



Riley Hospital for Children
Indiana University Health

PRE-TRANSPLANT PHASE

PRE-TRANSPLANT

PEOPLE YOU MAY MEET

Stem Cell Transplant Clinical Coordinator:

The transplant coordinator is usually your first contact with the transplant team and will be your primary contact person during the pre-transplant phase. She will be scheduling tests, clinic visits, consults and helping prepare you/your family for the upcoming transplant. Your coordinator will also be the person who will update you on any donor searches, any procedures to be scheduled, admission plans etc. If you have any questions during this time about your upcoming transplant, please do not hesitate to call the coordinator.

Clinic Staff:

If you/your child is still receiving medical therapy, you will continue to see your regular hematologist/oncologist and/or nurse practitioner during this time. Our transplant team is always available to answer any specific transplant questions you may have.

Social Worker:

If you already have an assigned social worker at Riley, you will continue to see that person. If you are new to Riley, your family will be assigned a social worker who follows your child throughout his or her transplant. The social workers can help you cope with the stresses of illness and disability and can provide you with support and information. They can also offer help with emotional difficulties, unemployment, family or marital problems, or other problems that may be troubling you or your family.

Child Life Specialist:

A Child Life Specialist assists children, adolescents and their families adjust to illness and extended hospitalizations. They focus on the emotional and developmental needs of children throughout the transplant process. You/your child usually will have an opportunity to meet with a Child Life Specialist before you/your child's transplant admit. Also, if you have a child who will be the stem

cell donor, child life will meet with both donor and recipient to provide “medical play” opportunities for them. This can often help in the transition to transplant.

Physician:

These doctors are board certified in pediatric hematology and oncology and have also received additional specific training for transplant. You will meet one of the transplant physician's for a "consult" meeting (sometimes referred to as a “transplant 101 meeting”). During this meeting, the physician and coordinator will explain more about stem cell transplantation. Please do not hesitate to ask questions! We want you to understand this process as much as possible. After your consultation meeting, you may have as many conferences with the transplant physician as you need to feel comfortable and informed about the whole process. Please ask your coordinator if you have any questions!

MEETINGS BEFORE THE TRANSPLANT ADMIT

Stem Cell Transplant Consult (“101 Stem Cell Transplant Meeting”)

As mentioned above, you/your child will meet with a transplant physician and coordinator prior to your stem cell transplant admit. During this meeting, some of the things we will discuss include the following:

- Your child’s treatment plan (sometimes called “conditioning prep”), including chemotherapy and the possibility of Total Body Irradiation (TBI). We will discuss possible side effects and possible risks and benefits.
- How long you/your child is expected to be in the hospital for the Stem Cell Transplant admission as well as frequency of follow up appointments in clinic after you are discharged from the hospital.
- Special care needed for you/your child after transplant and why this is so important.

We know this is a lot information to absorb! Feel free to ask questions. This conference typically occurs about 1-2 months prior to you/your child’s expected admit for transplant. The length of the meeting depends upon how many questions you might have, but generally is at least 60 minutes. The decision to have the patient attend the conference will depend upon the child’s age and maturity level. Your transplant coordinator can discuss this further with you.

Consent Conference

You/your child will be scheduled for a second physician conference to review all your pre Stem Cell Transplant work-up testing results, to review the treatment plans and to ask any remaining questions you might have regarding the transplant process. At the end of the meeting, you/your child will be asked to sign legal consents for the transplant. Whenever possible, your coordinator will provide copies of these consent forms for your review prior to the meeting. Also at this appointment, the patient is seen by a Stem Cell Transplant physician and Nurse Practitioner to ensure the patient is able to proceed to transplant. This meeting usually occurs about one week before you/your child is expected to be admitted for transplant.

WHAT IS STEM CELL TRANSPLANTATION?

Stem cell transplant is a treatment plan which consists of high dose chemotherapy and possibly total body irradiation (TBI), followed by a "rescue" with stem cells. Bone marrow is a spongy material found in the center of your bones. It is the "factory" where your body's blood cells are made. Inside your bone marrow are worker cells called stem cells. Their job is to produce three types of blood cells: red blood cells, white blood cells and platelets. These stem cells may be from your child (autologous) or from another source, such as a brother, sister, parent (allogeneic) or even a donor who is not related to your child (unrelated allogeneic).

Your clinical coordinator and your social worker will give you books and/or pamphlets to read to help you better understand this process. During your transplant conference, the transplant physician will explain how a stem cell transplant/bone marrow transplant will specifically help you/your child.

AUTOLOGOUS OR ALLOGENEIC?

