

# Stem Cell Donor Handbook

Saskatchewan Stem Cell  
Transplant and Cellular Therapy  
Program



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# Stem Cell Donor Information

## Welcome to the Saskatchewan Stem Cell Transplant and Cellular Therapy Program

As you embark upon your journey to becoming a donor, we hope to provide you with the information you need to feel well informed. The information in this guide is intended to supplement discussions with your health care team as you learn what it means to be a stem cell donor. We know that this decision is a significant one that affects not only you, but others close to you and your family member as well. Importantly, the decision to become a donor must be voluntary.

The physician responsible for your care as a donor will be different than the physician caring for your family member. Your physician is dedicated to evaluating your health to ensure that you are fit to donate stem cells and that your stem cells are safe for your family member. This is to ensure that you have an independent and confidential evaluation.

In the following pages, you will find information on:

- Your health care team and their contact information
- Stem cells and allogeneic stem cell transplant
- Preparation, collection and recovery
- Peripheral blood stem cell collection
- Bone marrow harvest
- Costs



Dr. Mohamed Elemetry  
Director of Stem Cell

# Contact Information

**Saskatoon Cancer Centre** (306) 655-2662  
20 Campus Drive  
Saskatoon, SK  
S7N 4H4

**Transplant Coordinator** \_\_\_\_\_ (306) 655- \_\_\_\_\_  
Your Transplant Coordinator is a registered nurse who will guide you through the donation process and can answer any questions you may have. You may call anytime during office hours, 8:00am-4:30pm Monday-Friday, excluding statutory holidays.

**Hematologist On-Call** (306) 655-1000  
For urgent matters weekdays after 4:30pm, weekends or statutory holidays call Royal University Hospital Switchboard and ask to page the Hematologist on call and they will call you back.

**Social Worker** \_\_\_\_\_ (306) 655- \_\_\_\_\_  
Your social worker is an important part of your health care team, and can assist with practical issues such as travel, accommodations and finances as well as emotional support. The social worker on your team will be different than that of your family member. This provides you with confidential and independent support.

**Royal University Hospital** (306) 655-1000  
In case of emergency while in Saskatoon, please go to Royal University Hospital Emergency Room.

**Out of Town Emergencies** 911 or local hospital phone number  
In case of emergencies outside of Saskatoon, please visit your local emergency room.

# Introduction To Allogeneic Stem Cell Transplant

## What Are Stem Cells?

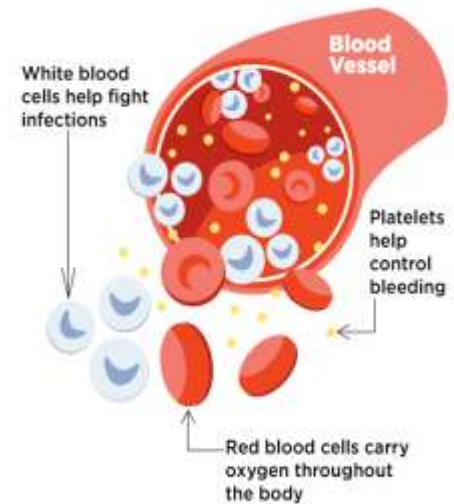
Hematopoietic (blood) stem cells are the “parent” cells of the blood supply. They are capable of self-renewal and develop into:

- Red blood cells, which carry oxygen throughout our body
- White blood cells, which help fight infections
- Platelets, which help form clots to prevent bleeding

Most stem cells are found in the bone marrow, mainly in the large hip bones and other long and flat bones. Normally there are very few stem cells found in the bloodstream.

## What Is Stem Cell Transplant?

An allogeneic stem cell transplant is when healthy stem cells are collected from a donor before being infused into a patient with a certain type of cancer or bone marrow disorder. The patient receives chemotherapy and sometimes radiation to clean out their bone marrow and kill cancer cells along with killing normal stem cells. Donor stem cells are then infused into the patient and eventually make their way to the bone marrow where they start to produce normal blood cells that can also fight cancer cells.

