CookChildren's®

Bone Marrow and Stem Cell Transplant Program

From the desk of Gretchen Eames, M.D., MPH

Cook Children's Hematology and Oncology Center is nationally recognized for the work we do in the fight against childhood cancers and blood disorders. We have been serving patients and their families since 1982. Cook Children's team of highly-skilled professionals is committed to helping patients and their families improve the quality of life for children, adolescents and young adults with caner or blood disorders. We do this every day by providing family-centered, personalized support and comprehensive instruction for families going through treatment.

The mission of Cook Children's Bone Marrow and Stem Cell Transplant program is two-fold; first, to provide the best possible care for you child and your family; second, to focus on prevention and finding the cure for these childhood cancers and blood disorders through dedicated scientific research and innovative treatment plans. Our program is one of the most diverse and experienced pediatric transplant programs in the Southwest.

As you enter into this chapter with your child, we are here to partner with you through every step of the way. Thank you for choosing Cook Children's.

Gretchen Eames, M.D., MPH

Medical Director
Cook Children's Hematology and Oncology Center
Bone Marrow and Stem Cell Transplant Program

Welcome to Cook Children's

For nearly 100 years, Cook Children's has been serving the community by providing expert medical care for pediatric patients.

- Our service area covers nearly half of the state of Texas.
- We impact the lives of children from around the country and around the world.
- Our award-winning medical center provides leading-edge technology and therapies through more than 30 specialties and subspecialties.
- Each year, we have more than one million patient visits to our medical center, neighborhood clinics, primary care offices and specialty clinics.

At Cook Children's, we understand that kids are not small adults and that their health care needs are different.

That's why our services are geared only to kids.

- From our child-sized equipment and furnishings to our child-friendly care environment, children are at the center of all we do.
- The result is a medical center that cares for the whole child, physically, emotionally and spiritually, and recognizes the important role that family members play in the healing process.

Pediatricians and pediatric specialists at Cook Children's are board-certified or board-eligible physicians. The medical center's staff of nurses, therapists, technologists and other clinical professionals also has expertise in the care of young patients. The skills of our staff are backed by a commitment to provide access to the latest technology and new medical techniques.

The goals of our Stem Cell Transplant program

1. To provide a stem cell or marrow transplant to any child who needs one.
2. To provide additional therapy options that will improve the lives of these children.

We work to achieve these goals through excellent clinical care from several services within Cook Children's, quality initiatives and ongoing comparison of our processes and performance against large academic transplant centers and international data.

Cook Children's Bone Marrow and Stem Cell Transplant program has been performing transplants in children with cancer, blood disorders or inherited conditions since 1986. Through the program's affiliation with the National Marrow Donor Program (NMDP), Cook Children's has access to donor registries from all over the world. These registries can find donors for bone marrow, peripheral blood stem cell and umbilical cord blood transplants. The Cook Children's Bone Marrow and Stem Cell Transplant program is a member of the Center for International Blood and Marrow Transplant Registry (CIBMTR), the Pediatric Bone Marrow Transplant Consortium (PBMTC) and the Children's Oncology Group (COG).

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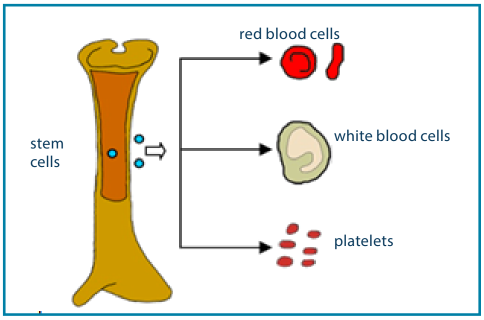
Understanding transplant

This page is for your notes

Stem cells

Think of stem cells as seeds



Blood is made up of four different types of cells

We need all of these cells to have a healthy body:

1. White blood cells — to fight infections.
2. Red blood cells — to carry oxygen and energy to our tissues.
3. Platelets — to stop bleeding and bruising.
4. Immune cells — to help protect us from infections.

