Being a Stem Cell Donor
By completing the following pages, you will make this book unique. We hope that you learn a lot about being a donor and be proud of the work you do. Feel free to use colored pencils, pens, or markers. Be creative and have fun!
To parents, family members, and caregivers: When a child with cancer needs a stem cell transplant, we often focus so much on that child's well-being that we underestimate the concerns of the sibling stem cell donor.

Without preparation, stem cell donation can be frightening for sibling donors. Feeling prepared eases fears and allows sibling donors to feel included in their ill sibling's treatment.

This booklet can help prepare sibling donors for the stem cell donation. It will explain the transplant procedure and donation/collection process and allow them to express their feelings. In order for this book to reflect each sibling's unique experience, let the child choose what pages and activities he or she wants to complete first.

While going through the questions and activities in this booklet, it is important to let the sibling donor know that you will help him or her through each step of donation. It is important that the child does not feel responsible for the sibling's illness or the outcome of the transplant.
By now you’ve probably been told that you are a “match” for your brother or sister’s stem cell transplant. Your parents and family may have asked you to be a donor. But what does that mean? This booklet will help answer your questions about what it means to be a donor and how stem cell transplants work.

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There are 3 main types of cells that stem cells can become.

1. White blood cells that help fight infection
2. Red blood cells that carry oxygen to organs and tissues all over the body
3. Platelets that help blood clot and stop bleeding.

What are stem cells? Stem cells are “progenitor” or “parent” cells in bone marrow that develop into different kinds of blood cells.

Where do stem cells come from? Most stem cells are found in bone marrow, the soft sponge-like material found inside our bones. Some stem cells are found in the bloodstream and are called peripheral blood stem cells (PBSCs for short). Stem cells are also found in the blood of an umbilical cord. All three types of stem cells can be used in transplants.
**What is a transplant?** A transplant is a form of treatment for people with cancer. Giving healthy stem cells to children with cancer, like your brother or sister, can help fight their cancer. There are different types of transplants. We will talk about bone marrow transplants (BMTs) and peripheral blood stem cell transplants (PBSCTs).

Here is a drawing of a healthy cell

![Healthy cell drawing](image)

**Where do the healthy stem cells come from?** Healthy stem cells come from healthy people like you. These people are called donors. Before you can be a donor, doctors will check to see if your stem cells are similar to your brother’s or sister’s stem cells. If they are similar enough, you will be called a “match” and will be able to donate your stem cells to your sibling.

**Draw what you think a cancer cell looks like:**

![Cancer cell drawing](image)
more likely to match than other people. Your blood stem cells have features most like your brother/sister’s. That is why you are a match. Your stem cells’ features match that of your brother/sister’s better than anyone else in your family. This match makes you the best donor for stem cells for your brother/sister. Being a match does not mean that you are responsible for curing your brother/sister’s cancer. It just means that the cells in your blood have the best chance of helping your brother or sister feel better.

Why is a match important? If doctors didn’t use a HLA-matched donor’s stem cells, the transplanted cells could make the recipient sick or the recipient’s body might reject the new cells (this is called “graft failure”). By choosing a donor that is the best HLA-match, doctors reduce the risk of making the recipient sick. But remember, even matched stem cells sometimes don’t work, no matter how perfect they are.

Which one of the faces below best describes how you felt when you heard you were a donor match for your brother/sister?

Now which one of the faces below best describes how you would have felt if you were not chosen to be a match?
Stem cells from healthy donors or bone marrow is removed and given to people with cancer, like your brother or sister.

About five days before your sibling receives your donated stem cells, you may be given injections of the drug, granulocyte colony stimulating factor (called GCS-F or filixastrin, for short). Your doctor will let you know if this is needed. GCS-F helps bring bone marrow stem cells into the bloodstream. This is the same drug your brother or sister may have received to help white blood cells come back after chemotherapy. No one likes to get shots, but the nurses can give you something to numb your skin so that you won’t feel the needle prick as much. If the needle worries you, ask to see the needle before you get the shot so that you know what to expect. The needle is very small.

There are different ways for stem cells to be used: Bone Marrow Transplantation (BMT) or Peripheral Blood Stem Cell Transplantation (PBSCT).