Your child's physicians will make a decision about the best source of the stem cells. This decision depends in part upon your child's diagnosis. An autologous transplant is when the stem cells transplanted into the patient are his/her own cells. An allogeneic transplant uses stem cells from another person. Your physician will discuss this with you in detail.

CONDITIONING REGIMEN:

You will be hearing the words "conditioning" or "preparative regimen." This refers to the therapy your child will receive before the infusion of stem cells. The type of conditioning depends upon your child's disease and the source of the stem cells. Conditioning may include IV chemotherapy and/or radiation. The purpose of the conditioning regimen is to prepare your child's body for the stem cell transplant. This may be necessary in order to:

1. destroy any cancer or abnormal cells that might be present
2. prevent the body's immune system from rejecting the transplanted stem cells

Chemotherapy is given in large doses through you/your child's central line, to destroy the cancer or abnormal cells. However, it will also destroy the bone marrow, preventing the body from making red blood cells, white blood cells and platelets. The body's ability to fight infection is also affected. The drugs and their side effects, which can range from mild to severe, will be discussed with you by the transplant physician during the pre-transplant conference.

Total body irradiation (TBI) is radiation treatment to the entire body. This also destroys the bone marrow and causes similar side effects as the chemotherapy. TBI is usually given over 3-4 days, depending on your child's research protocol or treatment plan. Your child will go to the Radiation Oncology Department for these treatments. TBI may be done as an outpatient or inpatient depending upon you/your child's treatment plan. If TBI is done as an outpatient, your child will need to stay in Indianapolis (usually stay at the Ronald McDonald House if you live out of town) during that time. This will be decided by the transplant physicians on an individual basis

HLA TYPING

Depending on your child's disease and/or type of transplant, your child's doctor may have requested that your child and immediate family members (parents of child and full siblings) have a blood test called Human Leukocyte Antigen, or HLA typing. This is a blood test taken from a vein in you/your child's arm (like other lab tests you/your child may have had before). The lab technician will collect a small amount of blood, and it will be sent to a lab in Riley Hospital. The lab then does a series of tests on this blood to see if anyone in the family is a "match" (has the same tissue type). The lab will be looking at the chromosomes, or the cells that make up who we are. To be a good "match", a donor must have nearly identical cells to the patient. The blood "type" (A, B, etc.) may be the same or different. This will not have an effect on a stem cell donor match.

Everyone is born with pairs of chromosomes (genetic material): half from their mother, half from their father. In a family, each child has a one in four chance of having the same set of genes as his/her brothers or sisters. This is because the chromosomes from mother and father can combine in four different ways.

This does not mean if you have more than four children, you will have a match. The chances are 25% with each child. Think of it like a coin toss. With each toss there is a 50% chance of it being "heads". The clinical coordinator or your child's transplant physician will explain this to you in greater detail.

The HLA typing results should be available in 7-10 business days (i.e. does not include weekend days or holidays). Your child's primary hematology/oncology doctor will let you know as soon as the results are available.

DONOR SEARCH

If your child does not have a close match within your immediate family, we may proceed to a "donor search". There are two sources of unrelated stem cells to be searched: bone marrow registries and cord blood registries.

The National Marrow Donor Program (NMDP)

The search for adult bone marrow donors is done through the National Marrow Donor Program (NMDP), which is also referred to as the Be The Match Registry. The NMDP is a non-profit organization which works to find bone marrow donors for patients of all ages. It is a worldwide network, with over **11** million potential donors and more than 193,000 umbilical cord blood units in the registry.

Searching through this bank for a potential donor for you/your child is a process involving many steps. First, your child's HLA typing will be entered by your transplant coordinator into the registry. You/your child's HLA typing is then compared to all of the potential donors in the registry. Usually on the same day we enter this information into the registry, we receive a preliminary search report, which provides a "first look" about how many potential donors your child may have. You will receive an information packet in the mail from the NMDP after the initial search is completed which will give you basic information about the registry and bone marrow transplants.

From this report, the transplant physicians will decide which, if any, donors on the list are potentially good matches for your child. At this time, we will request further testing of this donor and a formal search is activated within the NMDP. In other words, the NMDP will then attempt to contact the potential donor(s) we request for further testing. This is referred to as the "confirmatory typing" stage of the process. Blood will be drawn from a donor in a lab near where he/she lives and will then be shipped to our lab for comparison to your child's blood. The coordinator will keep you updated as to how the search process is going. ***Please Note: this can be a long and frustrating experience for you. The average time it takes for a patient to be transplanted (with bone marrow from an unrelated donor) from the time a search is activated is 3- 6 months!** Sometimes, a donor's situation has changed and they are unable to be contacted or for a variety

of reasons, are no longer able or willing to be a donor. We tell you this not because we want to scare or worry you, but so you know what to expect.

Once a donor is identified through the NMDP to be a confirmed match, a chain of events is set into motion. The transplant physicians will discuss with your primary doctor and you the best timing for your child's transplant. If your donor is an unrelated adult donor, the donor is notified that she/he has been requested for a certain patient. The donor is then scheduled for an information session. During the information session, the donor is told the process of donating marrow, as well as the risks involved. The donor will then undergo a physical exam and lab work to ensure that she/he is in good health. The donor will be asked to sign a "letter of intent", which says that she/he has agreed to be a stem cell/bone marrow donor. The tentative date of the transplant would then be set. The donor's stem cells are harvested in a donor center near where she/he lives, and the cells are hand carried to our hospital where they are then infused into your child, usually on the same day they are collected. If we are using cord blood cells, the Cord Blood Unit, which is stored frozen, will be shipped directly to the transplant center, usually arriving in our lab 2 days before starting you/your child's preparative regimen (high dose chemo, radiation, etc.).

IMPORTANT NOTE: You will not know the name, location or any contact information of your donor at the time of you/your child's transplant.

We are required to follow strict National Marrow Donor Program (NMDP) confidentiality rules to protect the privacy of both you/your child and you/your child's donor. You will not be able to learn the name of your donor for AT LEAST one year after your transplant. Sometimes you may never learn the identity of your donor. Your coordinator can further explain this process to you.

Cord Blood Banks:

Unrelated stem cells may also be found through the cord blood registries which are part of the National Marrow Donor Program (NMDP). When a mother gives birth to a baby in participating hospitals, the placenta may be "drained" of all the blood, which is really rich in stem cells. This blood is then typed and frozen for later use. At the same time a NMDP adult donor search is initiated, a cord blood search is too. If a cord blood match is found and felt to be a potentially appropriate donor

choice, additional testing called confirmatory typing will be performed on the cord blood. Once it has been determined that a cord unit is a match, is an appropriate donor choice for the patient and the patient has successfully completed work-up testing, the cord blood unit is ordered and sent to our hospital to be used for transplant when the patient is ready. Because the cord blood units are frozen, they are readily available for use once confirmatory typing is complete, usually within 2 – 3 weeks of being requested.

PRE-TRANSPLANT WORK-UP PHASE

Once a tentative admission date for your child's transplant has been scheduled, the clinical coordinator will schedule a number of tests and labs to evaluate the current overall status of your child's health. These tests are usually referred to as “work-up testing”. The following is a list and explanation of most of the tests. This list may change with each child, depending on his/her needs. The clinical coordinator will further explain anything not included on this list. Some of these tests may take up to 7 business days to be processed before results will be known.

PRE TRANSPLANT TESTS:

Infectious Disease screen: This is a blood test to check for any infectious diseases your child may have been exposed to. Some of these include the following: hepatitis viruses, varicella (chicken pox), herpes virus, cytomegalo virus, and the human immunodeficiency virus. All of these tests are required before transplant by state law for both the patient and the donor.

Blood typing: This is done on both the donor and the patient. It gives us more detail about each person's blood type.

Immunoglobulin levels: Tests current state of immune system.

Thyroid and hormone levels: Tests current state of thyroid and hormonal function.

Coagulation studies: Tests how well the blood clots.

Echocardiogram: Checks how well the heart muscle is pumping blood.

EKG: Checks the heart's electrical system.

Pulmonary function Tests (PFT's): tests the lung functioning (not usually done on children <7 years old).

Urine for creatinine clearance: This is a 24 hour collection and checks how well the kidneys functions (usually only done if the blood draw GFR is not available).

Blood Draw GFR (Glomerular Filtration Rate): Checks how well the kidneys function. This test involves an injection of dye into one of the lumens of the patient's central line, port or peripheral IV. Blood samples are then drawn 1 hour

and 3 hours after the injection from the other lumen of the central line, port or peripheral IV. It is important you/your child drinks lots of fluids the day before and the morning of this test as not having enough to drink may affect the results.

Audiogram: Baseline hearing test (depends upon patient's previous treatment)

Dental Exam: Looking for cavities or other problems in the mouth which could cause infections during or after Stem Cell Transplant.

Bone marrow aspirate and biopsy: If your child has a disease involving the marrow, a marrow aspirate will be done prior to treatment. Depending on the disease and type of donor, a marrow biopsy may also be done.

Lumbar puncture: In children with oncologic diseases the spinal fluid will be checked pre-treatment for presence of disease.

Specific diagnostic scans including CT scans, MIBG scans, MRI, or various x-rays may be done depending on your child's disease.

Child psychology: If your child has been seen previously by this department or has concerns about coping with the transplant, the coordinator can arrange for a consult pre admission. Most patients interact with Child Psych in some form during transplant. All patients admitted for transplant are seen at least once by the child psychology team during their admission.

Social Work Pre Assessment: In order to authorize or "pre-certify" stem cell transplant admissions, most insurance companies now require a licensed social worker meet with you/your child before transplant. During this meeting, your Riley social worker will ask you/your child basic questions about who lives in your home, what your plans are for care during and after transplant and will explain to you/your child important transplant resources.

WHEN WILL MY CHILD BE ADMITTED?

Your child's primary hematology/oncology doctor will be talking often with the transplant clinical coordinator and the transplant physicians to ensure the best timing of the transplant. Sometimes, a child may go almost immediately to transplant after he/she is referred to the transplant team. More often, it may be many months up to even a year before the transplant occurs. Once an admission date is planned, the coordinator will work closely with you to make the admission process run as smoothly as possible. You will receive a calendar from your transplant coordinator with upcoming dates for work-up testing and transplant admission plans once this information is known. It is important to remember this information changes quickly and it is very likely you will receive several updated calendars before the actual transplant admit!

BEFORE YOU ARE ADMITTED:

You will be given a tour of the Stem Cell Transplant (SCT) Unit before your child's admission, usually by your clinical coordinator or by the SCT unit staff. During your pre Stem Cell Transplant conference/101 with the transplant physician and coordinator and through general education from your coordinator, you will learn about the following:

- What to bring to SCT
- Expected length of stay
- Inpatient Staff Members
- Isolation requirements
- Visiting hours
- Nutrition during and after transplant
- Discharge planning (preparing for home after transplant)

This information is presented in the in-patient section of this book in greater detail and sections will also be reviewed in greater detail by your inpatient nursing team.

ADMISSION DAY:

On the day of your child's admission to the hospital, you will need to register before coming to the SCT Unit. Registration is located in the main lobby of the Simon Family Tower. Your coordinator will let you know what time you should arrive. Please bring you/your child's insurance cards with you when you register.

PRECAUTIONS PRE-TRANSPLANT

Once it is known you/your child will have a transplant, we recommend you/your child observe the following guidelines:

1. Avoid areas of construction.
2. Avoid trips to wooded areas and farms.
3. Avoid trips to foreign countries.
4. Avoid open fires (i.e. campfires, wood-burning stoves)
5. Avoid people who are sick

IMPORTANT NOTE:

* If your child develops a cold, cough, etc. just prior to transplant admit date, it is very likely that the transplant will be postponed until you/your child is healthy.

Please contact your coordinator as soon as possible if you notice any cough, cold, fever, etc.

ALTERNATIVE MEDICINE

There are many forms of alternative medicine available. Many of these therapies may be harmful, especially in a child who is preparing for or who has undergone a stem cell transplant. Some of the therapies have led to injury such as infections, muscle and bone damage, nausea, vomiting, extra hospitalizations, dehydration, changes in body metabolism and rarely death.

If you choose to use alternative therapies, we ask that you tell us which treatments are being used. This will enable us to evaluate their side effects with you, investigate potential interactions with prescribed medications and review with you any potential harm they may cause.

Some examples of common alternative medicines are listed below. Not all listed have harmful side effects and we would be happy to review any information you have regarding any of these or other therapies:

1. Vitamins: megavitamins.
2. Herbal medicines: Chinese preparations, Native American preparations, homeopathy, naturopathic medicine, flower therapy.
3. Dietary: macrobiotic diets, vegetarianism, dietary supplements.
4. Glutathione: Mucositis
5. Meditation: biofeedback, hypnosis, Klerian photographs, qigong.
6. Biological treatments: biological cancer treatments, epitherapy, biological dentistry, cell therapy, chelation therapy, colon detoxification (enemas), enzyme therapy, neural therapy, oxygen/ozone therapy, shark/bovine cartilage.
7. Body work: acupuncture, Alexander technique, craniosacral therapy, hydrotherapy, reflexology, rolfing, Tai Chi, yoga.
8. Sense therapy: aromatherapy, humor therapy, light therapy, sound therapy.

9. External energy: crystals, electromagnetic, faith healing, shamanism, therapeutic touch.

10. Use of marijuana.

If you have an interest in a therapy not listed, please let us know so we can research any potentially harmful side effects.

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