

SIBLING DONOR HANDBOOK



Children's Mercy
KANSAS CITY

Hello, future bone marrow donor!

My name is Ellie, and I was a bone marrow donor 5 years ago. I was almost 11 years old when my little sister had her transplant. I was very scared, nervous and unsure about everything related to donating bone marrow and being in the hospital. I also had (and still have!) a major fear of needles. But it was not bad at all! I can honestly say that it was totally fine. I remember going to sleep with anesthesia, and when I woke up it was all over! It was so much easier than I expected, and the doctors and nurses took great care of me. And the most important part – it helped my sister tremendously. I am so grateful that I was able to donate. This will be an amazing and unbelievable gift that only you can give your sibling, and it's something that you will always be proud of. Best of luck! You will be great!

-Ellie, age 10 (at time of transplant)

ALL ABOUT _____

MY FRIENDS ARE:

I AM
○
YEARS
OLD

WHEN I GROW UP,
I WANT TO BE:

BOOKS I
LIKE TO READ:

I LIKE
TO WATCH:

MY
FAVORITE:

Color: _____

Animal: _____

Food: _____

MY FAVORITE
ACTIVITIES:

WHO WILL TAKE CARE OF ME?

BMT Physician Team:

Doug, Erin and Ibrahim are on the BMT Physician Team. Their job is to make sure that you are healthy enough to be the donor for your sibling. They can also answer any questions your caregiver might have about your donation.



Dr. Doug Myers



Dr. Erin Hall



Dr. Ibrahim Ahmed

Donor Advocate

The donor advocate is also a Child Life Specialist. Her job is to make sure that you know what is going to happen when you donate your cells to your loved one. She also is there to help with procedures and lab pokes.



Ashley Smith

Transplant Nurse Coordinators

Their job is to make sure that you and your caregiver know what to expect for the whole transplant process. They will also give you a calendar for your appointments and are always available to answer your questions. They will also be in the operating room with you.



Courtney Schwartz



Kim Miller

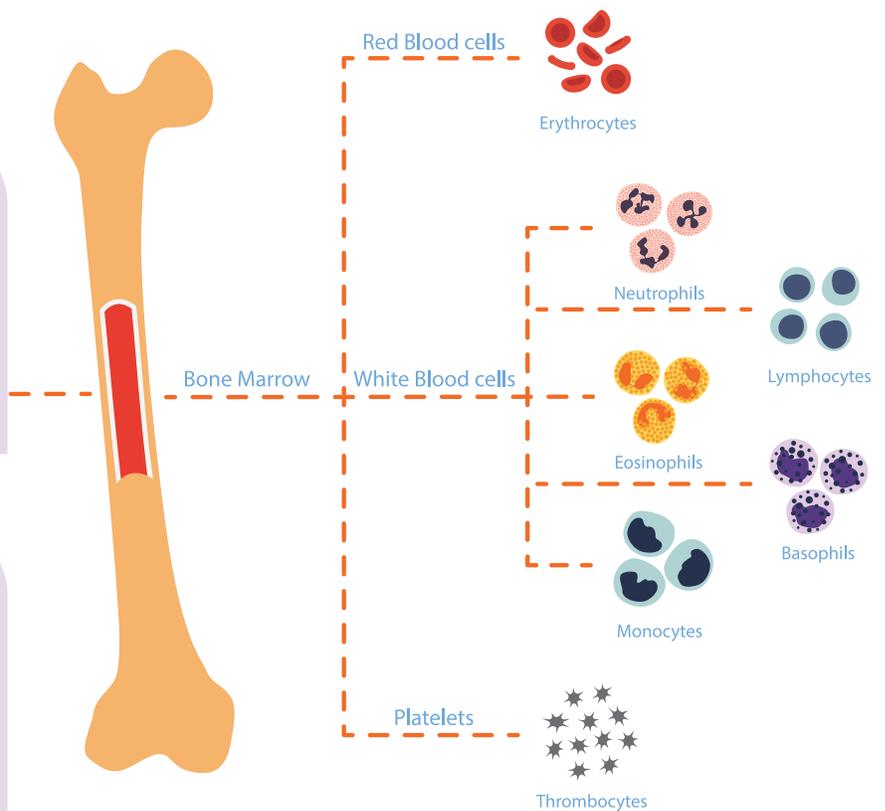
WHAT IS A BONE MARROW TRANSPLANT?