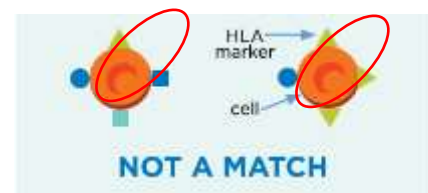
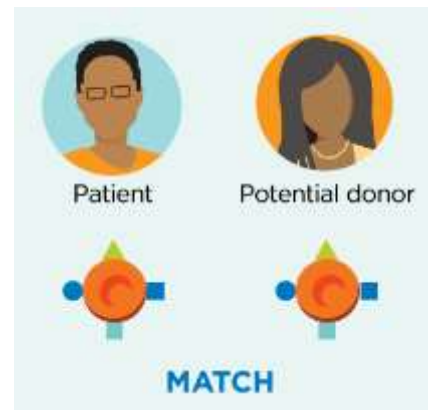


## STEM CELL DONOR INFORMATION

### Finding a Donor

Potential donors undergo a blood test to see if they are appropriately matched to the patient. This test is called human leukocyte antigen testing (or HLA typing). HLA is a protein, or marker, found on most cells of the body. Your immune system uses HLA markers to know which cells belong to your body (“self”) and which do not (“foreign”). Since half of your HLA markers are inherited from your mother and half are from your father, each brother or sister sharing the same mother and father has only a 25% or 1 in 4 chance of matching a sibling.

Unrelated volunteer donors may also provide a suitable match. In the event that a fully matched related or unrelated donor is not found, an alternate source from related children, a partially matched sibling or a parent, called a haploidentical match, may be considered.



### Consent and Confidentiality

After learning that you are a suitable HLA match for your family member, it is important to understand that the decision to donate stem cells or bone marrow is **voluntary** and requires your informed consent. Informed consent is a process to ensure that you understand the potential risks and benefits to becoming a donor, and alternatives for your relative. While there is no direct benefit to you to being a stem cell donor, many donors feel the benefit is in doing whatever they can to help their family member.

If you choose not to donate your stem cells or bone marrow, other options would need to be considered by your relative's physician. For this reason, we encourage you to share your decision not to proceed as a donor as early as possible to provide us with opportunity to find another suitable donor in a timely manner. The reasons for your decision are confidential and as such will not be shared with your family member.

Your health information is protected as personal and confidential, with only very specific information shared with your family member's care team such as results of the HLA blood test, blood group, serious allergies, and other potentially transmissible diseases or risk factors that may place your family member at increased risk following infusion of your stem cells. Any abnormal results found in your screening process will be shared with your family physician to ensure appropriate follow up.

It is important to understand that stem cell recipients can develop a condition called “graft-versus-host disease” (GVHD), which can occur when donor stem cells recognize

## **STEM CELL DONOR INFORMATION**

the recipient's body as foreign and attack the gut, liver, and/or skin to varying degrees. This can lead to very serious illness or even death in the recipient. It can be particularly difficult for a donor to see the recipient suffering in this way. It is very important to understand that you, as the donor, are not responsible for the recipient developing GVHD. Many factors can contribute to the development of GVHD, factors which are taken into account at the time of donor selection by the recipient's physician. In fact, a small amount of GVHD is often considered good. The challenge is that it is not possible to predict or control the extent of GVHD in any particular patient.

### **Psychological Effects**

Becoming a donor to a family member needing an allogeneic stem cell transplant can be a very emotional experience, ranging from excitement to anxiety and fear. It can feel good to know you are doing everything you can to help your family member. But it can also be difficult if your family member does not respond to the stem cell transplant as intended. Your health care team is available to support you through these emotions during and following the donation process.

### **Second Donations**

On occasion, a donor may be asked to consider a second donation of stem cells. Most commonly, this is because the patient's disease has relapsed without graft-versus-host disease (GVHD), but it may also be due to a failure of the stem cells to work ("graft failure") or a weak graft.