All of these cells begin as "stem cells"

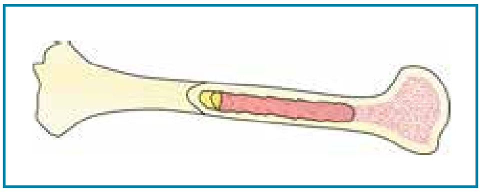
- Think of stem cells as seeds.
- Stem cells can grow up to become any type of blood cell that our body needs.
- For example, if our body needs more white blood cells, some of the stem cells will grow up to become white blood cells.

Stem cells and the bone marrow

Think of bone marrow as a big factory

Where we find stem cells

1. Think of bone marrow as a big factory that makes billions of stem cells for your body to use.
   Bone marrow is the spongy stuff inside all of our bones.
2. The stem cells are stored in the bone marrow until they are needed.
3. When they grow up, the stem cells leave the bone marrow and move into the blood, where they can do their jobs.



Stem cell transplant

Stem cell transplant can give you a new bone marrow factory

If your child's bone marrow factory is not working right because of cancer or another kind of damage, a stem cell transplant will get rid of your child's "old" factory and give them a brand-new factory that works the right way.

The doctors will decide who will be the best source of stem cells for your child's transplant.

The decision is based on your child's diagnosis and special blood testing called tissue typing (more about that later). In general, there are two types of stem cell transplant, and we define the type based on who will be giving the stem cells:

Autologous:

- Your child will receive their own stem cells.
- This type of transplant is often used for children with neuroblastoma; this type of transplant might also be used for Hodgkin lymphoma or certain types of brain tumors.

Allogeneic:

- Your child will receive stem cells from someone else who has a similar tissue type (more on this later). This donor might be a brother or a sister or maybe even someone you have never met.
- This type of transplant is often used for children with leukemia, lymphoma, severe aplastic anemia, certain metabolic or certain types of inherited problems of the immune system.

There are several steps in getting a stem cell transplant:
What happens during each step will depend on whether your child will be getting an autologous transplant or an allogeneic transplant.

Step 1: Finding the donor

Step 2: Harvest

Step 3: Conditioning

Step 4: Transplant

Autologous transplant

Autologous transplant is like "rescue therapy"

1. We give very high doses of chemotherapy to kill the tumor.
2. The high doses of chemotherapy will kill the tumor, but they will also wipe out your child's bone marrow factory.
3. After getting the high-dose chemotherapy, we give your child's own stem cells back to him or her. These stem cells will renew the marrow factory that was wiped out.

Step 1: Finding the donor

With autologous transplant, we collect your child's own stem cells.

Step 2: Harvest

Most autologous transplants involve collecting stem cells from the blood.

1. Your child's stem cells will be collected a few weeks or months before the transplant, after a cycle of regular chemotherapy.
2. After this cycle of regular chemotherapy, your child will be given daily shots of a special medicine called a growth factor. This growth factor causes the bone marrow to make more stem cell seeds.
3. We will check your child's blood every day to watch for signs that there are enough stem cell seeds to start collecting them.
4. When we are ready to start collecting, we will send your child to surgery to put in a special catheter to collect the stem cells.
    - This catheter is called an apheresis catheter.
    - It has two tubes (called lumens).
    - Your child will keep this catheter for several days, or maybe even several weeks.
5. We will collect your child's stem cells using a special machine.
    - The machine looks a lot like a fancy washing machine.
    - We do the collection in your child's hospital room.
    - A collection usually takes about four hours.
    - Sometimes we might need to do collections for two or three days to get enough stem cells for your child.

Autologous transplant

6. During the collection:
    - We connect your child's apheresis catheter to the special machine.
    - The machine will draw your child's blood through one of the tubes of the apheresis catheter.
    - The machine will spin the blood very fast (like the spin cycle on a washing machine), and the stem cells will separate out into a special collection bag.
    - The rest of your child's blood will go back into their body through the other tube of the apheresis catheter.
7. What to expect:
    - We will be checking blood pressure and temperature every 15 minutes.
    - Your child will need to stay in bed. Be sure to have things to do like read, watch movies, listen to music, play quietly or talk with family and friends.
    - Your child will not feel any pain during stem cell collection.
    - Tingling in the lips, fingers or toes; muscles twitching; or stomachache can all be signs of low calcium. This is caused by one of the chemicals used to keep the blood flowing through the tubing of the machine.
8. All the stem cells that we collect will be put into a special bag and then kept in a special freezer until your child is ready for them.