The stem cells used for BMTs come from the bone marrow, the center of the bone. The process of collecting the bone marrow from the bone is called “harvesting.” During harvesting, donors like you are given anesthesia (pronounced an-esth-these-ee-uh), which will put you to sleep for the rest of the procedure. While you are asleep, the doctor will collect the stem cells from your bone marrow by using needles inserted through the skin over the hip bone. This is called bone marrow aspiration. **You will not feel or see any needles during the harvesting.** Harvesting usually takes about an hour. After the bone marrow is collected, it is prepared for the recipient (your brother or sister).
When you wake up from the anesthesia after bone marrow harvesting, you parents and family will be with you in the hospital room and doctors will come in to check on you. You will probably feel sore and tired from the harvest, but the doctors can give you medicine to help relieve the soreness.

After your stem cell collection is over, you may need to stay in the hospital for about a day to let your body rest. You may have some bruises from the bone marrow collection, but don't worry. The bruises will fade over time just like other bruises you have had. Since bleeding and infection are possible after bone marrow donation, your doctors will be checking you closely. You will probably have a follow-up meeting with the doctors and nurses as well as a social worker or psychologist to discuss how you feel and to help answer your questions. Your family and friends will be there to help check up on your health after the bone marrow collection and will take care of you.

Although unlikely, if not enough stem cells are collected during bone marrow donation, it might be necessary to continue filgastrin (GCS-F) shots and donate stem cells again using apheresis (a machine that separates blood parts).

At some point after your brother or sister receives the stem cells, you may be asked to donate more white cells called “lymphocytes.” You will not need more GCS-F shots. (Turn to page 11 to learn about GCS-F.)

Lymphocytes help enhance your sibling's immune responses to the tumor. Like stem cell collection, lymphocyte collection uses apheresis. Again, you will not need GCS-F injections for lymphocyte collection. Lymphocyte collection usually takes between 2 to 4 hours. Lymphocytes will be given to your brother or sister using infusions just like those for the stem cell transplant.
Here are some questions that other donors, just like you, have asked:

What is GCS-F? GCS-F (granulocyte colony stimulating factor or filigastrin, for short) is a drug that helps bring bone marrow stem cells into the bloodstream. You will receive this drug by injection about 5 days before the transplant.

Does GCS-F have side effects? You may feel some bone pain or get headaches. You can get pain relievers to help you feel better.

How many cells will I need to donate? Your brother or sister needs thousands of new stem cells to replace the ones that had cancer, but don't worry. You will have more than enough cells left in your body.

Will the surgery hurt? You will be asleep during the surgery. The doctors will give you a special kind of sleep medicine that will make sure that you are asleep for the entire procedure. When you wake up after the surgery, you may be sore, but the doctors can give you medicine to relieve the pain.

Will the surgery put holes in my bones? No. The stem cells are collected from the marrow very carefully with a needle. After the stem cells are collected, your body will already be making new stem cells to replace the ones collected. Your bones will continue to grow as usual.


Will anything bad happen to me when I donate my stem cells? No. The doctors take extra precautions to make sure you are very safe. You may feel tired and sore after the donation, but this will pass after you get some rest. You may have some bruises on your hips where the stem cells were collected, but these will fade just like any other bruise.

What happens afterwards? You will have a hospital room to rest in after the bone marrow donation surgery. Your family and friends can be there to help keep you company and make sure you get everything you need to feel your best.

When will my sister/brother get my stem cells? The doctors will store the harvested stem cells in a special freezer until it is time for your brother or sister's transplant. It may be several weeks before the transplant happens. The doctor will be able to tell you exactly when your brother/sister will be ready for your stem cells.
A peripheral blood stem cell (PBSC) transplant involves a process of taking stem cells directly from the bloodstream instead of from bone marrow. There are fewer stem cells in the bloodstream than in bone marrow, so donors have to take a drug that will help increase the number of stem cells in the bloodstream.

About five days before the stem cell donation, the donor is given injections of the drug, granulocyte colony stimulating factor (called GCS-F or filgrastim, for short). This drug helps bring bone marrow stem cells into the bloodstream. This drug helps your body produce more stem cells.

No one likes to get shots, but the nurses can give you something to numb your skin so you won’t feel the needle prick as much. Remember, you can ask to see the needle before you get the shot so you know what to expect. The needle is VERY small. If you don’t want to see the needle, try to think of something fun.

Draw a picture of what you would think about:

![Picture of a child getting a shot]

Because the drug causes your body to make more stem cells than usual, you may feel some pain in your bones or get headaches, but usually these can be treated with pain relievers just like any other headache you might have had. Make sure to tell your parents or doctors how you feel during the days you get the shots so that they can help you feel as good as possible before donation begins.

Which best describes how you feel about getting the filgrastim shots?