# Preparing To Donate Stem Cells

Donors undergo specific tests and assessments before collection of stem cells to ensure:

- Medical fitness of the donor to donate stem cells
- Safety of the recipient from transmissible conditions

## Donor Evaluation And Consultation

The initial donor evaluation and consultation must be done at the Saskatoon Cancer Centre and will take about 2½ hours. It includes the following:

### Blood Work

Regular blood work such as CBC, electrolytes, liver function tests, and kidney function tests will be done, as well as infectious disease testing, such as Toxoplasmosis, Hepatitis B, Hepatitis C, Cytomegalovirus, HIV, HTLV, Syphilis and West Nile Virus (during certain months or based on travel). Pregnancy testing for females of child-bearing years is also done.

### Tests

An ECG to monitor your heart electrical activity is required. This will be done in the Royal University Hospital Test Centre after you have your blood work done.

A chest x-ray may be done if you are a smoker or have a history of any lung disease such as asthma.

A bone marrow aspirate is required if you are 60 years old or older. This is done to rule out any bone marrow disorders. This is a short procedure done with local anesthetic. A needle is inserted into the back of your hip bone and a small sample of bone marrow is collected.

Other testing may be required based on the results of your physical examination.



## Health History and Physical Examination

A detailed health history questionnaire will be completed with the assistance of the transplant coordinator. A physical examination will be performed by one of our transplant physicians.

## Pharmacy Review

Please bring a list of your medications, vitamins and supplements.

BE SURE TO NOTIFY THE TRANSPLANT  
COORDINATOR OF ANY CHANGES WITH YOUR  
HEALTH AFTER YOUR CONSULTATION

# How Stem Cells Are Collected

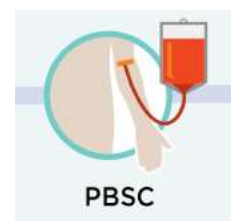
There are two methods used to collect stem cells. Your physician will decide which one of these methods will be used based on a number of factors including your family member's situation.

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## 1

### Peripheral Blood Stem Cell (PBSC) Collection

Peripheral blood stem cell collection is an outpatient procedure, with the use of stem cell-stimulating injections and an apheresis machine.



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## 2

### Bone Marrow Harvest

Bone marrow harvest is a surgical procedure in the operating room, where bone marrow is withdrawn from the back of the hip bones.



# Peripheral Blood Stem Cell (PBSC) Donation

## Overview



Peripheral blood stem cell collection is an outpatient procedure that uses 5 days of growth factor injections (G-CSF, filgrastim, grastofil) to move stem cells out of the bone marrow into the blood stream where they can be more easily collected. Stem cell collection, or "harvest", is accomplished using a special cell-separating machine called an apheresis machine. This machine requires two intravenous sites, one in each arm. The blood moves from the vein in one arm, through the apheresis machine before being returned back to the donor through the vein in the other arm.

The apheresis machine uses a centrifuge to separate the blood into the different components (red cells, white cells, plasma and platelets). The stem cells, which are found in the white blood cell layer, are collected into a bag while all the other blood components are returned back to you. The stem cell collection is usually completed in one day over 4-6 hours. Rarely a return visit the next day may be required.

If the veins in your arms are not adequate for this procedure, it may be necessary to insert a temporary central venous catheter into a large vein in the neck. If a temporary central venous catheter is inserted, it will be removed upon completion of the stem cell collection.

## Apheresis Donor Process

### 1. Apheresis Nurse

Following the initial donor evaluation and consultation, you will meet with an apheresis nurse who performs the peripheral blood stem cell collection. She will explain the apheresis procedure and will assess your veins to see if a central venous catheter may be required. If it looks like your veins may not be able to tolerate the stem cell collection, arrangements will be made for a central venous catheter ("line") to be inserted prior to apheresis.

