-hours). • Notice anything unusual about your condition

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## **Important Reminders**

#### Things to keep in mind:

- I. The Hematology Apheresis Unit (HAU) can be reached at 604-875-4626.
- 2. The Donor Physician can be reached at 604-875-4863 or 604-875-4343 (24-hours).
- Appointment times for stem cell collections at the HAU are usually between 8:00 am and 9:00 am.
- 4. The entire process can take up to 4–6 hours from start to finish. This makes for a very long day. You may wish to bring your own lunch and snacks. The HAU can provide juice, cookies and a limited selection of sandwiches.
- 5. It is very important that you have breakfast before coming to the unit, preferably one that is rich in calcium. Do not drink coffee or tea before the procedure, as you will not be able to get up to use the washroom once you are hooked up to the machine.
- 6. Please use the washroom facilities in the HAU just before the procedure begins. If you need to go to the bathroom during the procedure, bedpans are available. A nurse will help you with this. It is recommended that you wear comfortable and loose fitting clothing (i.e., pants with an elastic waistband may make things easier).

It's very important that you have breakfast before coming to the unit, preferably one that is rich in calcium

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7. You will have your own television available for your use during the apheresis procedure. Also, unless you have a St. Paul's Catheter, reading materials would be inappropriate to bring, as you will not have the use of your arms.

8. Once the procedure has started, the nurses will allow one visitor to stay with you.

9. It is very important to notify the nurses right away if you feel lightheaded, dizzy, nauseated, cold, or have tingling around the lips, fingers or toes, during the procedure. Slowing or stopping the procedure for a short time can sometimes resolve some of these symptoms.

## **Frequently Asked Questions**

If I come from out-of-town, will my travel, accommodation and living expenses be covered?

Unfortunately, these expenses will not be covered and will be the donor's responsibility.

#### Are the health care costs related to the collection of stem cells covered?

Yes. The cost of the G-CSF therapy as well as the donor's health care costs related to the stem cell collection are covered by the Province of British Columbia.

#### How long would I need to take time off work?

We strongly recommend that you plan to stay in Vancouver for at least 3 weeks.

## If I come from out-of-town, do I have to purchase insurance?

It is strongly recommended that you purchase travel, medical and flight cancellation insurance if you do not have such coverage. We make this recommendation to our donors because changes are very often made to admission and transplant schedules with very short notice. For example, cancelling flight reservations will be costly if you do not purchase cancellation insurance.

## Will there be any last minute changes to my stem cell collection schedule?

Last minute changes to the stem cell collection schedule are very common! We emphasize to our donors that they need to be very flexible and be prepared for last minute changes. Purchasing travel and flight cancellation insurance is also highly recommended for the same reason.

Last minute changes to the stem cell collection schedule are very common! This is because the stem cell collection schedule is directly affected by your sibling's transplant schedule.

Transplant schedules can be moved ahead or delayed with very short notice depending on bed availability or the health of the patient. Stem cells are preferably collected as close to the transplant date as possible so they stay "fresh".

For this reason, we emphasize to our donors that they need to be very flexible and be prepared for last minute changes. Purchasing travel and flight cancellation insurance is also highly recommended for the same reason.

If your work or home life absolutely cannot accommodate last minute changes, please discuss this with the BMT doctor and BMT Coordinator as soon as possible.

## **Helping Others**

Are you interested in donating your stem cells or bone marrow anonymously to help others? You can join the **One Match Stem Cell and Marrow Network**, an initiative of the Canadian Blood Services.

Refer to the brochures included in this booklet.

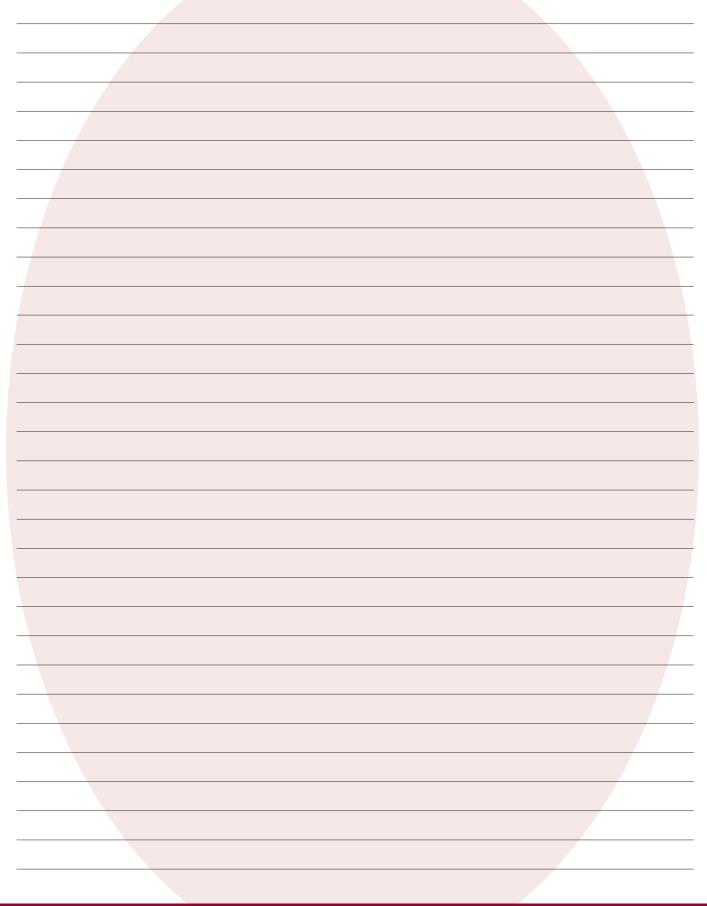
For more information:

- I. Visit the One Match Stem Cell and Marrow Network web site at www.onematch.ca
- 2. Visit the Canadian Blood Services web site at www.bloodservices.ca
- 3. Call I-888-2-DONATE (I-888-236-6283)



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# Notes



# Notes


## L/BMT Patient Education Manual • Donor Module



## Leukemia / Bone Marrow Transplant (BMT) Program of British Columbia

#### Mailing Address:

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