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After about five days of injections the donor is admitted to the Apheresis (pronounced “a-fur-ee-sis”) Unit where the stem cells will be collected. The blood is collected using special catheters placed in the veins in each arm. The apheresis team will give you a local pain reliever so that the needles from the catheter won’t hurt as much. Blood is drawn from one location (usually the arm) and passed through a machine that separates the stem cells from the rest of the blood. This process is called apheresis.

Depending on your age, a member of the apheresis team may ask you questions about your personal health history. Your answers to these questions are kept completely confidential.

In rare cases, the veins in the arm may not be the best place to collect stem cells. If it seems that the veins in your arms cannot be used, doctors will look for different veins in your body that will work best. No one likes to be stuck by a needle more than they have to be, but doctors will give you some medicine to minimize the pain as much as possible. If you feel uncomfortable, just talk to the nurses in the apheresis unit. They will do their very best to make you as comfortable as possible during the apheresis process.

Once the stem cells are separated, the rest of the blood is returned to your body through a vein in your other arm. The procedure can last 4 to 8 hours, but during stem cell collection, you can read, sleep, or watch TV or movies. After the stem cells are collected, you can go home. The stem cells you donated will be stored until your brother or sister is ready for the transplant. It is possible, although unlikely, that you may have to continue GCS-F for a couple of collections over a few days to make sure that the doctors collect enough stem cells.

After your stem cell collection is over, you can leave the hospital. You will probably have a follow-up meeting with the doctors and nurses as well as a social worker or psychologist to discuss how you feel and to help answer your questions. If you have bruises from the lines used to collect your stem cells during apheresis, don’t worry. The bruises will fade with time just like other bruises you have had. Your family and friends will be with you after the apheresis, and they will take care of you.

At some point after your brother or sister receives the stem cells, you may be asked to donate more white cells, called lymphocytes. You will not need more GCS-F shots. (See page 11 to learn about GCS-F).
Here are some questions that other donors, just like you, have asked.

**Will it hurt when my body is making extra cells?** Your bones may ache and you may have headaches. Your parents or the doctors can give you medicine to help the pain (the same medicine you usually take for a headache). It’s important to let your parents or the doctors know if you feel pain, so that they can help you and do their best to take care of you.

**How many cells will I need to donate?** Your brother or sister needs thousands of new stem cells to replace the ones that had cancer, but don’t worry. You will have more than enough cells left in your body.

**Are they going to drain my blood?** No. During the apheresis, just a little blood is taken out at a time. The machine quickly separates stem cells from other cells in your blood and puts the blood right back into your body. It might look like a lot of blood, but you have so much blood in your body, the amount that goes through the machine at any one moment is very small.

**Will I get cancer?** Being a donor does not put you at risk for getting cancer. You cannot catch cancer by donating stem cells.

**Will apheresis hurt?** The experts in the apheresis unit will numb your arms with a special medicine made just for kids like you so that you won’t feel the needles. Some people say that their arms feel a little tingly and sore from having to hold still, but the nurses will help you get comfortable. They will give you cushions to rest your arms on, and pillows for your head while you donate.

**Do I have to sit still the entire time?** It is very important to hold still and move as little as possible while you are donating cells, but you don’t have to stay completely still. You can lie in bed or sit up and watch movies, sleep, read, or listen to music. When you need to change positions, the nurses in the apheresis unit will help you.

**How big are the needles?** The needles are not much bigger than needles used when you get shots. If you don’t want to see them, you don’t have to. You can close your eyes when they are put into place.

**Will anything bad happen to me when I donate my stem cells?** No. The doctors take extra precautions to make sure you are very safe. You may feel tired after the donation, but this will pass after you get some rest. You may have some small bruises on your arms from where the lines were in place in your arm, but these will fade just like any other bruise.

**Will I see any blood?** The blood travels from one arm to the apheresis machine through a very small plastic tube (called a “line”) and back from the machine to the other arm through another line. This is the only blood that you will see, and it may be possible for the nurses to cover your arms with a blanket so that you don’t see it.
Will my blood be ok without the stem cells? Yes. You will still have some stem cells in your blood stream, and remember, your body makes lots of new stem cells all the time in your bone marrow. Very soon, body will make new cells to replace the ones you donated.

What does the machine do? The machine separates stem cells from the rest of the blood (platelets, red blood cells, white blood cells, and plasma). It collects stem cells in a special bag so that they can be given right away to your brother or sister. The rest of the blood will be put back into your body.

Can my parents come? Yes. Your mom and dad, family, and friends are all very welcome to keep you company during the apheresis. You can watch movies together, or read, or just sit and talk.

What will happen afterwards? After the apheresis is over, you will probably sit in the room for a bit and rest while the nurses make sure that everything is ok. After that, you and your family will be able to leave the apheresis unit.

When will my brother/sister get my cells? After you have donated your stem cells, the cells will be stored for a little while until they are given to your brother or sister. This should happen very soon after your donation. The doctor can tell you exactly when the transplant will occur.
Now that you know all about how the transplant procedures work, you can get ready to donate. The hospital transplant team will be able to give you a tour of the hospital and show you where you will donate your stem cells. They will also help you get ready by answering your questions about donation and the transplant.

Fill in the name of each member of the Team:

Write down 5 questions you might ask the hospital team:

1

2

3

4

5
In the days before the stem cell donation, your body may feel different because of the GCS-F shots. Use these journal pages to write how you feel each day and how your body feels. Record any concerns and questions you have so that you can share them with the doctors and nurses before your stem cell donation. Feel free to draw if you have trouble thinking words to describe your thoughts.

**What happened today:**

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**Today I felt:**

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other: [ ] [ ]
What happened today:

Date:

Weather:

Music:

TV Shows:

Book/Magazine:

Today I felt:

other:
What happened today:

Date: / / 

Weather

Music:

TV Shows:

Book/Magazine:

Today I felt:

Other:
You may want to bring your favorite movies or video games, books, music, or toys to help you pass the time either during the donation process or while you are resting in the hospital. Sometimes the hospital will have movies for you to choose from too. Be sure to ask the hospital staff when you get there.

What are your favorite movies?

1

2

3

What is your favorite book?

What music do you like?

What is your favorite website?
How does my brother/sister get my stem cells? Several weeks after you donate your stem cells, it will be time for the transplant. Your brother/sister will get your stem cells like they would get a blood transfusion: through a central I.V. line (plastic tube connected to the body). A needle is inserted into a vein and the bone marrow cells are injected. Once inside the body, stem cells find their own way to the bone marrow and settle there. It will take some time for your stem cells to get comfortable in their new home, but eventually the stem cells should begin to grow and become different types of blood cells in the blood stream.

It can take several weeks for the new stem cells to begin to grow. During this time, your brother or sister will have to stay in their hospital room and stay as far away from germs as possible because your sibling's body is still weak and hasn't made a new blood-forming system yet. You may feel frustrated while you wait to see if the new stem cells will grow or not. It just takes time. Not even the doctors will know if the transplant will work or not.
It is hard to say how long your brother or sister will stay in the hospital, because it depends on how quickly the stem cells “take” but it could be as short as two weeks or as long as two months. If the stem cells do work well together, and your brother or sister does not get an infection, your sibling will be able to leave the hospital.

Sometimes, no matter how perfect your cells are, the stem cells cannot help, and your brother or sister cannot get better. Sometimes your brother or sister’s cells will not work together with your stem cells. This is called “rejection” because your brother or sister’s stem cells are refusing your stem cells. Your brother or sister may even become sick with something called “Graft versus Host Disease” (GvHD for short). Graft-versus-Host-Disease is similar to rejection except that instead of the body rejecting the new cells, the stem cells have a reaction to the tissues in the recipient’s body. If that happens, it is not your fault and has nothing to do with your stem cells or you. The doctors have no way of knowing how well the transplant will work.

Can the doctors prevent GvHD?
Sometimes the doctors can give your brother or sister drugs to prevent GvHD. There are also some other medical procedures used to prevent GvHD. However, there is no guarantee that your sister or brother won’t get GvHD. Just know that the doctors will do everything they can to take care of your sibling, and that nothing you did could ever cause GvHD or rejection. Your cells are doing their best, but sometimes GvHD or rejection still occurs.

Are there medicines to treat GvHD? There are different types of GvHD, and there are different therapies depending on the type. The doctors will decide what kind of GvHD your sibling has and will give the best medicines available to treat it.

What can I do? There is nothing you can do to make the transplant work, but you can help keep your brother or sister safe from infections by washing your hands before you go visit. In rare circumstances, you may even wear a special gown and mask to prevent spreading germs.
Create your own word search at: http://www.kokolikoko.com/word_search_puzzle/
Changes In Progress

suggestions: Sudoku Crossword
You may hear a lot of medical terms while you are at the hospital before and after the transplant. Here are some definitions of words you might hear discussed.

**Allogeneic:** A graft from someone other than the patient, usually a matched brother or sister donor.

**Apheresis:** The process of separating blood into its different components to collect a component.

**Aseptic:** Being free from germs and infection.

**Aspiration:** Removing marrow from the bone.

**Bone Marrow:** A soft, spongy material in the center of bones that produces blood cells.

**Chemotherapy:** Treatment that destroys cancer cells with drugs.

**Conditioning Regimen:** High-dose therapy that kills a BMT patient’s cancer cells and bone marrow cells in preparation for a transplant; also called marrow ablation, preparation or preparative regimen.

**Engraftment:** The successful implantation and function of stem cells in the patient’s bone marrow cavities.

**Graft-Versus-Host Disease (GVHD):** A disease where the stem cells from the donor do not get along with the patient’s stem cells.

**Granulocyte Colony Stimulating Factor (G-CSF):** A substance that stimulates white blood cell growth. Sometimes referred to as “filigastrin.”

**Hemoglobin:** The part of red blood cells that carries oxygen.

**Histocompatibility:** How well the donor and the patient stem cells are matched.

**HLA:** Human leukocyte antigens. The proteins present on the surface of the white blood cell, and most other cells of the human body.

**HLA Typing:** The method doctors use to see if donors are a match.

**Immunosuppression:** Reduction of the function of the immune system to prevent a reaction against donor marrow or stem cells and to prevent GVHD.

**Intravenous (IV):** Within or into a vein.

**Lymphocyte:** A type of white blood cells that help fight diseases.

**Match:** Similarity in HLA typing between the donor and the recipient.

**Neutrophil:** Type of white blood cell in the bloodstream that helps defend against bacterial infections.

**Peripheral Blood Stem Cells (PBSC):** Stem cells found in the bloodstream that develop into other blood cells.

**Platelets:** Blood cells that help clotting and stopping bleeding.

**White Blood Cells (leukocytes):** Blood cells that fight infection in the body.

Here are some resources for more information for both you and your child to learn more about cancer and about becoming a donor.

**American Camp Association**
1-800-428-2267
www.acacamps.org
The American Camp Association is a resource that can provide information on camps specifically for siblings of children with cancer.

**American Cancer Society (ACS)**
1-800-ACS-2345 (1-800-227-2345)
www.cancer.org
The ACS offers a 24-hr hotline to information specialists that can provide answers to your questions about cancer and direct you to other resources.

**CancerCare**
1-800-813-HOPE (1-800-813-4673)
www.cancercare.org
CancerCare provides information and support to anyone affected by cancer. The site includes online support groups for teens who have a brother or sister with cancer.

**Candlelighters Childhood Cancer Foundation**
1-800-366-CCCF (1-800-366-2223)
www.candlelighters.org
**Seattle Cancer Alliance — Pediatric Bone Marrow Transplant Program**

www.seattlecca.org/patientsandfamilies/pediatric-Care/pediatricBoneMarrowTransplant/

This site offers information on the transplant process including a special section on siblings as donors.

**The Starlight Starbright Children's Foundation**

(310) 479-1212

www.slshb.org

Starlight Starbright Children's Foundation is a non-profit organization dedicated to making a world of difference for seriously ill children and their families.

**Virtual Children's Hospital**

www.vh.org/pediatric/

This digital health sciences library created by the University of Iowa helps meet the information needs of health care providers and patients. The library includes the online textbook, Pediatric Bone Marrow Transplant: A Guide for Families.

**The Wellness Community**

1-888-793-WELL (1-888-793-9355)

www.thewellnesscommunity.org

The Wellness Community provides support, education and hope to people with cancer and their loved ones.

**Resources for Children and Teens**

**The Adventures of Captain Chemo and Chemo Command**

http://www.royalmarsden.org/captchemo/

Watch Captain Chemo and his cadets as they embark on five adventures dealing with cancer-related issues. Find out more about cancer, its treatment, side effects, and tests.

**The Gift—For Children Who Are Bone Marrow Donors**

Available through Palmetto Health South Carolina Cancer Center


This book is ideal for helping children, teens, young adults, and caregivers prepare for and cope with being a bone marrow donor.

**SuperSibs!**

1-866-444-SIBS (1-866-444-7427)

www.supersibs.org

SuperSibs! is a national non-profit organization providing free services to siblings of children with cancer by providing children and teens with ongoing recognition and support. SuperSibs! Helps children redefine the “cancer sibling” experience.