On the day of collection circumstances occasionally arise that require an urgent line insertion, even after starting the collection using your veins. It is therefore important to understand that the need for a line insertion can occur at any time.

### 2. Mobilization of Stem Cells

"Mobilization" refers to the process of stimulating the bone marrow to produce large amount of stem cells for release into the blood stream using a growth factor medication. This medication is called G-CSF (Granulocyte Colony Stimulating Factor).

Once your family member is admitted to hospital to start chemotherapy, you will need to pick up this medication from the Saskatoon Cancer Centre. You will be taught how to store it properly and how to give it yourself a subcutaneous needle. The injections are started 4 days before the stem cell collection date as well as on the day of stem cell collection for a total of 5 days.

Common side effects from growth factor injections include:

- Mild to moderate muscle aches or bone pain
- Headache
- Fatigue
- Flu-like symptoms

These side effects can be managed using acetaminophen (Tylenol) and usually go away within a few days of completing the injections. It is important to avoid taking aspirin, ibuprofen or other similar medications because of an increased risk of bleeding.

Rare but serious side effects, although uncommon, have occasionally been reported.

### 3. Central Venous Catheter Insertion (if needed)

If you need a central venous catheter, it will usually be inserted the day prior to stem cell collection. In this procedure, a small central venous catheter is inserted into a large vein in the neck under local anesthetic, and then removed at the end of the apheresis procedure. The procedure takes

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place in Royal University Hospital Medical Imaging Department vascular suite. An interventional radiologist will explain the procedure along with potential complications to obtain your consent prior to the procedure.

On occasion, the unexpected insertion of a central venous catheter becomes necessary the day of stem cell collection.

### 4. Day(s) of Stem Cell Collection

You must arrive at the Admitting Department of Royal University Hospital at 8:00am on the day of your stem cell collection. You will then be directed to the Apheresis Unit in the Oncology Day Centre (ODC).

Common side effects during apheresis are:

- Tingling around mouth, tingling of fingertips or vibrations in your chest (can be caused by low calcium levels in your body)
- Feeling cold
- Lightheadedness

Be sure to tell the nurse if you have any of these symptoms. A nurse will be with you throughout the procedure.

As it can feel like a long day sitting/reclining in a large comfortable lazy boy recliner, you are encouraged to bring diversions such as books, laptop, and so on. There is a TV on the unit as well. Visitors are welcome, but please limit the number to one or two, as space is limited. Lunch and snacks are provided, but you can bring food of your own.

Please bring any medications that you normally take during the day with you but **DO NOT** take blood pressure medications the morning of stem cell collection. You will be given a calcium infusion to help maintain the calcium level in your body. Bathroom privileges are limited to the use of a commode or urinal while you are connected to the machine.

Your family member's physician will prescribe the number of stem cells required for their transplant, based on their weight. When the target number of stem cells have been collected, they will first be taken to the lab before being infused into your sibling, which usually happens on the same day. Occasionally stem cells may be collected and stored by means of cryopreservation (freezing) for later use.

The average time to complete a harvest is four hours; however, this time varies according to your stem cell count and your family member's weight. Most of the time, the collection will only take one day, but occasionally the collection may take two days. You must have a driver to pick you up following the stem cell donation procedure.



- **DO NOT** take blood pressure medications the morning of stem cell collection
- **DO** remember to bring all your pills with you!
- Eat a breakfast high in calcium
- Wear loose fitting, comfortable clothing
- Be sure to have a driver available to take you home

### 5. After Peripheral Blood Stem Cell Donation

If you had a central venous catheter inserted, the nurse will remove it at the end of the stem cell collection. Air travel is permitted 24 hours after the removal of the central line. Do not get the bandage wet for 24 hours. The bandage can be removed after this time.

Commonly you will be given prescriptions to take for 1 month: Calcium Citrate (starting the week prior to stem cell collection), Ferrous Sulfate, Folic Acid and Vitamin B-12.