Bone Marrow

Bone marrow is in the middle of your bones. It is red and spongy. It is like a factory. Its job is to make the cells in your blood.

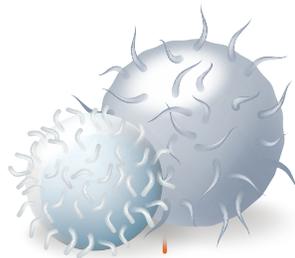
Stem Cells

Stem cells live in the bone marrow and will become the cells that make up your blood and immune system. This includes red blood cells, white blood cells, and platelets.



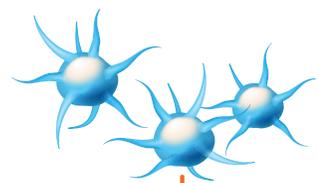
Red Blood Cells

Red blood cells are like delivery people. They deliver air (oxygen) all over your body and give you energy.



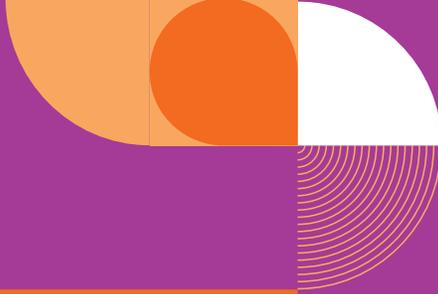
White Blood Cells

White blood cells act like police officers in your body to help protect you from infection (germs).



Platelets

Platelets are like construction workers in your body. They help build a scab to stop bleeding.

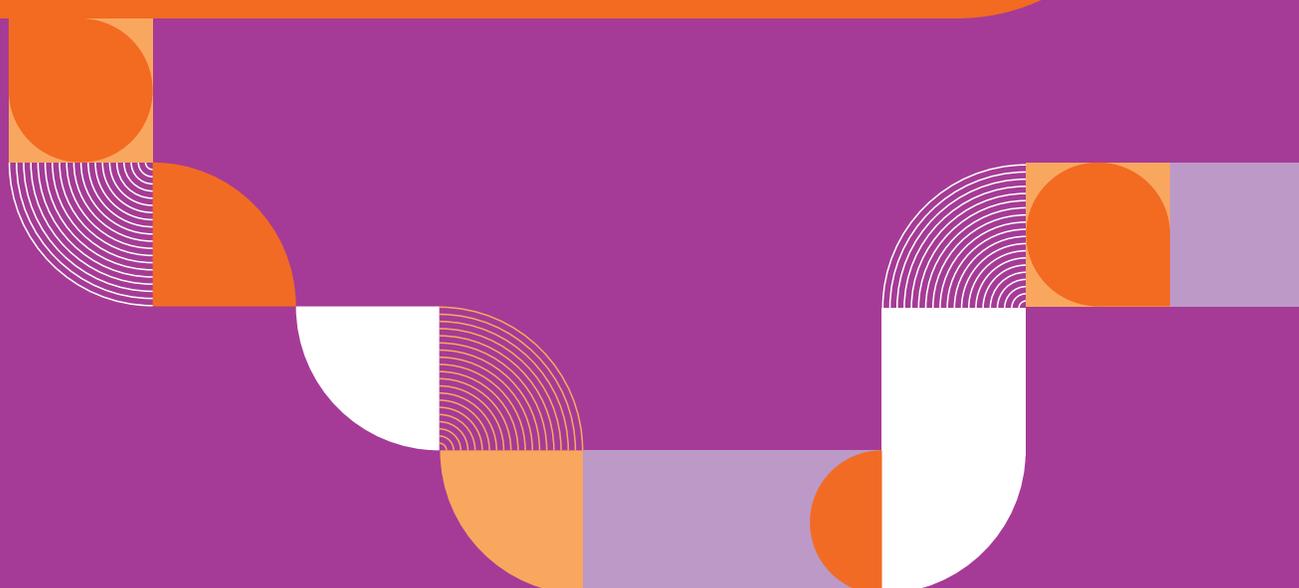


WHAT IF BONE MARROW IS NOT WORKING?

When the factory workers do not do their job correctly, that person's body doesn't make enough healthy cells. Sometimes it helps to get healthy cells from another person. These healthy cells come from a donor through a process called Bone Marrow Transplant.

WHAT DOES IT MEAN IF YOU ARE A DONOR?

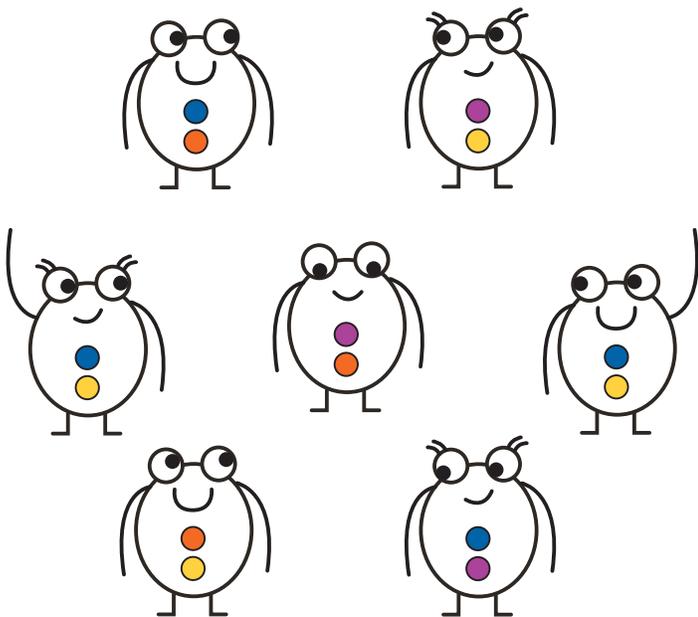
If you are chosen to be a donor for your sibling, that means your bone marrow is a good match with your sibling's bone marrow. Your healthy marrow can help their body grow healthy cells.



TIMELINE

1 Matching

We need to test your blood to see if your cells are a good match for your sibling.



2 Work Up Day

If you are a possible donor, you will get to meet the Donor Team – BMT Physician, Donor Advocate and a transplant coordinator. You will have some more blood tests, a chest X-ray and an EKG to make sure you are healthy and able to give your cells, if you want to.

3 Pre-Donation Testing Appointment

This usually happens right around the donation. We will need a few more blood tests and you will get a bracelet to wear for donation day. You and your caregiver will go through the consent with the physician. You will have the opportunity to ask additional questions.

4 Donation Day

We will let you know what time to come in the morning. It is usually very early! They will tell you what time to stop eating and drinking. You will come to the Same Day Surgery Clinic and the doctor will listen to your heart and lungs. At this time you can ask them any questions. After your procedure, they will do a blood test to make sure it is safe for you to go home. While this is happening, your cells are going to be counted and ready to give to your sibling. When the cells are ready, they will be given to them through their IV. If you would like to, you can watch. Afterwards, you can go home and rest. Your caregiver can give you pain medicine, if you are hurting anywhere. Please see pgs. 6-9 for more detailed information about your donation day.

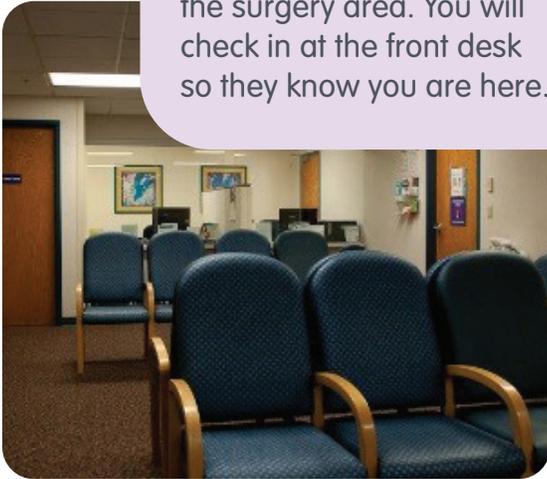
5 Follow-Up

Some one will call you a few days later to check in and make sure you are feeling better. You may need to come back to the clinic to see your doctor or you may follow up with your home doctor. They may want to do a blood test to make sure your cells are back to normal.

BONE MARROW HARVEST

What to expect

Your bone marrow procedure will take place in the surgery area. You will check in at the front desk so they know you are here.



You will have your blood pressure and temperature taken as well as your height and weight – these are called vital signs.



While you wait, the doctor will come visit you and your caregiver. This is a great time for you to ask any questions you might have.



You will pick out what you want your sleepy air to smell like.



When it is your turn to go back for your surgery, the nurse will walk you back. At that time you will tell your caregiver, "see ya later!"



The Operating Room

Your bone marrow harvest will take place in an operating room. You will sit on the bed in the middle of the room. Above you, you will see big lights that help the doctors see really well. This room is used for many different surgeries, so not everything that you see in the room will be used for you.



The Harvest

When you are asleep, lying on your stomach, the doctors will take some of the bone marrow from your hip bone. They will just take out the amount that is needed. You will wake up in the recovery room. It may be a little bit noisy because other children will also be waking up from surgeries. A nurse will be with you.

Transplant

When the person you're donating for gets your bone marrow, it will be like getting blood. They may feel pretty sleepy that day.



STEM CELL HARVEST

What to expect

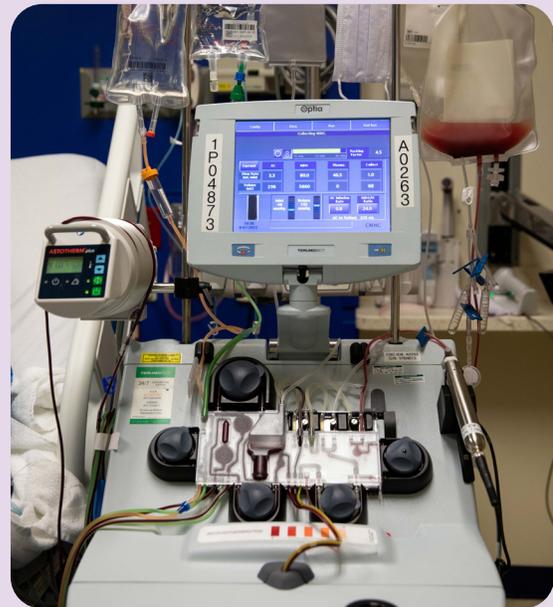


When you wake up, this is what your tubes will look like. They will have a special band-aid on them to keep them in the right spot.



When it is time for your harvest, your tubes will be hooked up to this machine. It does not hurt at all to get your tubes hooked up to the machine.

This is the machine that will harvest your cells. The machine's job is to separate the cells it needs from your blood. Some of your blood will go through your tubes and into the machine to be separated. The cells that are needed will be saved in a bag and the rest of your blood will go right back into your body through the tubes. This is called "harvesting." It's ok for the machine to take a little bit out of your blood. Your body still has all of the blood that it needs. While the machine is working, you will have to stay in your bed. You can watch a movie, play or rest in your bed during your harvest.





After your harvest, your tubes will be unhooked from the machine, and then you can get your tubes taken out. The nurse or doctor that takes your tubes out will use special soap to take the band-aid off first.



Once the band-aid is off, the nurse or doctor will use scissors to cut the stitches that are helping to keep your tubes in the right place. The scissors will never touch your skin or cut you, they are only to cut the string.



Next, the nurse or doctor will pull your tube out. They will ask you to take a breath in and then blow a big breath out. While you are blowing out, the nurse or doctor will pull the tube out. The nurse or doctor will then hold some gauze on your neck for approximately 15 minutes. After that, you'll get a new band-aid; then you're done!

AFTER THE TRANSPLANT

After the person you're donating for gets the new bone marrow, they will still need to stay in the hospital for a few weeks. This gives the new bone marrow time to travel all through their body and start making healthy cells.



BMT Unit

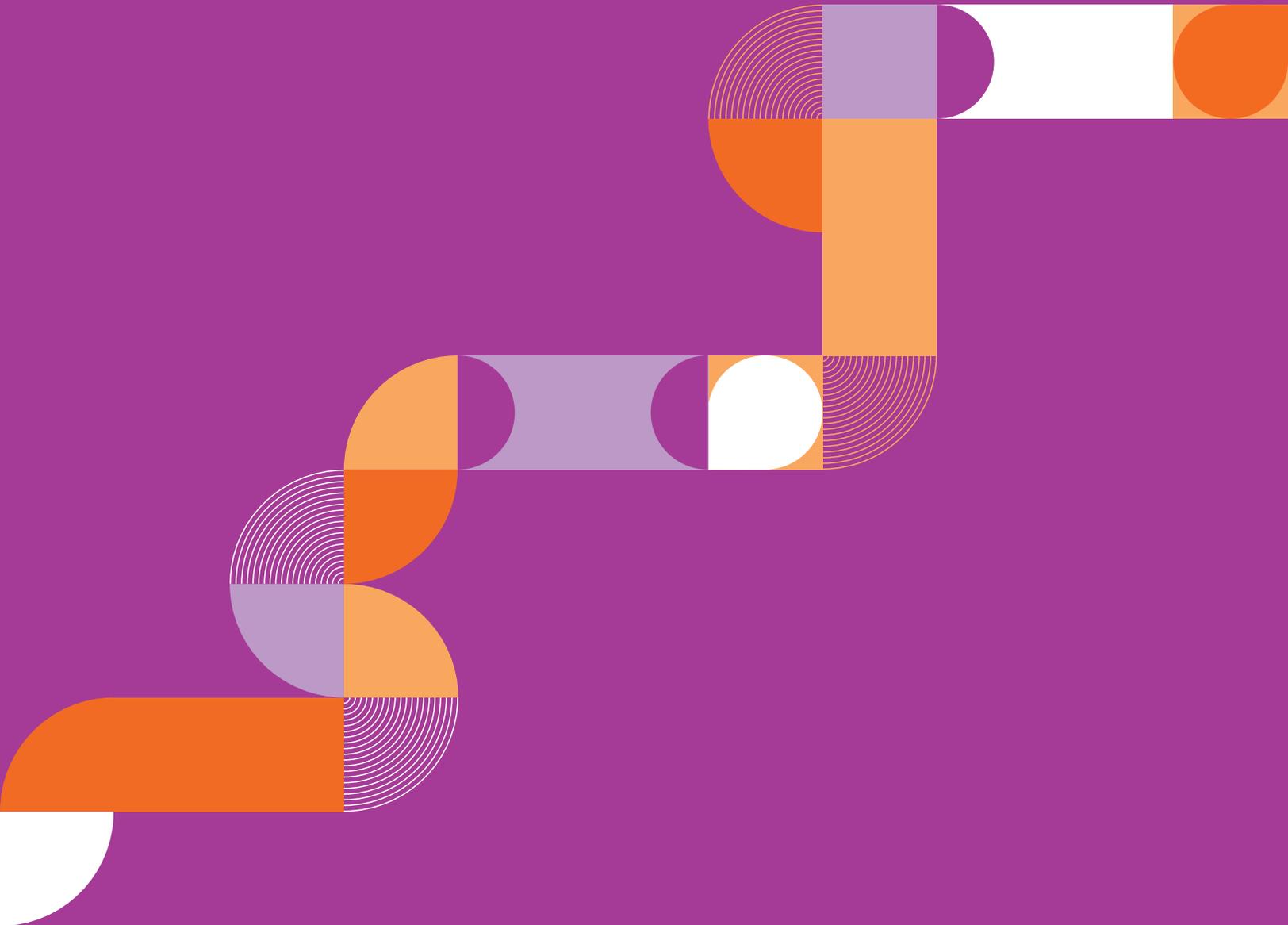
This is an example of where your loved one will be while they are in the hospital for the transplant. They will not be able to leave this area. This is to help keep them from catching germs while waiting for their new bone marrow to start working.

DONOR QUESTIONS

Word for Word by Julia

Julia's brother Jack has cancer and needs a bone marrow transplant. These are some of Julia's questions for her care team when she was thinking about becoming a donor for Jack.

1. How do you take the medicine out of me and put it in Jack?
2. How do you know how to put kids in the hospital?
3. Why is Jack in the hospital? (She would like to know how he got cancer).
4. This is a tricky question: why do the moms and dads have to wear hospital bracelets?
5. Why do parents have to be at the hospital with Jack and kids can't at night?
6. Why does Jack have to have a procedure on Wednesday? I mean dressing change.
7. Why do I have to give Jack the bone marrow transplant?
8. Will you have to do a needle through my skin?
9. What happens to Jack if you cannot find someone to match my brother?
10. How do you put the medicine in my brother without hurting him?
11. How do you get the medicine out of me?
12. Does it hurt when you get the bone marrow in Jack?
13. Will it hurt me?



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