Be sure to tell the nurse about any of these symptoms so we can give your child calcium to help these symptoms go away.

Step 3: Conditioning — high-dose chemotherapy

1. A few days before your child receives their transplant, your child will be admitted to the Bone Marrow Transplant unit.
2. High doses of chemotherapy will be given over a few days.
3. The chemotherapy is given at much higher doses than before, in order to kill any tumor cells that might still be in your child's body.
4. After the last day of high-dose chemotherapy, your child may have a day of rest.

Step 4: Transplant

1. The day of transplant is called Day 0 (Day zero).
2. After being carefully checked by the doctors and nurses, your child's stem cells will be given through the central line like a blood transfusion.

Allogeneic transplant

Allogeneic transplants are done using stem cells that come from someone else

1. This person must have the same (or nearly the same) human leukocyte antigen (HLA) tissue type as your child.
2. Tissue type is determined by a special test called HLA typing where the doctors look at 10-12 special markers on the cells of possible donors.

HLA markers	HLA inheritance	HLA testing	HLA match
• Stands for human leukocyte antigen • Special proteins on outside of all our cells that help cells recognize foreign invaders • These proteins are called HLA markers	• People get half of HLA markers from mother and half from father • Two children with the same mother and father have a 25% chance of being an HLA match	• Compares 10-12 HLA markers • The test can be done on blood or by swabbing the inside of the mouth • We will test your child, any brothers and sisters and maybe even a parent	• The more markers that are the same, the better the match • The better the match, the less chance of a serious side effect called graft-versus-host disease (more about this later)

Step 1: Finding the donor

1. Allogeneic stem cells can come from different sources:
   - A fully matched related donor (usually a brother or sister who has the same mom and dad).
   - A fully matched unrelated donor (someone you have never met, who volunteered to help by signing up through a national or international donor registry).
   - Haploidentical—a donor who is a half-match, which is usually a mom, dad or a sibling. Parents are always a half-match for their children. Siblings (brothers or sisters) have a 50% chance of being a half-match for each other.
   - Umbilical cord (from mothers who generously donate the rich blood from their umbilical cord at the time that they give birth to a baby).
2. As soon as the doctors know that your child will need an allogeneic transplant, they will begin searching for the best donor.
   - This search may take weeks or months, depending on your child's unique HLA type.
   - First, we will check brothers and sisters to see if anyone is a match.
   - If there is not a good match in the family, we will begin a worldwide search through the National Marrow Donor Program (NMDP). The NMDP lists more than 10 million potential volunteer donors. The volunteers come from the United States, as well as around the world. Many cord blood programs also are included in the search.
   - All donors are volunteers. They do not receive payment for their stem cells.
3. Once we find the person with the best HLA match, whether related or unrelated, that person will have more bloodwork done to be sure that they are healthy. They will also have a physical exam.
4. When the doctors give final approval for the donor, your child's transplant date can be set.
5. We understand the wait for a donor may be very stressful.
6. The transplant coordinator will call you periodically with updates.
7. You are also welcome to call your transplant coordinator to discuss your concerns.

Allogeneic transplant

Step 2: Harvest

1. We usually collect the donor's cells on the same day that your child will receive them. This takes a lot of careful timing, especially if the donor is out of town.
2. The stem cells from a related or unrelated donor can be harvested from bone marrow or collected from peripheral blood. Your doctors and the donor's doctors will decide what is best.
3. If a brother or sister is a donor, your transplant coordinator will help you prepare the child for everything involved in being a sibling donor.

BONE MARROW

- When bone marrow is harvested, the donor is taken to the operating room for the procedure.
- The donor is asleep under general anesthesia.
- We take bone marrow from the hip bones using a syringe and needle.
- Collection usually takes about one to two hours.
- The donor usually feels some hip discomfort after the procedure.
- Pain medicine will be ordered if needed.
- Most donors go home the same day.

CORD BLOOD

- The umbilical cord of a newborn baby has a high number of stem cells.
- We can collect cord blood right after the delivery of a baby.
- Saving cord blood does not interfere with the normal birth process.
- We can store the blood in a cord blood bank freezer until needed.

Allogeneic transplant

Step 3: Conditioning

Before we can transplant the new stem cells, your body must be ready to receive them

1. About a week before the transplant, your child will have a central line put in. Even if they already have a port, we will put in a central line. Doing this will ensure that there are enough places to put all the IVs needed before, during and after transplant.
2. Your child will be admitted to the bone marrow transplant unit to begin the conditioning treatment. This is also called the preparative ("prep") regimen.
3. Think of it as cleaning the house before company comes.

What is the conditioning phase?

1. We use high doses of chemotherapy to get rid of all the bone marrow cells.
2. This includes the bad cells (the cancer cells) and also the good cells.
3. We may also use radiation therapy for conditioning.
4. Side effects of the conditioning regimen may include nausea, vomiting, mouth sores, diarrhea, fever, headaches, tiredness and jaw pain.
5. We will give your child medicines to help with all of these side effects.

Chemotherapy:

1. Destroys bad cells in the body (the cancer cells).
2. Destroys the immune system so it cannot fight against the new cells.
3. Empties the bone marrow to make more space for the new cells.

Radiation therapy (TBI)

1. TBI stands for total body irradiation. It is high-energy radiation we give over the whole body to kill any cancer cells that were not killed by the chemotherapy.
2. TBI will destroy the immune system so it will not be able to reject new cells.
3. Not all types of transplants need TBI as part of the conditioning regimen.
4. If your child is not able to lie still during the radiation treatment time, the doctor may decide to give your child medicine to put him or her to sleep for each TBI treatment.

Step 4: Transplant

The day of transplant is called Day 0 (Day zero).

After being carefully checked by your doctors and nurses, your child's stem cells will be given through the central line like a blood transfusion.

Allogeneic transplant

When a parent or sibling is the donor

If the tests show that a brother, sister or parent is a good HLA match

- We need to make sure the possible donor is in a good state of health.
- We will schedule a checkup and run more blood tests.

Families naturally tend to focus on their child who is ill

1. It is important, however, also to give extra attention to a brother or sister who is donating stem cells.
2. The brother or sister who is a donor should know that their contribution is precious and that donating marrow or stem cells is a selfless act of kindness.
3. It is also important to let the donor know what to expect.
4. Children cope better when they have information.
5. We can help you explain the transplant process in terms your child can understand.

If the stem cell recipient experiences serious problems,
it is very important that the donor understand the problems are not their fault.
Some donors feel guilty when a brother or sister remains ill after the transplant.

When the donor is unrelated

The donor may be a matched unrelated donor (MUD) or an umbilical cord blood unit (CBU).

- Your child's transplant doctor will discuss what the best option is for a stem cell source, MUD or CBU.
- The decision is based on degree of match and/or availability of donors.

All donors in the registries are volunteers. They receive no payment for their stem cells.

- Your transplant coordinator will not know the name of an unrelated donor matched to a patient.
- We are not allowed to reveal where the donor lives.
- Stem cell recipients are told their donor's age, gender, ethnic background and blood type.

NMDP allows anonymous contact between a donor and recipient during the first year following transplant.

- We encourage families to write to their donor and share how their child is doing.
- Often, donors wonder how their recipients are doing and are glad to get news.
- In your letter, no names or places of residence may be revealed.
- All letters must go through your transplant coordinator.
- If both parties agree, NMDP will release identifying information to donor and recipient.
- International registries may have different contact rules. Your transplant coordinator will have details.
- No information or contact is permitted if your child receives stem cells from an unrelated cord blood donation.