No further appointments will be scheduled at the Saskatoon Cancer Centre. You will be given a requisition to have blood work done one day and one month after the collection. Results of this blood work will be forwarded to your family physician. Your physician will also receive a letter indicating that you were a stem cell donor. The Transplant Coordinator will contact you one week after the collection to see how you are feeling. If you have any questions about how you are feeling, please contact the Transplant Coordinator. If you feel unwell, please see your family physician. For any medical emergency, please call 911 or go to the nearest Emergency Room.

You can expect to return to work within 1-7 days after the stem cell collection, depending on the type of job you have and how you are feeling. Please let the Transplant Coordinator know if you require a note to be away from work for the stem cell collection.

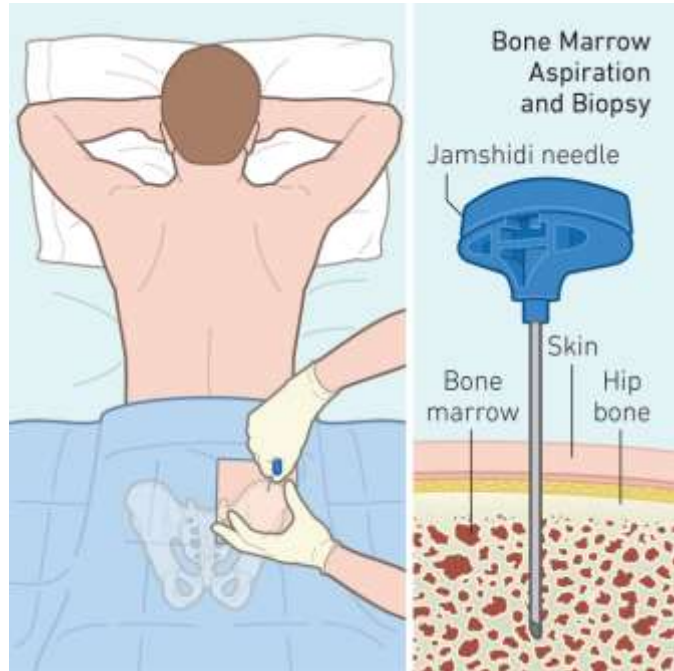
### 6. Costs of Stem Cell Donation

There are no direct costs to the donor for all medical appointments, tests and procedures. However travel, food, hotel and parking costs are not covered. Parking at Royal University Hospital is currently \$3/hour, with a 24-hour pass (including in/out

# Bone Marrow Harvest

## Overview

A bone marrow harvest is the collection of stem cells performed under anesthetic in the operating room. During this procedure, stem cells are collected from the back of both hip bones by 2 transplant doctors using needles.



### 1. Anesthesia

Donors undergoing a bone marrow harvest require an evaluation by an anesthetist in addition to the donor evaluation and consultation. Anesthesia is medication given in the operating room to block feeling during the bone marrow harvest. The anesthetist will discuss using a general anesthetic or local anesthetic.

General anesthesia is given by intravenous (IV) throughout the bone marrow harvest to keep you unconscious so that you are completely unaware during the procedure. You will have a breathing tube in your throat so when you wake up you may notice a sore throat.

Spinal anesthesia may also be considered. This form of anesthesia is injected near the spinal cord to block feeling in your hips and legs, but you remain awake throughout the procedure.

### 2. Timing of Bone Marrow Harvest

Once you have been medically cleared to be a stem cell donor for your family member, the transplant coordinator will give you a schedule for the bone marrow donation. The bone marrow harvest will be timed to take place once your family member has been admitted to hospital and started chemotherapy.



### 3. Preparation for Bone Marrow Harvest

In preparation for your bone marrow harvest:

- Arrange to have a companion with you for 24 hours following the procedure
- Have ice packs or frozen vegetables ready at home to use after the harvest

For 14 days before the harvest:

- Do NOT take herbal products unless approved by physician

For 7 days before the bone marrow harvest:

- Do NOT take any medication with aspirin or ASA (E.g. Entrophen®) or ASA products (E.g. Anacin®, Bufferin®, Alka Seltzer®, Midol®, Dristan®, Percodan®, Robaxisal®)
- Do NOT take anti-inflammatory pills such as Aspirin®, ibuprofen and Advil®
- Do NOT use alcohol
- NOTE: It is acceptable to take Tylenol® (acetaminophen) at any time prior to harvest

The night before:

- Do NOT eat/drink after midnight prior to the bone marrow harvest
- Have a shower or bath

### 4. Day of Bone Marrow Harvest

You will need to register at Royal University Hospital Admitting as instructed; expect this to be an early morning appointment.

Remember to:

- Bring your health card
- Bring loose-fitting, comfortable clothing to wear after the harvest
- Bring an overnight bag in case you have to stay overnight

A nurse will prepare you for the operating room. You will be asked to:

- Wear a hospital gown
- Empty your bladder
- Remove all jewelry and body piercings
- Remove dentures, hearing aids, prosthesis
- Remove make-up and nail polish
- Remove glasses or contact lenses

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In the operating room, you will be positioned lying face down. The areas on the back of your hips will be cleansed before the doctor places a hollow needle through the skin and bone into the bone marrow. Bone marrow is removed using a syringe, and looks very similar to blood. This process is repeated by doctors on each of your hips many times until the desired number of stem cells is collected or the maximum volume of marrow has been reached.

The amount of bone marrow cells collected is based on the weight of the patient, usually about 1000 mL (4 cups). Don't worry; you will still have numerous stem cells left to grow and replace your own bone marrow which takes about 6 weeks.

On the outside of your skin, about 5-6 pokes where the needle went through your skin will be visible. Following the bone marrow harvest, a large pressure dressing is applied to the puncture sites. The dressing will be removed the day after your bone marrow harvest. The entire procedure usually takes 1-2 hours.

### 5. After Bone Marrow Harvest

You will be taken to the Post Anesthesia Care Unit (PACU), then to Day Surgery for recovery. A physician will assess you and decide if you can be discharged later that day or if you should be admitted to hospital overnight. If you are discharged the same day as the procedure, you will need someone to drive you home. You will have a follow up appointment at the Cancer Centre the next day.

Plan to have a companion with you for the first 24 hours following discharge from the hospital. You will need to stay in the vicinity of Royal University Hospital for the first 24 hours after the bone marrow harvest if your residence is more than 1 hour from Saskatoon.

Following general anesthesia, it is important to:

- Refrain from driving, operating machinery, or any other task that may be dangerous if you are not alert for at least 24 hours after the general anesthetic
- Refrain from drinking alcohol or taking other medications unless approved by your physician

Common side effects following a bone marrow harvest are:

- Stiffness or aches in lower back. May last for 1-2 weeks; use acetaminophen with codeine if needed.
- Nausea, vomiting or light-headedness. Due to anesthetic, usually improves within a few days.

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- General swelling from IV fluids during the procedure. Should only last a couple of days.
- Fatigue. May be due to lower than normal blood levels, and can last up to 1 month after harvest.

## 6. Follow Up Care

If you are discharged home the same day as the bone marrow procedure, you will need to return to the Saskatoon Cancer Centre the next day to have the bandages removed and replaced. You will have blood work on the day after the bone marrow harvest, and will be sent with a requisition to have blood work repeated in 1 month. Results of this blood work will be forwarded to your family physician. The Transplant Coordinator will contact you 1 week after the bone marrow harvest to see how you are feeling, but you can also contact her if you have any concerns or questions.

A letter will be sent to your family physician indicating that you were a stem cell donor along with recommendations for any follow up required.

Please report the following symptoms to the Transplant Coordinator:

- Fatigue that worsens or does not improve after 2 weeks
- Fever over 38.0 degrees Celsius
- Infection (redness, pain, pus, odor) at site of bone marrow harvest
- Any other concerning symptoms
- Significant anxiety or changes in mood

Some other post-harvest instructions include:

- At home, use ice packs or frozen vegetables to puncture sites as needed to reduce swelling
- Avoid tub baths and hot tubs for 48 hours after bone marrow harvest
- No driving or heavy equipment operation, or other tasks that require alertness for 24 hours after the harvest
- No heavy lifting or strenuous exercise for a minimum of 48 hours after the harvest
- Air travel is permitted 24 hours after the procedure
- You will be given prescriptions for iron tablets, folic acid and vitamin B12 to take for 4 weeks and Tylenol #3 if required for pain; take iron with vitamin C-rich foods such as orange juice and green leafy vegetables to increase absorption and increase fiber and fluids to prevent constipation from Tylenol #3
- Avoid alcohol and caffeine
- Use laxatives if constipation is a problem

You can expect to return to work within 7 days after the bone marrow harvest, and possibly longer if your job is physically demanding or if you continue to experience pain.

## STEM CELL DONOR INFORMATION

Please let the Transplant Coordinator know if you require a note to be away from work for the bone marrow harvest.

### 7. Costs of Bone Marrow Harvest

There are no direct costs to the donor for medical appointments, tests, and procedures. However travel, food, hotel and parking costs are not covered. Parking at Royal University Hospital is currently \$3/hour, with a 24-hour pass (including in/out privileges) costing \$18 (subject to change). If you are from out of country, we recommend you purchase travel insurance.



# Glossary

<b>Allogeneic</b>	Transplant in which the donor is someone other than the patient
<b>Anesthesia</b>	Medications that cause temporary loss of sensation or awareness
<b>Anesthetist</b>	Physician specially trained to administer anesthesia
<b>Apheresis</b>	The process of removing blood from a patient, separating out the stem cells, and then returning remaining portions back to the patient
<b>Bone Marrow</b>	This is the tissue found in the soft center of bones. It creates blood cells (red blood cells, white blood cells and platelets)
<b>Central Venous Catheter (CVC)</b>	A temporary catheter inserted under local anesthetic into the neck for the purpose of collecting peripheral blood stem cells. Sometimes referred to as a "line".
<b>Collection</b>	The process of collecting stem cells through a bone marrow or PBSC donation
<b>Graft-Versus-Host Disease (GVHD)</b>	A process whereby transplanted donor stem cells ("graft") recognize the recipient ("host") as foreign and cause damage to major organs such as the skin, gut and liver
<b>Donor</b>	Person donating stem cells for infusion into a stem cell recipient Often a relative such as a fully-matched brother or sister, but may be an unrelated donor or alternate donor such as a child or parent
<b>Haploidentical</b>	Alternate donor source of stem cells using a partially matched relative, usually parent or child; may be considered when a fully matched donor is not available
<b>Harvest</b>	Term sometimes used interchangeably with "apheresis" or "collection"
<b>Hematopoietic</b>	Blood-forming cells
<b>HLA</b>	Human leukocyte antigen; HLA is a protein, or marker, found on most cells in your body. Your immune system uses HLA markers to know which cells belong in your body ("self") and which do not ("foreign")
<b>Mobilization</b>	The process of using medications called growth factors to cause the movement of stem cells from the bone marrow into the blood stream
<b>Peripheral Blood Stem Cells (PBSC)</b>	Stem cells that have moved to the peripheral blood from the bone marrow
<b>Recipient</b>	Person receiving stem cell infusions to treat their disease
<b>Stem Cells</b>	Self-renewing blood cells that give rise to all other blood cells. These can turn into red blood cells (which carry oxygen), white blood cells (which fight infection) or platelets (which help to stop bleeding). Bone marrow is a main source for stem cells, but they can also be found in your blood system and in umbilical cord blood (blood inside your umbilical cord).

## STEM CELL DONOR INFORMATION

### NOTES:
