

PENN STATE CHILDREN'S HOSPITAL



**PEDIATRIC STEM CELL TRANSPLANT
PATIENT CARE GUIDELINES**

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IMPORTANT PHONE NUMBERS

- **Children’s Hospital Toll-Free Number** 1-866-204-0035
- **Hershey Medical Center Operator** 717-531-8521
- **Keri Blouch, RN** 717-531-0003 ext. 285868
 Pre -Transplant Coordinator
 Pager: 717-531-8521, pager 2400
- **Outpatient Pediatric Stem Cell Transplant Clinic** 717-531-4904
- **Pediatric Hematology/Oncology Office** 717-531-6012

WHEN AND WHO TO CALL...

- Monday-Friday 8:00 a.m. 4:00 p.m., call the Outpatient Pediatric Stem Cell Transplant Clinic at (717) 531-4904 or call The Children’s Hospital operator toll-free at 1-866-204-0035 and ask to be transferred to the Outpatient Pediatric Stem Cell Transplant (Bone Marrow Transplant) Clinic at extension 4904.

- Emergencies, after 4:00 p.m. on weekdays, all day Saturday and Sunday, and holidays, call the Hershey Medical Center operator at (717) 531-8521 or call the Children’s Hospital operator toll-free at 1-866-204-0035. Tell the operator that your child has had a stem cell transplant and ask to have the Pediatric Stem Cell Transplant (Bone Marrow Transplant) Attending Physician On-Call Paged.

I. INTRODUCTION

The prospect of your child undergoing a stem cell (bone marrow, peripheral blood stem cell, or umbilical cord blood) transplant often results in many new questions and concerns. We have prepared this handbook to help you and your family understand what happens before, during and after transplant.

A stem cell transplant requires a team effort. You are an important part of that team. You have the right to be informed about your child's condition as well as the right to understand treatments, tests and procedures that may be part of your child's care. During your stay at Penn State Children's Hospital, the transplant team will discuss your child's treatment every day. As part of our team, we value your input and participation in these discussions.

We encourage you and your child to ask questions and to express your concerns. Writing down your questions may help to remember them when we talk. There is a Notes section in the back of this book for this purpose. You may want to also obtain a small spiral-bound notebook in which to write down your questions and to keep track of major events during transplant.

Your child's nurse, physicians and other members of the transplant team will review things with you one step at a time. Please ask about anything you don't understand.

This handbook is yours to keep. You may need to refer to it often, so please keep it handy. We ask that you share it with family and friends. Feel free to write on any of the pages and fill in the "blanks" provided for you.

OVERVIEW OF TRANSPLANT

Body Systems

In order to prepare you and your child for stem cell transplantation, a general understanding of body systems is helpful. This section briefly outlines the functions of the body systems most commonly affected by transplantation.

A. Bone Marrow Bone marrow is the spongy material in the center of the bones. It is the blood factory for the body where three types of blood cells are made:

- **Red blood cells (RBCs)** are the oxygen carriers of the body
- **White blood cells (WBCs)** are infection fighting cells
- **Platelets** are helpful in forming clots which stop bleeding

Stem cells are immature cells from which red blood cells, white blood cells and platelets all develop. Many of the bones in our body contain bone marrow. The most accessible part of bone marrow is in the hip bones (iliac crests). This is the location that is used most often to harvest and test bone marrow.

B. The Immune System The immune system is made up of many different organs including the thymus gland, the spleen, lymph nodes and bone marrow. The cells of the immune system are the white blood cells. They help the body to fight infections and to recognize tissues which are not its own. When your child receives a stem cell transplant, we temporarily “turn off” the immune system with either chemotherapy alone or a combination of chemotherapy and radiation therapy. Other medications your child may receive (steroids, ATG) also affect the immune system. These disruptions of the normal immune system temporarily increase the risk of infections and other complications.

C. The Heart and Lungs These organs are responsible for keeping the blood circulating and for keeping the right amount of oxygen and carbon dioxide in the bloodstream.

D. The Liver and Kidneys These organs are responsible for processing substances within the body and for removing harmful materials as they accumulate.

What is a Stem Cell Transplant?

A ***transplant*** is the transfer of a living organ or tissue from one person to another or from one body part to another. In this case, the transplanted tissue is bone marrow, peripheral blood stem cells, or umbilical cord blood. These are taken from a donor and then administered to your child after chemotherapy (and possibly radiation therapy) has been given.

Some diseases treated with stem cell transplantation include:

- Acute Lymphoblastic Leukemia (ALL)
- Acute Myelogenous Leukemia (AML)
- Chronic Myelogenous Leukemia (CML)
- Lymphomas
- Neuroblastoma
- Metabolic Disorders (Hurler's, Krabbe's, Adrenoleukodystrophy)
- Solid tumors
- Brain tumors
- Immune deficiencies (SCID)
- Aplastic Anemia (AA)
- Bone Marrow Failure Syndrome
- Hemoglobin problems (Sickle cell disease, Thalassemia)

There are several types of transplants. Each type is named according to the donor of the stem cells.

- **Allogeneic** The infusion of stem cells (bone marrow or cord blood) from one person to another. Stem cells are usually from a specifically-typed and matched family member (sibling or parent) but may be from an unrelated donor.
- **Syngeneic** The infusion of stem cells from one identical twin to the other.
- **Autologous** The infusion of your child's own stem cells. The stem cells are removed, treated, usually stored by freezing and then given back to the patient at a later date.

A stem cell transplant may be necessary for several reasons:

- When the body stops producing enough of one or all of the blood cells that it needs
- When the body produces abnormal (cancer) cells
- When the body receives extremely high doses of chemotherapy that would otherwise kill the bone marrow. Here, the transplant is used as a “rescue” to restore the bone marrow
- To correct a genetic or metabolic defect by replacing a missing substance (enzyme) in the body

Blood Counts

Blood specimens will be taken frequently from your child in order to measure the amount of circulating white blood cells, red blood cells and platelets. The results of this laboratory test are known as a “**blood count**”. Blood counts are not only important in helping us determine if and when your child needs transfusions of red blood cells or platelets, but they can also give us an idea of the child’s progress post-transplant.

As mentioned earlier, there are three major types of blood cells that are produced by the bone marrow: red blood cells, white blood cells and platelets. These cells start out as immature forms (stem cells) in the bone marrow. Once they mature, they are slowly released into the blood stream.

Chemotherapy works by killing cells that grow rapidly in the body. Cancer cells grow rapidly, so they are killed by chemotherapy. Other cells in the body (hair making cells, skin cells, blood-forming cells and cells lining the mouth and intestines) also grow rapidly, so they are also injured by chemotherapy. Because blood-forming cells grow rapidly, chemotherapy causes a decrease in the number of these cells. We call this a **low blood count** and it is an expected part of the transplant. Your child’s red blood cell count, white blood cell count and platelet count will all be extremely low during transplant. The white cell count will usually drop to zero.

Until your child’s transplanted stem cells have a chance to recover and begin making blood cells, your child will require red blood cell and platelet transfusions to replace the cells that are not being made. Unfortunately, it is not always possible to give WBC transfusions in this manner. Instead, your child will receive medications (antibiotics) to help fight infections. A medication, growth factor (Granulocyte Colony Stimulating Factor or GCSF) may be used to help your child’s white blood cells to grow more rapidly.

You may want to know how to read and understand a blood count. The following section may help you. Please refer to the chart of **Normal Blood Count Values** at the end of the section.

A. Red Blood Cells carry oxygen from the lungs to all areas of the body. Once they release oxygen to the tissues, they transport a waste product called carbon dioxide back to the lungs to be released as we breathe out (exhale).

- Hemoglobin is the part of the red cell that carries the oxygen. When the hemoglobin (Hgb) is low, we call a patient anemic. When your child is anemic, they experience symptoms that may include: shortness of breath, weakness, tiredness, paleness, dizziness, “racing of the heart”, irritability and a cool feeling of the body, especially the arms and legs. *Red blood cell transfusions are usually given for a hemoglobin value less than 8.0.*
- Hematocrit (Hct) is the percentage of blood, by volume, made up of red blood cells. When the hemoglobin is low, the hematocrit is also usually low.

B. White Blood Cells help prevent and fight infections. The WBC count is actually the total number of white cells counted in a certain volume of blood. Because there are different types of WBCs , (listed below) we also perform a **differential** that counts the percentage (the number per 100 WBCs) of these different types.

Types of White Blood Cells:

- Neutrophils are the body's first line of defense in fighting infections, particularly bacterial infections.
- Lymphocytes (lymphs) produce antibodies, fight viral and fungal infections, and ward off chronic infections.
- Monocytes (monos) play a minor role in infections. They are often the first cells to return in recovering marrow.
- Eosinophils (eos) play a role in allergic reactions.
- Basophils (basos) increase blood flow to injured tissues.

One measure of how well your child can fight an infection is the **Absolute Neutrophil Count** (ANC). The ANC tells us the number of cells that are mature enough to fight infections. The following formula is used to calculate the ANC:

Total WBC x (% Neutrophils) = ANC

Example: WBC's = $2.0 \times 10^3 = 2000$
 (Add three places after the decimal point)
 Neutrophils = 48%

$$2000 \times .48 = 960 \quad \mathbf{ANC = 960}$$

Here are some for you to try:

- | | |
|---------------------------------------|--|
| 1. WBCs = 1000
16% Neutrophils | 2. WBCs = 2,500
25% Neutrophils |
| 3. WBCs = 850
8% Neutrophils | 4. WBCs = 100
2% Neutrophils |

Answers: 1. 160 2. 625 3. 68 4. 2

When your child's ANC drops below 500 they are at an increased risk for infection and must wear a mask when out of their room.

Signs of infection include:

- Temperature greater than 38°C (100.4F) by mouth/axilla
- Cough, rapid breathing
- Runny nose
- Diarrhea (loose, watery stools)
- Sore throat, earache
- Burning with urination
- Redness, warmth or swelling in an area (especially at central line site)
- Drainage from an open area or wound

C. **Platelets** are cell fragments that help prevent bleeding. They act like tiny patches that plug up leaks. When your child's platelet (plt) count gets low, their risk of bleeding increases. Signs of bleeding include:

- Bruising
- Nose bleeds
- Bleeding around teeth and gums
- Bleeding around puncture sites, cuts, scrapes
- Blood in urine
- Blood in stool (stool may be very dark)
- Petechiae (small red or dark purple spots the size of a pencil point on the skin)

Usually, a platelet transfusion will be given to your child if their platelet count drops to 20,000 or less.

NORMAL BLOOD COUNT VALUES			
<u>WBC's</u>		4.0 - 10.0	
	Segs	54 - 75%	<u>Hct</u> Male .39 - .49
	Bands	3 - 8%	Female .33 - .43
	lymphs	25 - 40%	
	Monos	2 - 8%	
	EOS	1 - 4%	
	Basos	0 - 1%	
			<u>Platelets</u> 150,000-450,000
<u>Hgb</u>	Male	10.5 - 16.0	
	Female	12.0 - 15.0	

II. PREPARING FOR TRANSPLANT

Family Conference

Before your child's treatment begins, you and your family will be asked to participate in general consultations with members of our team who will be directly involved in your child's care. You will be given information about the transplant process and will have many opportunities to ask questions. A great deal of information will be provided to you during this conference.

In a separate meeting, you will be asked to sign consent forms giving permission for your child's transplant. You will be given copies of these forms after you sign them. **You are encouraged to put your copy of the consent(s) in this section of your handbook.** All of the information given to you will be repeated many times during your child's admission, so do not worry if it seems as though you cannot "digest" it all. All parents feel this way!

Pre-transplant work-up

Your child will need to undergo a number of tests and procedures prior to receiving their stem cell transplant. Many of these will be done in the outpatient department. Some of the things that may be done include, but are not limited to:

- Blood work
- Chest X-ray or CT of chest
- Heart studies (ECHO)
- Lung studies (Pulmonary function tests)
- Eye and dental examinations
- Spinal tap
- Bone marrow aspirate/biopsy

There may be other imaging studies (x-rays, scans) that are necessary to evaluate the extent of your child's disease. These studies are done so that we know the exact state of your child's health prior to the transplant. You will be well informed as to which of these tests your child will need. Your child will have a double lumen, central venous catheter placed.

As many of these tests and procedures as possible will be scheduled for your child prior to their actual admission to the transplant unit. The work-up process may take one to two weeks.

Central Line Catheter Placement

For your child's stem cell transplant, they will need a special IV (catheter), called a central line, which will be inserted by a surgeon early on in the transplant process. This catheter is generally called a "Broviac catheter". The advantage of having a central line is that it eliminates most of the need to draw blood by a needle stick. We can use this central line to give chemotherapy and other medications, to give blood products, to give nutritional fluids, to draw blood and to infuse bone marrow, stem cells or cord blood. **Remember**, there may still be times when blood must be drawn from your child by a needle stick.

The Broviac catheter will be inserted in the operating room or in the radiology department while your child is asleep. The catheter itself is a soft, flexible tube that is inserted into a large vein in the chest that leads to the heart. This tube extends to the outside of the chest where it exits and may divide into two or three separate tubes (lumens). The Broviac catheter will remain in place throughout the stem cell transplant and most likely will be left in place for many weeks or even months. We will teach you and your child how to care for this line on your own so that you can care for it properly after you leave the hospital. The surgeon will fully inform you of the risks and benefits of central line placement prior to the surgery.

What to bring to the hospital

We want to make your child's stay in the hospital as pleasant as possible. However, space is extremely limited on the unit. For this reason, we ask that you limit the amount of personal items that you bring for both yourself and your child. We highly recommend that your child wear their own clothes everyday.

The following is a checklist of some items you may want to bring with you for your child:

- One week's worth of clothes (Please wash before bringing them and place in plastic bags or totes)
- Pajamas
- Basic toiletries, including a child-size soft toothbrush
- Slippers or sandals
- Favorite pillow/blanket/comforter
- Favorite toys/games/stuffed animals (wash twice and pack in plastic bag or totes)
- Books (especially school books and supplies)
- Your child's Individualized Educational Plan (IEP) if pertinent
- Thermometer (will be needed prior to discharge)
- Items to decorate room (pictures of family/friends, posters, etc)
- Favorite CDs/DVD's or Play Station II games
- Laptop computer (some are available on the unit)

The following is a checklist of items you may want to bring for you:

- Clothes - closet space for parents is extremely limited. Many of your personal items will need to be kept somewhere outside of the hospital. You may want to bring a small set of plastic stacking drawers to store clothing for you and your child
- Toiletries
- Reading material
- Address book with addresses/e-mail addresses/phone numbers of family and friends
- Insurance cards, prescription cards, etc.
- Laundry supplies

Transplant Health Care Team

Many health care professionals will be involved in your child's care while you are going through the transplant process. At times, the number of people that you may deal with may seem overwhelming. Just remember, we are all here to help you and to work with you to speed your child's recovery. Below is a list that will help you to become quickly oriented to our team.

PHYSICIANS

The **Attending** physician is fully trained in pediatrics and hematology oncology. They have completed at least four years of medical school, three years of pediatric residency and three years of a pediatric hematology-oncology fellowship. They supervise the medical care given on the unit and are directly responsible for your child's care. The attending physician on the transplant unit changes every 1-3 weeks and weekend coverage rotates.

Names: _____

The **Fellow** is a fully trained pediatrician who is now learning the specialized care of hematology-oncology patients. The fellow spends part of their training period on the transplant unit. There is not a fellow on the unit every month.

Names: _____

The attending physician may call on the expertise of **consulting physicians** to assist in your child's care if specific problems arise. These consulting physicians specialize in pediatric cardiology, pulmonary medicine, renal diseases, gastrointestinal diseases, infectious diseases, neurology, dermatology, surgery, etc. Interns and residents actively participate in the care of Stem Cell Transplant patients.

NURSES

The ***Nurse Practitioner (NP)*** works under the supervision of the attending MD. The NP provides for daily clinical care of your child. They perform physical exams, write orders and prescriptions and can answer many of your questions regarding transplant-related problems. Nurse practitioners rotate between the inpatient (hospital) and outpatient (clinic) settings, so you will see them frequently during your stay in Hershey.

Names: _____

The ***Nurse Manager (NM)*** will direct the day-to-day operations of the unit and supervise the nursing staff. Feel free to contact the manager with questions/ concerns regarding your child's nursing care.

Nurse Manager: _____

Your child's nurse assists the physicians and nurse practitioner in coordinating your child's care. They provide direct patient care (administration of medication and blood products, physical assessments, comfort measures, etc.) during their shift.

The Transplant coordinator consults with attending physicians to coordinate evaluation of new patients pre-transplant. They serve as the main contact to patients and families during evaluation week and serve as educators and resource contacts throughout the pre-transplant process.

Names: _____

The **Patient Care Assistant (PCA)** works with your child's nurses to help provide thorough nursing care. Nursing assistants obtain vital signs and weights, measure intake and output, may help bathe your child, etc. They will also stock your room with necessary supplies.

Names: _____

OTHER TEAM MEMBERS

The **Chaplain** is concerned with the spiritual needs of you, your child and your family. They are available to you for counseling, prayer or just listening.

Name: _____

The **Child Life Therapist/Child Life Volunteers** help your child to cope with the transplant experience through preparation and support. The Child Life Program assists with your child's adjustment to prolonged hospital isolation. They support normal, developmental growth by offering age appropriate divisional activities.

Names: _____

The **Dietician** monitors your child's nutritional status and needs. They make recommendations regarding nutrition to our physician on a daily basis.

Names: _____

The **Environmental Services Housekeeper** is responsible for maintaining the cleanliness of your child's room and our unit.

Names: _____

The **Occupational Therapist** will evaluate your child on admission and may see your child to help increase function with daily life tasks (ex: eating, playing)

Names: _____

The **Pharmacist** is concerned with the medications that your child is receiving, their side effects, dosages and drug interactions. They participate in daily rounds and are happy to answer your questions about specific medications.

Names: _____

The **Physical Therapist (PT)** evaluates your child's physical abilities on admission and will help to maintain your child's physical abilities through exercise and play as needed.

Names: _____

The **School Teacher** provides ongoing learning opportunities for children in grades kindergarten through high school. They meet with children individually in their rooms and coordinate school assignments with the child's home teacher(s) when possible.

Name: _____

The **Social Worker** is concerned with the social and emotional well being of you, your child and family and also acts as a resource regarding lodging, transportation and financial concerns.

Names: _____

The ***Insurance Counselor*** arranges your child's admission to the hospital and acts as a resource regarding financial and insurance concerns.

Names: _____

What to expect on the Pediatric Stem Cell Unit

The Unit

The Pediatric Stem Cell Transplant inpatient unit is located on 7 West of the Penn State Children's Hospital and is a part of a protective isolation care unit, consisting of fifteen patient rooms. The unit has been designed to meet the needs of both you and your child. Each stem cell transplant room has its own bathroom, refrigerator, TV, DVD player, and Play Station II game. We ask that you not go behind the nursing stations or in the staff workroom for reasons of patient confidentiality.

The Ronald McDonald room on 7 South is stocked with videos, video games, a computer, refrigerator, microwave, sink, TV, washer, dryer, bathroom and parental shower facilities. This area is used as a parent lounge.

If you need supplies or equipment, please ask one of our nurses, nursing assistants or secretaries and we will be glad to assist you.

Daily routine

A daily routine will be established for your child soon after they arrive on the unit. A daily routine helps your child to understand what to expect each day and to understand what is expected of them. This provides a sense of security. The routine will include:

- A daily bath (in the tub, if at all possible) and good skin care
- Weigh-in (first thing each morning)
- Frequent mouth care (four times a day)
- Vital signs at least every four hours
- Broviac catheter care (dressing change at least once a week)
- Blood draws (from catheter) are generally at 4:00 am - 6:00 am and then as needed
- Exercise and walks as permitted
- Playtime/naps
- School (K-12)
- Physical, occupational or speech therapy may be added

Mouth care

It is important to begin good mouth care early and to continue it throughout the hospitalization. **Mucositis** (mouth sores) can be a side effect of both chemotherapy and radiation therapy. Mucositis occurs when the tissues of the mouth, tongue and throat become red, swollen and blistered. At this time, your child may experience discomfort, bleeding or infection. Proper mouth care can prevent or lessen the chance of mucositis and oral infections. Proper mouth care will include:

- Brushing your child's teeth--Soft sponge brushes, called "toothettes" (provided by the unit) will be used to cleanse the mouth four times a day. Your child should also brush their teeth at least once a day with a soft toothbrush.
- Rinsing with Chlorhexidine mouth rinses. These will help keep your child's mouth more comfortable and help prevent dangerous mouth infections

Isolation (Please see the Unit Guidelines following this section)

The treatment that your child will receive will cause their blood counts to become extremely low, putting them at risk for developing an infection. For this reason, it will be very important to protect your child from exposure to infection-causing germs. In order to do this, we will need help from you, your child and your family/friends.

Our unit is designed to protect your child from developing an infection. The unit and individual patient rooms are equipped with an airflow system (HEPA filter) that is designed to filter and flush the air. For this reason, the door to your child's room will be kept closed at all times. Housekeeping staff that are specially trained in infection control cleaning will clean your child's room every day. Fresh flowers, plants and fresh fruits and vegetables will **not** be permitted in your child's room because they harbor germs, especially mold spores. Remember, **if in doubt**, check with a member of the transplant team before bringing anything on the unit.

Strict hand washing for all persons on the unit will be enforced. This is the best way to prevent the spread of infections. Sometimes, despite all of our precautions, your child may develop an infection. Special isolation procedures (requiring the use of gowns, gloves or masks) may be put into place so that the infection is not spread to other children on the unit at which time, your nurse will go over the special isolation requirements.

Unit Guidelines

Introduction: We welcome you to 7 West. Your child will be assigned their room when you arrive on the unit for admission. Your child's nurse for the day will orient you to the unit. Please read the accompanying materials about the functioning of our unit areas so that we can make 7 West a special place for everyone.

1. Handwashing

Good hand-washing is the best way to prevent infections on our unit! Strict hand-washing for everyone entering the unit will be enforced. Everyone is encouraged to help ensure that all visitors and hospital personnel entering our unit have adequately washed their hands. A fifteen-second hand wash with the provided soap and water is adequate. An alternative to hand-washing is the use of disinfectant gel, which is also available on the unit. Since there are only two accessible sinks on 7 West, the antimicrobial gel is available through the unit and its use is **STRONGLY** encouraged.

2. Visitor Policy

Parents and primary caregivers, as determined by the Pediatric BMT team during their initial and ongoing assessments, will be allowed to visit 24 hours a day. One adult, 18 years of age or over, is strongly encouraged to stay in the patient's room overnight to ensure a good night's rest for everyone and to enable the nurses to have physical access to the parent overnight. Both parents may spend the night but only one sleeping cot will be provided. All other adult visitors are limited to regular hospital visiting hours. We strongly encourage other adult visitors to be limited to immediate family members and key non-family members who provide emotional support to the child and their family (religious advisor, close family friend, etc.). This policy is to protect all the children.

If you are sick with fever, cold, sore throat, eye infection, rash, diarrhea, etc, please do not enter the unit. **When in doubt, ask a nurse.** Please do not enter any rooms other than that of the person you are visiting. All first-time visitors should introduce themselves to the charge nurse. Adults and children who have had live vaccines (oral polio, MMR, varicella vaccine, smallpox vaccine or Flu-mist) within the last thirty days also should not visit with the patient or enter the unit. All visitors will be required to complete a health assessment questionnaire prior to entering a patient's room which will be reviewed by a staff nurse.

Siblings

Siblings are important members of the support team for the patient. They also have unique needs and experience stress as their family member goes through the transplant process. We encourage siblings to visit and will try to involve them in supervised activities.

In order to maintain a safe environment for siblings and patients, we need to restrict access to shared patient areas. Therefore:

- Siblings are allowed to use the bathroom in the Ronald McDonald room.
- For regular meals, siblings must eat away from the unit (in the cafeteria or outside the hospital). Siblings cannot eat in the patient's room.
- Siblings are encouraged to visit with their parents. They must visit their brother or sister in the patient's room.
- Siblings of the 7 West patients are limited to the patient's room. All Siblings on the unit under the age of 18 should be accompanied by an adult at all times. Siblings are only allowed in the hallway if they are in transit.

We recognize that some guidelines may present some challenges to sibling visitation. However, they have been created to provide the highest level of protection for all patients, who are always our first priority. Thank you for your cooperation.

Young Visitors

Visitors under 18 years of age will be limited to immediate family members or close friends of older children and their visiting hours are limited to regular hospital visiting hours. Visitors less than 18 years old should wait by the nurses station until a nurse completes a health screen assessment, which must be repeated every two weeks. Young visitors to 7 West are limited to the patient's room (with the exception of supervised activities) or common play areas for the patients. **All** visitors on the unit under the age of 18 **MUST** be accompanied by an **ADULT AT ALL TIMES**.

Number of Visitors

Due to the constraints of the HEPA filtration system, the number of individuals occupying the patient's room for more than ten minutes should be limited to only two adults plus the patient, or two young siblings, one adult, and the patient. Nursing and medical staff are not limited by this quota due to the generally short duration of their presence in the patient's room. If additional family members need to be in the room for an extended time, this must be cleared with the attending physician.

The Attending Physician on service or Penn State Children's Hospital Infection Control may, at any time, (especially during seasonal viral outbreaks) limit visitation on the unit to protect our patients.

Special Visitors

Under special circumstances, a special visitor (athletes or celebrities) may visit if approved by the attending physician.

3. Out-of-Room Policy

Patients may leave their room supervised and walk in the hallway wearing a mask when there is evidence of engraftment post-BMT with an ANC of $>500/\mu\text{L}$ on two consecutive days. All newly transplanted patients must wear masks when leaving the unit. No active transplant patients may be off the unit (except for necessary tests and procedures). Patients transitioning to the outpatient setting may be allowed to go on short passes outside of the hospital. This will be determined by an Attending Physician who will write an order in the chart documenting the necessity for a pass.

All patients and visitors should be in their rooms or in the connection between the hours of 7:00 a.m. to 8:00 a.m., 3:00 p.m. to 4:00 p.m., 7:00 p.m. to 8:00 p.m., and 11:00 p.m. to midnight during nursing report. This is to protect patient confidentiality and to allow an uninterrupted passing of information from nurse to nurse.

4. Eating/Drinking

All patients must eat in their own room. Primary caregivers may eat or drink in the patient's room if it is not disturbing to their child. Special care must be taken to clean up all food, trays, and wrappers that may be used during the meal. Other family members and siblings must eat and drink off the unit. No open containers of food should be in the hallways. The room refrigerator is for the patient's food only. Caregivers may keep their food items in the refrigerator in the Ronald McDonald room. All foods must be labeled with the family's name, room number, and the date before the item is placed in the refrigerator. Any refrigerated perishable items should be discarded within 24 hours.

5. Laundry

One washer/dryer unit is available for use by all families with hospitalized children. Before and after each use, please wipe the inside and top of the washer with germicidal sani-cloths. Detergents and softeners are not provided. All detergents must be kept out of your child's reach.

6. Bathrooms

The bathrooms in the patients' rooms are for patient use only. The bathroom in the Ronald McDonald room is for visitors and caregiver use. All families should clean and protect the shared bathroom facilities.

7. Cleanliness

Parents are encouraged to “cycle” toys, clothes, and games on a weekly basis rather than storing all of the patient’s possessions in the room at all times. No pets, flowers, latex balloons, or plants are allowed on the unit. Parents are required to keep the floors and counter spaces of the patient’s room clear to allow the housekeeping staff to thoroughly clean the patient’s room at the required intervals.

Patients should use individual art supplies that they do not share with other patients.

**THANK YOU VERY MUCH FOR HELPING TO KEEP OUR PATIENTS SAFE
AND HEALTHY!**

Penn State Children's Hospital Stem Cell Transplant Family Contract

I have read the attached Unit Guidelines and agree to follow them while I am on
7 West with _____ (patient's name).

<u>Date</u>	<u>Signature</u>	<u>Relationship to Patient</u>
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

III. Psychosocial Services

Your decision to bring your child to Penn State Children's Hospital for a Stem Cell Transplant may cause a wide range of feelings and emotions for your entire family. No longer surrounded by the comforts of home and the health care team you are used to, you and your child face a variety of unknowns. There are new doctors, nurses, and staff; a new environment with different machines, routines, and rules; and an unknown treatment outcome. Some of you may also be dealing with a new diagnosis.

Anxiety, fear, relief, and hope are real and common feelings for all families. You may also be having feelings of sadness or grief. It is important to realize that all of these feelings are normal and may go away or come back at any time before, during, or after your child's stem cell transplant. Loneliness and anxiety may occur because you are away from home. Feelings of being overwhelmed by all of the activity in the transplant unit are common. Your sense of time, (and your child's), may become distorted as you learn to live around the transplant schedule. Feelings of loss of privacy and decreased quality time with your family are common. We will do our best to work with you to provide quiet times for being together.

You may find that your emotions or feelings are not experienced by other family members at the same time. This does not mean that your feelings are any less important or real than those of other family members. Your feelings are very important and we strongly encourage you to share them with us as you feel able.

The transplant experience can be draining both physically and emotionally. Taking care of yourself is extremely important. Allowing time for a short walk out of the room or a nap in the afternoon can be very helpful. Encourage other family/ friends to relieve you so that you can have time for yourself. "Switching off" with another adult family member so that you can get a good night's sleep outside of the hospital is encouraged. Remember, your child needs you to be well-rested and healthy in order to support them.

Child Life

The goal of the Child Life program is to help children understand and cope with the experience of illness and hospitalization. Child Life specialists are specifically trained and certified in child development and how children respond to illness and hospitalization. Child Life specialists use procedural preparation and support as well as play and expressive activities. Through play, patients can express themselves, gain mastery and control, build self-esteem, develop and maintain peer interactions and learn to trust their environment. Interventions are available for the patient and the patient's siblings. Specific services include:

- Developmentally appropriate teaching about diagnosis and treatment
- Group and individual therapeutic expressive activities
- Development of coping and pain management skills
- Assistance with compliance issues

Social Work

The goal of Social Work is to empower families to integrate the experiences of illness and hospitalizations into their lives with minimal disruption. This is achieved through counseling, education, advocacy and resource referral. Help can be provided for a variety of issues. Specific services include:

- Supportive counseling
- Medical crisis and adjustment to illness
- Complicated family and social situations
- Emotional and psychosocial distress
- Grief, loss and bereavement
- Parent support group (inpatient)
- Assistance with identifying lodging and transportation options
- Link to available disease-specific organizations for financial assistance, as well as to various community resources

Psychological Services

The pediatric psychologist is available to provide support for parents and children who face stress associated with illness and transplantation. The team recognizes the day-to-day stress of dealing with your child's illness and understands that this can be overwhelming and emotionally debilitating. As part of the team working with your child, the clinical psychologist is available to provide support in the following areas:

- Individual adult and child therapy
- Family therapy (sibling support, marital counseling)
- Grief/bereavement support
- Pain management
- Developmental and neuropsychological assessments
- Medication compliance
- Parent education related to behavior management, explaining illness to young children, child development & growth, post-discharge expectations & school reentry

School Program

The goal of the school program is to continue a child's education during hospitalization. Attending school in the hospital helps to provide a child with a sense of control, a chance to be successful, a more familiar environment and hope for the future. The school program helps patients keep up with their academic skills and enables them to make an easier transition to home and school. The program is available to hospitalized children from kindergarten through grade 12. Instruction may take place in the classroom, bedside or in outpatient clinics. Bringing textbooks and/or assignments, when possible, will facilitate the transition to the hospital school. Services include:

- Assessment of educational needs
- Instruction throughout hospitalization
- Coordination of school assignments with home school
- Current textbooks provided by your school district
- Interactive computer equipment
- Transition from hospital school to either homebound or home school setting

Chaplain

As a member of your health care team, your chaplain's goal is to find out and support what helps your family. We are here to attend to the needs of the human spirit. Hospital chaplains support your family's particular beliefs & activities. Specific services include:

- 24-hour & 7-day a week availability (weekday unit chaplain & 24-hour on-call chaplain)
- Routine visitation on unit (clinic visitation by request or via chaplain's rounds)
- Respond to requests for prayer
- Spiritual care and support around specific life-meaning or coping issues (parents/patient)
- Spiritual support and religious care/referrals during times of grief, major loss or bereavement

About your Child:

It is important to be honest with your child from the very beginning. Open and honest communication can help to relieve your child's fears of the unknown. Every child needs to know, in words they can understand, why they are in the hospital and what they can expect while they are there. Encourage your child to ask questions and express any fears or concerns that they may have. If you cannot answer your child's questions, let them know that you will find someone who can. Use the expertise that is available to you from the transplant staff to help you talk with your child. We will make every effort to keep you and your child well informed about every aspect of the transplant. Information, plus your love and support, can make the transplant a less frightening experience for your child.

It is important that your child realize that there will be certain daily expectations of them while they are hospitalized. Normal discipline and rules can add comfort and security to an environment that is strange and frightening. Often an atmosphere of permissiveness or pity will only increase your child's fear. Your child may perceive him/herself as more sick than they are, if typically punished behavior is left unchecked. Therefore, we will help you and your child design a daily schedule that will add structure and expectations to their day.

Responses to Hospitalization:

Your child's response to the transplant experience will depend a great deal on their age. We would like to share with you a brief discussion of the kinds of things most children are trying to accomplish at certain ages and how hospitalization can impact these developmental tasks.

Infants (0-1 years)

Infants are working to develop a sense of trust. They need to be able to trust that their needs for food, comfort, stimulation and caring will be met. They fear strangers and separation from their parents (especially their mother). Therefore, we encourage you, or someone your child trusts to be with them as much as possible. Loving, touching, holding and rocking are extremely important to infants.

Infants may also fear loud noises, bright lights and sudden movements. We will try to maintain a quiet, calm environment for your infant as much as possible. Infants explore their world through touch and movement and by placing things in their mouth. Fatigue, pain, immobility and mucositis can all temporarily interfere with normal development. We will provide toys, mobiles, etc. to stimulate your infant when they are feeling well. You are encouraged to bring similar items from home.

Toddlers (1-3 Years)

Toddlers are starting to develop their language skills and to exert their independence ("me do it!", "no!") and must learn that there are limits placed on their behavior. Changes in discipline and routines while they are hospitalized can disturb their sense of security. Temper tantrums are common and may be exacerbated by pain and the side effects of steroids. Toddlers do not think logically and may be magical in their thinking. They believe the world revolves around them. They are becoming more aware of their bodies as they go through toilet-training and therefore, intrusive procedures are very frightening. It is very common for a previously toilet-trained toddler to go back to wearing diapers during their transplant. We will, however, be supportive of toilet training efforts in the hospital.

Toddlers are often afraid of strangers, especially when their parents are not present. Consistent caregivers are very important, as are touching and holding. Toddlers need to explore, play and experiment with their environment. We have many toys, games, etc. on the unit for this purpose.

Pre-schoolers (4-6 Years)

Preschoolers are active, energetic learners. They are also developing their physical skills and feel a sense of accomplishment when they master something new. We encourage preschoolers to help with their care and to continue active play as much as they are able.

Children at this age still use magical thinking and often think that just because they thought of something, it will happen. Preschoolers may no longer fear strangers, but often fear being left alone. They may also be afraid of the dark, of pain, and of having their bodies mutilated. We will do everything we can to keep your child free of pain. Working through these fears with play activities is helpful.

Preschoolers, as compared to toddlers, are more social and more willing to please others. Parents and family are of primary importance, but preschoolers start to develop friendships with other children. Keeping in touch with friends at home through letters, e-mail and telephone calls will make their hospitalization less stressful.

School-age Children (7-12 years)

School-age children are striving for increased independence from their parents and are focused on becoming proficient at accomplishing physical, social and academic tasks. They look to their peers for feedback as to what is socially acceptable and measure their competence against their peers. Conforming to the group is important. Most school-agers wish to please and try to be cooperative. While peers are an important social support for school-agers, they still rely heavily on parents and other family members. Increased dependence is often seen in the hospitalized school-ager.

Children this age need privacy and strenuous physical activity. Fears include losing control, failing to accomplish tasks, isolation from peers and the physical effects of their illness and treatment.

While in the hospital, your school-ager will continue their studies with the assistance of a hospital-based teacher. We encourage you to maintain realistic expectations about your child's ability to keep up with schoolwork. Maintaining contact with friends at home via letters, e-mail and telephone calls is also very important.

Providing your school-ager with honest information about their disease, treatment and complications will help them to maintain some sense of control. Actively involving them in their care, maintaining privacy, offering choices when possible, being consistent with discipline and praising your child's ability to cope are all ways to enhance their self-esteem.

Adolescents (13-18 years)

Teen-agers are trying to answer the question, “Who am I?” They are establishing their own identity, examining their values and beliefs, focusing on the future and adjusting to their rapidly-changing bodies. They are very introspective; they are able to reason and make predictions about things beyond their actual experience or knowledge.

Adolescents strive to be accepted and included by their peer group. Their self-esteem is influenced by their position within the peer group structure. Maintaining contact with their friends at home while hospitalized is vital. Establishing a new peer group of other transplant patients is also helpful.

Body-image issues are extremely important to this age group. Healthy teens are acutely self-conscious of bodily changes. Those hospitalized for a stem cell transplant must cope with additional changes related to their treatment. These include hair loss, skin changes, weight loss/gain, “moon face” due to steroids and increased facial hair growth due to Cyclosporine or Tacrolimus. It is very important to reassure the teen-ager that most of these bodily changes are temporary and that they will resolve after transplant. Suggesting ways of coping with or camouflaging body changes and focusing on good grooming and personal hygiene are helpful.

Teens fear losing their previously acquired level of independence. They may have difficulty asking for assistance or information. In an effort to cope with their illness, they may become withdrawn or outwardly hostile or rebellious. It is important to continue to tell your adolescent that you care for them and that you will help them get through the transplant process. It is also important to continue to foster independence, self-care and normalcy as much as possible during this time. Allowing the teen to collaborate in decision-making, providing for time alone for introspection and encouraging expression of anxieties and needs are all important. We may ask you to leave the room at times while we listen to your teen’s concerns and answer their questions. Your teen may also need help in developing a realistic focus and plan for the future. Help them to see their own strengths and how they may use them in an occupation or vocation.

You know your child better than we do and we need you to help us to get to know them. Please share any special needs or concerns you have with us. We will do our best to provide your child with individualized, holistic care.

Siblings

Brothers or sisters of the transplant patient have special needs that are also very important. Separation from you and their sibling during previous hospitalizations has probably occurred, but now they may face a much longer period of separation. Family life may seem upside-down and without any sense of normalcy. Below are some common reactions of brothers and sisters:

- Withdrawal may be seen in the sibling because of their fears of upsetting you. Some children behave in an opposite manner, becoming aggressive or showing attention-seeking behaviors.
- Resentment may be seen in relation to the attention given to the sick child.
- Depression or grief occurs frequently
- Changes in school work and friendships may develop

- A feeling of being burdened may be seen if the sibling assumes increased responsibility at home

You, as a parent, may feel overwhelmed by the many demands placed on you. Below are some suggestions to help you cope with your other children at home.

- Allow them to visit the hospital as much as they can. Take pictures of your child's room to alleviate fears the siblings may have about what is happening to their brother or sister.
- For younger siblings, give short, clear and honest answers to questions.
- Be honest with your feelings. Children are perceptive. If you feel that you need to cry, but hold it in, your children may be confused by this response. They need to know it is normal for them (and you) to feel and express emotions.
- Attempt to provide your other children with some time just for them so that they realize how special they are to the family. Share your feelings with your children and reassure them that support is available.
- Let them know that you realize it is very difficult for them, but that you can't be in two places at the same time. Make it clear that if they were the sick child that you would be there for them.
- While you are at the hospital, write them letters or e-mail them telling them about what is happening and how much you miss them.

The Pediatric Playroom and Teen Lounge are available for pediatric BMT/SCT brothers and sisters to use when visiting. The playroom is open from 9:30 a.m. to 8:00 p.m. A group activity occurs from 10:00-11:00 a.m. and 2:00-3:00 p.m. Monday thru Friday. There is a 10:00 a.m. group activity on Saturday and Sunday. Parents and caregivers need to supervise children while in the playroom. The Teen Lounge is open from 9:30 a.m. to 9:30 p.m. and is available to siblings who are 9 years and older.

Please be advised that these common areas are available for ALL inpatient pediatric patients and their families. When siblings visit, we advise families to visit in the patient room prior to visiting these common areas.

IV. TRANSPLANTATION

Conditioning

A. Chemotherapy

Your child's body must be prepared for a stem cell transplant. This preparation includes high-dose chemotherapy. In the transplant setting, chemotherapy is given for three reasons:

1. To destroy the immune system so that it will not be able to reject the new cord blood/bone marrow
2. To destroy cancer cells (if present) in the body
3. To empty the bone marrow, making space for new cells to grow.

Although chemotherapy is designed to destroy cancer cells, it also destroys some of the body's healthy cells in the process. These healthy cells are fast-growing cells found in the hair roots, skin, bone marrow and digestive tract (mouth, stomach, and intestines). Therefore, side effects can be seen in all of these areas. In addition, some chemotherapy drugs adversely affect specific organs, such as the heart, lungs, liver and kidneys.

Your child may receive one or a combination of several chemotherapy drugs. The amount given depends upon your child's disease and their height and weight. Your health care team will give you information on the specific side effects, dosage and mechanism of action of each of the drugs that your child will receive.

Some of the more common side effects of chemotherapy include:

- Nausea and vomiting
- Mouth sores
- Taste changes, dry mouth
- Diarrhea
- Loss of appetite
- Hair loss
- Skin rashes, peeling, and temporary darkening of the skin
- Infertility

B. Total Body Irradiation (TBI)

Most patients with leukemia, *unless they are younger than two years of age*, will receive TBI. TBI, the use of high-energy radiation over the entire body, is given for two reasons:

1. To destroy any cancer cells in the body that have not already been killed by previous chemotherapy
2. To destroy the immune system so that it will not be able to reject the new cord blood / bone marrow

TBI is a painless procedure that involves lying or sitting in front of a large machine that emits radiation beams. Your child will receive the treatments in the radiation oncology department. The actual treatment takes just minutes each session and is given one-two times a day for several days in a row. No one is allowed in the room with your child during the actual treatment, but you and the doctors and nurses will be in the next room and will be able to see your child at all times on a TV monitor. Your child will be able to talk to you over an intercom. Since it is necessary to hold very still during TBI, sometimes general anesthesia is required for young children.

Some of the more common side-effects of TBI include:

- Nausea, vomiting
- Diarrhea
- Fever
- Headaches
- Swelling of the parotid (saliva-producing) glands, located in front of the ears
- "Sunburn" of skin, dry skin that may peel

Additional side effects which may occur later:

- Hair loss
- Mouth sores
- Changes in skin color (darkening)
- Dry mouth
- Lung changes
- Cataracts
- Short adult height
- Infertility

During the conditioning (pre-transplant) phase of your child's treatment, your child will begin to experience the side effects of chemotherapy/radiation. Every effort will be made to keep your child comfortable. IV medication for nausea will be given. Pain medication will be given for mouth sores, headaches and parotid gland swelling. As needed, Tylenol will be offered for fever.

Your child will have frequent lab draws to monitor for side effects of chemotherapy. Urine, stool and emesis output will be measured and specimens tested. Your child may be placed on a cardiac monitor to watch for changes in

heart function. Three small sticky leads will be placed on the skin of your child's chest. (This is not painful). The leads will then be attached by cords to a monitor in your child's room. The amount of oxygen circulating in your child's blood may also be monitored by attaching a similar lead to your child's finger or toe. These measures are taken so that we can collect information that will help us to provide the best possible care for your child.

Your child's transplant will take place on "Day 0". Each day of your child's conditioning treatment before transplant will be counted down backwards (Day -2, Day -1, etc.)

Each day after the transplant is counted in order (Day +1, Day +2, etc.)

Our transplant team will give you a flow sheet (road map) that will spell out your child's specific treatment plan. You are encouraged to place it here in your notebook.

STEM CELL INFUSION

The Big Day!

Reinfusion of stem cells (bone marrow, peripheral blood stem cell, or umbilical cord blood) is a simple and painless procedure that takes place in your child's room on the unit. The stem cells are delivered in a bag similar to that of other blood products (platelets, PRBCs). If they have been previously frozen, they are generally thawed in the patient's room, but may be thawed in the transplant lab depending upon the situation. The stem cells will be infused through your child's central line. Your child will be placed on a cardiac monitor and vital signs will be taken frequently during the infusion and for two hours afterwards. If the stem cells were frozen, a preservative (DMSO) was added. DMSO may cause a funny taste in your child's mouth or cause nausea. Gum or hard candy may help disguise the taste. The body rids itself of the DMSO through breathing. Others entering the room will be able to smell a distinct odor, (described as creamed corn, garlic, oysters, stewed tomatoes). This smell will disappear within 24 hours of the transplant.

Medications

Your child will receive a variety of medications during their hospitalization. Some of the more common types of medications, with examples, are listed below.

You will be given information sheets for specific medications as they are added to your child's regimen. You are encouraged to place these information sheets in this section of your notebook, so that you can refer to them as needed.

Antiemetics:

Given to help relieve nausea/vomiting caused by chemotherapy/ radiation

Examples: Ondansetron (Zofran)
Promethazine (Phenergan)
Lorazepam (Ativan)
Metoclopramide (Reglan)

• **Antibiotics:**

Used to fight bacterial infections. Antibiotics will be started with the first fever and continued until the WBC count has risen to a normal level.

Examples: Cefepime
Gentamicin
Vancomycin

• **Anti-viral agents:**

Used to fight viral infections

Examples: Acyclovir
Foscarnet
Ganciclovir

• **Anti-fungal agents:**

Used to fight fungal infections

Examples: Amphotericin B
Caspofungin
Fluconazole
Voriconazole

• **Analgesics:**

Pain Medications

Examples: Tylenol
Morphine
Fentanyl
Hydromorphone
Oxycodone

- **Immunosuppressants:** Used to prevent graft-vs-host disease and cord blood/bone marrow rejection
Examples: Anti-thymocyte globulin (ATG)
CellCept
Cyclosporine (Neoral)
Methylprednisolone (Solumedrol)
Tacrolimus (FK506)
- **Growth Factors:** Hormones used to stimulate the growth of WBC's
Examples: Filgrastim (GCSF)
- **Oral Contraceptives:** Used for menstruating females to stop vaginal bleeding while platelet and red cell counts are low
- **Antihypertensives:** Used to control high blood pressure
Examples: Amlodipine (Norvasc)
Clonidine

Nutrition

Ensuring that your child receives the proper nutrition during a stem cell transplant may be challenging. Most children do not feel like eating or drinking for a period of time due to the expected side effects of chemotherapy and/or TBI and other medications. Complications (infections, graft-vs-host disease) during transplant may also cause your child to not feel like eating.

A neutropenic diet should be followed from the day your child starts chemotherapy and/or TBI. This will help to minimize infections and gastrointestinal problems. The Food Safety Guidelines should also be followed before, during and after transplant.

We recommend that your child discontinue any herbal supplement, non-prescription drug and/or mega-dose vitamin/mineral/antioxidant. While undergoing conditioning, check with your doctor about regular multivitamins.

All children are encouraged to eat and drink as they are able. Nursing staff will question you each day about the amount of fluid your child is drinking. You may find it helpful to write this down. All of your child's intake (fluids taken by mouth, IV fluids) and output (urine, stool, emesis) will be measured daily. This is to help monitor for **fluid retention**, a common problem during transplant. Please do not dispose of body fluids until they are measured and tested by the nursing staff.

All food should be eaten within one hour of its preparation. This includes food from the cafeteria and from fast food restaurants. In the hospital, food should be eaten within one hour of tray delivery. Single serving drinks should be discarded after one hour. No drinks from soda fountain allowed.

Total Parenteral Nutrition (TPN, IV nutrition) may be started if your child is unable to eat or drink. This solution is given through your child's central line and provides all necessary nutrients: protein, carbohydrates, fat, vitamins, minerals, etc. The doctor and dietician develop the TPN plan daily based on your child's nutritional needs. The TPN will continue until your child is able to consume enough calories by eating and drinking on their own.

Penn State Children's Hospital Dietary Guidelines

Transplant Grocery List

While you are in the hospital you may want to snack on particular foods that are not available through the hospital food service. Many of the foods listed may be available, but you may prefer a specific brand or flavor.

High Protein Foods:

Pasteurized cheese

Cold Cuts (no deli-sliced; purchase a packaged brand, such as Oscar Meyer®)

Boxed macaroni and cheese (Kraft Easy Mac®)

Breads, Cereals, Pasta, & Rice:

All breads, bagels, muffins, rolls, and cereals without dried fruit, nuts or seeds

Crackers

Soft tortillas

Pasta (no macaroni or pasta salad with raw vegetables)

Rice

Rice Cakes

Instant oatmeal or other hot cereal

English Muffins

Fruits & Vegetables:

Canned fruits

Well-washed fresh fruits or vegetables

Fruit juice (no fresh squeezed)

Vegetable Juice (no fresh squeezed)

Beverages, Desserts, & Miscellaneous:

Coffee, tea (no herbal tea) or milk

Jell-O®

Popsicles

Ice-cream

Candy

Pickles

Olives

Sugar

Soda**

Peanut Butter (no chunky) **

Pretzels**

Chips**

Relish**

Jelly/Jam**

**Try to purchase single serving containers of these items

DO NOT PURCHASE:

Grapefruit

Grapefruit Juice

Beverages containing grapefruit juice such as Sunny-D®

****Please note:** Products containing grapefruit and grapefruit juice can cause dangerous drug interactions with your child's medications.

DIET GUIDELINES FOR IMMUNOSUPPRESSED PATIENTS

Persons with decreased immune function due to chemotherapy and radiation are at increased risk of developing a food-related infection. The purpose of this diet is to help you avoid specific foods that are more likely to contain infection-causing organisms while allowing maximum healthy food choices. Choose foods from the “Approved” column. Do not eat foods in the “Not Allowed” column. You may want to discuss the safety of these or other foods with your dietitian.

This diet should be followed before and after all conditioning (chemotherapy and/or radiation) therapy. Your doctor and dietitian will provide guidelines as to when the diet is no longer required. In general, we are recommending that chemotherapy only, peripheral blood stem cell, and autologous transplant patients follow the diet during the first three months after chemotherapy or transplant. Allogeneic transplant patients should follow the diet until off all immunosuppressive therapy (e.g., cyclosporine, prednisone, tacrolimus, thalidomide, etc.). Prior to the end of these time periods, patients and their caregivers should discuss with their referring physician whether or not the diet or parts of the diet should be continued.

Immunosuppressed Patient Diet

<u>Food Groups</u>	<u>Allowed</u>	<u>Not Allowed</u>
<u>Dairy</u>	<p>All <u>pasteurized</u>, grade “A” milk and milk products</p> <p>Commercially-packaged cheese and cheese products made with pasteurized milk (e.g., mild and medium cheddar, mozzarella, parmesan, Swiss, etc.)</p> <p><u>Pasteurized</u> yogurt</p> <p>Dry, refrigerated, and frozen <u>pasteurized</u> whipped topping</p> <p>Ice cream, frozen yogurt, sherbert, ice cream bars, homemade milkshakes</p> <p>Commercial nutritional supplements and baby formulas, liquid and powdered</p> <p>Commercial <u>pasteurized</u> eggnog</p>	<p><u>Unpasteurized or raw</u> milk, cheese, yogurt, and other mild products</p> <p>Cheeses from delicatessens</p> <p>Cheeses containing chili peppers or other uncooked vegetables</p> <p>Cheeses with molds (e.g., blue, stilton, Roquefort, gorgonzola)</p> <p>Sharp cheddar, brie, camembert, feta cheese, farmer’s cheese</p>

<u>Food Groups</u>	<u>Allowed</u>	<u>Not Allowed</u>
<u>Meat and Meat Substitutes</u>	<p>All <u>well cooked or canned meats</u> (beef, pork, lamb, poultry, fish, shellfish, game, ham, bacon, sausage, hot dogs)</p> <p><u>Well cooked eggs</u> (White cooked firm with thickened yolk is acceptable)</p> <p><u>Well cooked pasteurized egg substitutes</u> (e.g., Egg Beaters®)</p> <p><u>Commercially-packaged salami, bologna, and other luncheon meats</u></p> <p>Canned and commercially-packaged <u>hard smoked fish</u>; refrigerate after opening</p> <p>Cooked tofu*</p>	<p><u>Raw or undercooked meat</u> poultry, fish, game, tofu*</p> <p><u>Raw or undercooked eggs</u> and egg substitutes</p> <p>Meats and cold cuts from delicatessens</p> <p>Hard cured salami in natural wrap</p> <p>Cold smoked salmon (fish); lox</p> <p>Pickeled fish</p> <p>Tempe (tempeh) products</p>
<u>Entrees, Soups</u>	All cooked entrees and soups	All miso products (e.g. miso soup)
<u>Fruits and Nuts</u>	<p>Canned and frozen fruit and fruit juices</p> <p><u>Well washed raw fruit</u>; foods containing well washed raw fruits</p> <p>Dried fruits Canned or bottled roasted nuts</p> <p>Nuts in baked products</p> <p>Commercially-packaged peanut butter</p>	<p><u>Unwashed raw fruits</u></p> <p>Unroasted raw nuts</p> <p>Roasted nuts in the shell</p> <p>Unpasteurized fruit and vegetable juices</p> <p>Grapefruit</p>

<u>Food Groups</u>	<u>Allowed</u>	<u>Not Allowed</u>
<u>Vegetables</u>	<p>All cooked frozen, canned, or fresh vegetables and potatoes</p> <p><u>Well-washed</u> raw vegetables</p> <p>Fresh, <u>well washed</u> herbs and dried herbs and spices (added to raw or cooked foods)</p>	<p>Unwashed raw vegetables or herbs</p> <p>All raw vegetable sprouts (alfalfa, radish, broccoli, mung bean, all others)</p> <p>Salads from delicatessens</p> <p>Commercial salsas stored in refrigerated case</p>
<u>Bread, Grain, and cereal products</u>	<p>**All breads, bagels, rolls, muffins, pancakes, sweet rolls, waffles, French toast</p> <p>Potato chips, corn chips, tortilla chips, pretzels, popcorn</p> <p>Cooked pasta, rice, and other grains</p> <p>All cereals, cooked and ready-to-eat</p>	<p>Raw grain products</p>
<u>Beverages</u>	<p>Tap water and ice made from tap water</p> <p>#Commercial bottled distilled, spring, and natural waters</p> <p>All canned, bottled, powdered beverages</p> <p>Instant and brewed coffee, tea; cold brewed tea made with boiling water</p> <p>Brewed herbal teas using commercially-packaged tea bags</p> <p>Commercial nutritional supplements liquid and powdered</p>	<p>Well water (unless tested frequently and found to be free of coliforms)</p> <p>Cold-brewed tea made with warm or cold water</p> <p>Non-pasteurized commercial fruit and vegetable juices</p> <p>Mate tea</p> <p>Grapefruit juice</p>

<u>Food Groups</u>	<u>Allowed</u>	<u>Not Allowed</u>
<u>Desserts</u>	<p>Refrigerated commercial and home-made cakes, pies, pastries, and pudding</p> <p>Refrigerated, cream-filled pastries</p> <p>Homemade and commercial cookies</p> <p>Shelf-stable^ cream-filled cupcakes (e.g., Twinkies, Ding-Dongs), fruit pies (e.g., Pop-Tarts, Hostess fruit pies), and canned pudding</p> <p>Ices, Popsicle-like products</p>	<p><u>Unrefrigerated, cream-filled</u> pastry products (not shelf-stable^)</p>
<u>Fats</u>	<p>Oil, shortening</p> <p>Refrigerated lard, margarine, butter</p> <p>Commercial, shelf-stable^ mayonnaise and salad dressings (including cheese-based salad dressing; refrigerated after opening)</p> <p>Cooked gravy and sauces</p>	<p>Fresh salad dressings containing aged cheese (e.g., blue, Roquefort) or raw eggs, stored in refrigerated case</p>
<u>Other</u>	<p>Salt, granulated sugar, brown sugar</p> <p>Jam, jelly, syrups; refrigerated after opening</p> <p>Commercial (heat-treated and/or pasteurized) honey##</p> <p>Catsup, mustard, barbeque sauce, soy sauce, other condiments (refrigerated after opening)</p> <p>Pickles, pickle relish, olives (refrigerated after opening)</p> <p>Candy, gum</p>	<p>Raw or non-heat treated honey; honey in the comb</p> <p>Herbal and nutrient supplement preparations – refer to “Patient Guidelines for Use of Herbal and Nutrient Supplements During HSCT and High-Dose Chemotherapy” in <i>Patient & Caregiver Resource Manual</i></p> <p>Brewer's yeast, if eaten uncooked</p>

Footnote Key

*Tofu must be cut into 1 – inch cubes, or smaller, and boiled a minimum of five minutes in water or broth before eating or using in recipes.

**Recommend patient themselves not make (mix, knead) any bread product containing yeast.

#If using a water service other than city water service recommend using distilled or bottled water. See SCCA Water Guidelines.

^"Shelf-stable" refers to unopened canned, bottled, or packaged food products that can be stored before opening at room temperature; container may require refrigeration after opening.

##No honey products allowed for children less than one year and all children with SCIDS until nine months posttransplant.

CAFETERIA GUIDELINES

- Ask to have all foods prepared fresh, including grilled items.
- No Sushi.
- No salad bar.
- No fountain sodas.
- No ice cream from the self-serve machine.
- No deli bar.
- No self-serve items that are not pre-packaged.
- All fresh fruits must be washed and wrapped by kitchen staff.
- If eating from the hot line, must be in the cafeteria when the line first opens:
 - Breakfast 6:30 am
 - Lunch 11:00 am
 - Dinner 4:30 pm

CALORIE INTAKE AND BODY WEIGHT

- Monitor your weight weekly
- Weight goal:
 - If you are at ideal/desirable body weight, the goal is to maintain your body weight
 - If you are less than your ideal body weight, the goal is to gain weight
 - If you are overweight, we suggest you maintain your weight until you are medically stable
- Your dietitian/dietetic technician will discuss your calorie needs.

Calorie Content of Selected Foods:

<u>Food</u>	<u>Serving size</u>	<u>Calories/Serving</u>
Lactaid 100%	1 cup	102
Lactaid, Skim	1 cup	86
Soy milk	1 cup	79
Tofu, well cooked	½ cup	94
Bread	1 slice	80
Bagel	1 whole	160
Petite croissants	1	117
Cooked pasta, peas, corn	½ cup	80
Potato	1 small	80
Danish	1	315
Chips	1 oz	180
Granola Bar, without raisins	1	135
Apple juice, pasteurized	1 cup	111
Grape juice, pasteurized	1 cup	155
Orange juice, pasteurized	1 cup	112
Vegetables, cooked	½ cup	25
Egg, hard boiled	1	75
Meatloaf, well cooked	1 oz	75
Pork chop, well cooked	1 oz	75
Chicken/turkey, dark meat without skin, well cooked	1 oz	55

<u>Food</u>	<u>Serving size</u>	<u>Calories/Serving</u>
Chicken/turkey, white meat without skin, well cooked	1 oz	35
Peanut Butter, smooth	2 Tbsp.	100
Margarine, butter, oils	1 tsp.	45
Pediasure	1 can	240

Protein

Proteins are used to build new tissue. They are used to repair worn-out body tissue proteins resulting from the continued wear and tear going on in the body. Protein is also important for immune system recovery.

Protein Content of Selected Foods:

<u>Food</u>	<u>Serving size</u>	<u>Grams/Serving</u>
Whole milk, 2%	1 cup	8
Skim milk	1 cup	8
Soy milk	1 cup	6.6
Egg, hard boiled	1	7
Chicken, fish, meat, well cooked	1 oz	7
Peanut butter, smooth	2 Tbsp.	7
Tofu, well cooked	4 oz	7
Beans, lentils, cooked	½ cup	9
Pork chop, well cooked	1 oz	7
Bacon, well cooked	1 slice	2
Pediasure	8 oz.	7

Calcium

Milk and milk products are one of the highest and best-absorbed sources of calcium. Some foods have calcium added to them. While you are on a diet that restricts milk and milk products, you can increase the calcium by choosing foods from the following list. Check with your health care team about introducing milk and milk products back into your diet.

Calcium Content of Selected Foods:

<u>Food</u>	<u>Serving size</u>	<u>Milligrams/Serving</u>
Milk	8 oz	300
Carnation Instant Breakfast	1 pkg. + 8 oz milk	441
Quaker Oatmeal, Extra Fortified	1 pkg.	222
Spinach, cooked	½ cup	89
Collard greens, cooked	½ cup	152
Turnip greens, cooked	½ cup	140
Broccoli, cooked	½ cup	67
Green soybeans, cooked	½ cup	130
Tofu, well cooked	½ cup	130
Calcium fortified OJ, pasteurized	1 cup	200

Potassium

Potassium is a mineral important for cell growth and maintenance. As a result of the treatment and/or some medications, some people tend to lose potassium from their bodies.

Potassium Content of Selected Foods:

<u>Food</u>	<u>Serving size</u>	<u>Milligrams/Serving</u>
Potatoes, boiled	1	443
Lima beans, boiled	1 cup	955
Tomatoes, boiled	½ cup	335
Lentils, boiled	1 cup	731
Spinach, boiled	½ cup	419
Orange	1 medium	250
Banana	1 medium	451
Honeydew	1 cup	461
Cantaloupe	1 cup	494
Peanut butter, smooth	2 Tbsp.	231
Avocado, cooked	1 medium	1097
Soybeans, boiled	1 cup	886

Potassium Content of Selected Foods (continued):

<u>Food</u>	<u>Serving size</u>	<u>Milligrams/Serving</u>
Broccoli, boiled	½ cup	228
Beets, boiled	½ cup	266

Magnesium

Magnesium is a mineral found mainly in the bones and muscles. It is needed for building bones, muscle contractions and relaxation, and nerve excitation. It is also essential for the production and transfer of energy for protein synthesis. Magnesium deficiency is uncommon. However, certain medications like Cyclosporine lead to loss of magnesium from the body. This often requires a magnesium supplement, in addition to eating magnesium- rich foods.

Magnesium Content of Selected Foods:

<u>Food</u>	<u>Serving size</u>	<u>Milligrams/Serving</u>
100% Bran	½ cup	134
All-Bran, Kellogg's	1/3 cup	122
Bran Flakes, Post	2/3 cup	68
Cheerios	1¼ cup	39
Honey nut Cheerios	¾ cup	33
Cracklin' Oat Bran	1/3 cup	45
Fortified Oat Flakes, Post	2/3 cup	
Grape Nut Flakes, Post	1 cup	34
Life, Quaker	2/3 cup	46
Shredded Wheat, Quaker	2 biscuits	67
Wheat Bran, Kretschmer	1/3 cup	180
Oatmeal, maple & brown sugar	1 pkg.	85
Granola, Nature Valley, no raisins	2/3 cup	58
Bran Chex	2/3 cup	73
Rye krisp crackers	5 oz	34
Bran muffins, homemade	1 small	35
Egg noodles, cooked, enriched	1 cup	31
Whole wheat macaroni	1 cup	42
Spaghetti, cooked, enriched		

Magnesium Content of Selected Foods (continued):

<u>Food</u>	<u>Serving size</u>	<u>Milligrams/Serving</u>
Spinach spaghetti, cooked	1 cup	87
Brown rice, long grain, cooked	1 cup	83
Wild rice, cooked	1 cup	53
Kidney beans, canned	1 cup	73
Vegetarian Baked Beans	1 cup	82
Refried beans, canned	1 cup	99
Chickpeas, boiled	1 cup	78
Blackeye peas, canned	1 cup	66
Lima beans, boiled	1 cup	82
Navy beans, boiled	1 cup	107
Split peas, boiled	1 cup	71
Baked potato without skin	1 small	39
Spinach, boiled	½ cup	79
Banana	1 medium	33
Pineapple, heavy syrup	1 cup	40
Peanut butter, smooth	2 Tbsp.	50
Peanuts, dry roasted	1 oz.	49
Almonds, dry roasted	1 oz.	86
Cashews, dry roasted	1 oz.	74

Steroids (Prednisone, Prednisolone, Methylprednisone, Solumedrol):

If your treatment requires the use of prednisone or Solumedrol, you may experience some of the following side effects:

- Increase in blood sugars
- Fluid retention
- Increase in blood cholesterol and triglycerides
- Excessive weight gain, especially in the face and abdomen
- Agitation

Steroids also increase muscle tissue breakdown. Therefore, your protein needs are high. It also increases the loss of calcium and potassium from your body.

For increased blood sugars:

- Avoid added sugars
- Eliminate regular sodas
- Avoid ice cream, cakes, cookies, muffins or candy
- Avoid sugar sweetened yogurt or cereals

To reduce fluid retention:

- Do not add salt in cooking or at the table
- Avoid canned soups and vegetables
- Avoid pickles
- Limit processed meats
- Choose low sodium convenience foods

To prevent muscle tissue breakdown:

- Increase protein in your diet
- Choose chicken, fish, meat or eggs
- Consume high protein beverages
- Choose lentils, beans or peanut butter

POST-TRANSPLANT COMPLICATIONS

1. Infections

Bacterial Infections

Bacterial infections are a possible complication in the immediate period following transplant. The skin, mouth, nose and intestinal tract normally contain bacteria that are not dangerous unless your child's blood counts are very low. White blood cells usually destroy foreign bacteria that enter the body. Therefore, when your child's WBC count is low, they are more likely to get a bacterial infection. Bacterial infections in the blood can be extremely serious and some can lead to a life-threatening situation called **septic shock** - (blood poisoning).

Due to the threat of bacterial infections, good hygiene and frequent mouth care will be required of all transplant patients. Nursing staff will be taking frequent temperatures in order to help detect infections. Antibiotics to treat possible infections are started with the first fever greater than 38.0 C (100.4 F). Other antibiotics and IV antibodies (immunoglobulins or IVIG) may be given to prevent certain infections.

Viral Infections

Viruses are smaller than bacteria, can only reproduce in a living organism and do not respond to most antibiotics. A viral infection can be very mild or life-threatening. The Herpes viruses sometimes cause infections in transplant patients. *Herpes Simplex Virus Type I (HSV I)* is a common virus which causes cold sores. *Herpes Simplex Virus II (HSV II)* causes genital lesions. HSV II is rare in our patient population. *Herpes Zoster (Shingles)* is caused by the chicken pox virus. It usually appears as a group of blisters on the legs or back. Your child may have fever, pain and itching with Herpes Zoster. This virus may be contagious to other transplant patients if they come into contact with the fluid in the blisters. Therefore, if your child develops Herpes Zoster, they will be placed on isolation and confined to their room until the blisters heal.

Herpes can remain dormant (sleeping) for years in people who have had these infections in the past. During an illness or other stress, when the body's ability to fight an infection is low, these lesions can reappear. Therefore, if your child has had cold sores in the past, they may develop severe mouth lesions. Your child may also develop Herpes Zoster if they have had chicken pox in the past.

Acyclovir is a medication which can be given IV, by mouth, or as an ointment to help prevent and/or treat the Herpes viruses. Your child will be placed on low doses of Acyclovir immediately before and for some time after transplant.

Cytomegalovirus (CMV) is a common infection. By adulthood, two out of three people have had the infection, although in many people, it may appear as a mild illness. Special tests will be done prior to your child's treatment to determine whether they have been exposed to CMV in the past. Like the Herpes viruses, CMV can remain dormant for years and can be reactivated after a stem cell transplant. A CMV infection can occur at any time after transplant, but is most common within the first few months. The infection can be very mild or life-threatening if the virus invades the blood, lungs, liver or other organs. A severe CMV infection may be difficult to treat. However, there are some anti-viral medications we have used with success. Your child will be monitored closely for evidence of CMV reactivation in the blood.

Polyoma virus can infect the bladder, causing painful urination and bloody urine. Increased IV fluids and medications to ease pain and bladder spasms are used to treat Polyoma.

During their transplant, your child is at risk for a variety of other viral infections. Some of these can be treated with medications. Some viruses do not have a known treatment, but most cause mild infections.

Fungal Infections

Mold and yeasts are examples of fungi. They are capable of causing infections in children who have an altered immune system. Antibiotic therapy can place your child at a higher risk for developing a fungal infection.

Candida (thrush, monilia) is a white yeast most commonly found in the mouth and vagina. It can also be found in the intestines. If your child develops mouth sores, *Candida* could have access to the blood stream. This could cause a serious infection.

Aspergillus is another type of fungal infection that can invade the tissues of any mucous membrane (mouth, intestines) and extend to other organs. Because fungal infections can be life-threatening, we use medication to help prevent fungal infections.

Protozoan Infections

Protozoans are microscopic one-celled organisms. *Pneumocystis carinii* is a protozoan that causes pneumonia in patients who are immunocompromised. Your child will receive a medication, Bactrim, Pentamidine or Dapsone prior to transplant and then beginning approximately 30 days after transplant to try and prevent this type of pneumonia.

2. Bleeding

Until your child's new cells begin to grow, there will be a period of time when they will have very low platelet counts. They will be at risk for bleeding at this time. Therefore, it is extremely important to avoid any trauma which may cause bruising or bleeding. Your child will be checked frequently for signs of easy bleeding. Their urine, stool and emesis will be monitored for the presence of blood. Please report any signs of bleeding to your child's nurse. Platelet counts will be done frequently and platelet transfusions will be given as necessary. Some children require 1-3 platelet transfusions each week while others require 1-2 transfusions each day. Some children require continuous infusions of platelets for a period of time. This does not have any bearing on the growth of the transplanted stem cells, nor does it predict your child's eventual outcome.

3. Graft-vs-Host Disease

Graft-vs-Host Disease (GVHD) occurs when an allogeneic transplant patient's new stem cells recognize their body as foreign and react against it. There are two types of GVHD: *acute* and *chronic*. The acute phase usually starts between 12 and 100 days after the transplant. It may affect the skin, intestinal tract, bone marrow or liver. The reaction varies from mild to severe.

GVHD is often first detected by skin changes. Skin reactions may be limited to an itchy red rash that often begins on the palms of the hands and soles of the feet, but may progress to bright red blisters and inflamed skin resembling a severe burn. Not every skin rash is caused by GVHD. Many children have temporary rashes that are caused by allergies to antibiotics, viral infections or unknown causes. Therefore, a skin biopsy may be required to accurately diagnose GVHD. The treatment for skin GVHD may include steroid creams and oral or IV medications.

Intestinal reactions can present as abdominal cramping, diarrhea, nausea and vomiting and shedding of the intestinal lining. This can lead to poor absorption of food and may become so severe that your child will not be able to eat or drink for several weeks. Total parenteral nutrition (TPN), IV nutrition given through your child's central line will be required. GVHD is not the only cause of nausea, vomiting and diarrhea. Therefore, a biopsy of the intestinal tract may be done to look for evidence of GVHD and other diseases that might cause similar symptoms.

Involvement of the liver is monitored by checking certain blood tests (liver function tests). Your doctor will explain these tests in more detail if your child's tests show possible GVHD.

Research and experience have shown that certain medications (Cyclosporine, Tacrolimus, Solumedrol, Methotrexate, Cellcept) can help to prevent GVHD from developing. Your child will be given one or more of these medications. Your doctors and nurses will discuss each of these with you in detail. GVHD can be very mild, or it can progress to a very life-threatening condition with many complications that are very difficult to treat.

There is a possibility that acute GVHD can turn into a chronic form. Chronic GVHD occurs after 100 days post-transplant. It is discussed in more detail in the Discharge Section of this Handbook. It, too, can occur in any of three target organs (skin, intestinal tract, liver) as well as in other organs.

4. Interstitial Pneumonitis

Interstitial Pneumonitis (IP) is a lung disease that may occur at any time during the first few months after transplant. It occurs when the lungs fill with fluid. This may be caused by an infection (bacterial, viral or fungal) or by a reaction to radiation (TBI) or chemotherapy. A *bronchoscopy* or *lung biopsy* may be necessary to diagnose this disease. IP may be mild or severe. Mild disease may require supportive oxygen therapy. In severe disease, your child may need to be transferred to the *Pediatric Intensive Care Unit (PICU)* so that their breathing can be supported with a breathing machine (*ventilator*). Your child may also require a *chest tube* to drain fluid off of the lung(s). Antibiotics, anti-viral medications or anti-fungal medications may also be prescribed.

5. Veno-Occlusive Disease

Veno-Occlusive Disease (VOD) is a complication which involves the liver. It is seen most commonly in patients who have abnormal liver function tests, occasionally a result of having previously been on chemotherapy. In VOD, the vessels of the liver become plugged, causing the liver to fill up with bile. This congestion of the liver causes tenderness over the liver (right side of the abdomen), weight gain, and a build-up of fluid in the abdomen (*ascites*). The patient's skin and whites of the eyes, (*sclera*), may become yellow in color, (*jaundiced*). This jaundice may cause the skin to itch. Urine may be amber in color.

Children in the transplant unit may be started on a continuous Heparin drip. Heparin helps to prevent clotting in the liver, thus reducing the chance of VOD. The heparin drip will continue until your child is ready for discharge. If your child's doctor suspects VOD, your child's weight, abdominal girth and labs will be monitored frequently. It is extremely important that all patients have their weight checked first thing in the morning to monitor for VOD and other fluid retention problems. VOD is a serious complication, but it can be treated successfully with medications.

6. Renal Failure

Renal (Kidney) Failure is a complication which can occur when the kidneys are injured. The kidneys can become injured by certain medications or by a drop in blood pressure. Your child's kidney function will be monitored frequently through lab tests. If kidney function does decrease, medications and IV fluids may be changed to help the kidneys. If severe kidney failure occurs, your child's blood may be filtered through a machine (*dialysis*) until the kidneys begin to function again. Dialysis can be done in any room on the unit. A specially-trained dialysis nurse performs the procedure.

7. Other Potential Long-Term Side Effects

It is important to be aware of some other side effects your child may experience after transplant.

Total body irradiation (TBI) may produce sterility, endocrine abnormalities and growth problems. Your child will probably need treatment with special growth hormones to help with this. TBI occasionally causes cataracts to form in the lens of the eye. This commonly occurs years after the transplant. It is important to notify your child's doctor of any changes in your child's vision. Loss of intellectual function may also occur following TBI given to small children. It is hard to predict how severe this might be. Some school subjects may be more difficult for your child to learn.

It is also important for you to know that there is a 1-3% risk that your child will develop a secondary cancer, perhaps years post-transplant. Please refer to your copy of your consent for additional information about specific long-term side effects for your child.

8. Failure to Engraft

Sometimes, transplant stem cells fail to *engraft* or grow. When a child's own cells begin to grow instead, it is called *auto-recovery* (relapse). These situations are disappointing for patients, families and the transplant team, because they mean that the transplant did not work. The patient is at risk for relapse of their disease and without red cells, white cells and platelets, is at continued risk for anemia, serious infections and bleeding.

In the event of graft failure, our transplant team will discuss with you all alternatives. Sometimes a second transplant is an option. A joint decision will be made by you and the team as to how to proceed.

9. Potential Relapse

Relapse of your child's disease may occur at any time after transplant. However, relapse usually occurs within the first one-two years. If a relapse does occur, a joint decision will be made by you, your child's physician and the transplant team as to which treatment plan will be most beneficial for your child. It is important to know that the medical team will be available to help you and your family come to a decision. Alternatives may include: receiving more chemotherapy, a second transplant, or discontinuation of treatment. If you decide to discontinue treatment, your child can receive supportive care at Penn State Children's Hospital, or your home hospital. It is important to be aware of the potential of relapse and to be able to discuss which option will be best for your child and family should relapse occur. Remember, discussing the "negatives" in no way should diminish your hopes of success. Planning ahead will prevent you from having to make difficult decisions under tremendous stress. All members of the transplant team are available at any time during the transplant process to discuss any concerns/questions that may arise.

VI. DISCHARGE

Congratulations! You have reached a very important stage of the stem cell transplant process --***your child's discharge!*** This is both a very exciting time and a time that can produce anxiety and uncertainty. These are very normal feelings and reactions for each and every family. It is important for you and your family to realize that we, as a team, feel that medically your child is ready for discharge. Their bone marrow has engrafted and they are getting stronger each day. We will make sure that you are fully prepared to take care of your child before the day you are discharged from the hospital. Your child's nurses will provide you with appropriate training and you will be assigned a home infusion company nurse who will help you to learn how to administer IV medications and/or TPN that your child may need. You are encouraged to place instructions from your home infusion company in this section of your handbook. You will learn how to care for your child's central line (flushing, changing the cap, changing the dressing, drawing labs). We will make sure that you know who to call should you have questions or problems. The home infusion company is on-call 24 hours a day should you need their assistance.

Your child will be monitored closely while an outpatient. They will be seen frequently in the PSCT clinic as needed. The frequency of your clinic visits will decrease as your child's health improves. It will not be unusual for your child to need to receive blood products in the clinic. There may also be times when your child will need IV fluids or medications as an outpatient. The pediatric nurses in the clinic are highly trained and capable to work with our transplant patients.

If your child needs medical attention at night when the clinic is closed, you will be asked to bring your child back to the emergency room where they will be evaluated in an isolation room by our staff. Alternatively, your child may be directly admitted to 7 West.

On the day of discharge you will be given written instructions to follow. These include a list of symptoms that require a phone call to one of our team members (following). Emergency phone numbers are found in this section of the handbook. **Remember** that you can call at **any** time for **any** concerns or questions. We will do all that we can to make this very exciting and special transition easy and smooth for you.

When to Call

1. Fever greater than 100.4 F or 38 C **(NO RECTAL TEMPERATURES)**
2. Any new or worsening skin rash
3. Diarrhea
4. Any blood in urine, stool or emesis (may be red or dark brown-black)
5. Burning with urination
6. Cough, cold or runny nose. Any green or yellow drainage from the nose or from a cough
7. Shortness of breath
8. Increased bruising or any bleeding
9. Vomiting
10. Visual changes, continual eye redness, “gritty” sensation of the eyes, eye drainage
11. Change in eating habits (not eating or loss of appetite)
12. Lethargy (unresponsiveness, difficulty waking up)
13. Irritability, fussiness
14. Pain not relieved by Tylenol or the pain medication you have been given by your child’s doctor
15. Any signs of infection at catheter site or any other area on the child's body. These signs are: tenderness, redness, warmth, swelling, any drainage from the site or a red streak going up along the catheter
16. Chicken pox exposure (even if your child has had the disease in the past)

Although the most common concerns are listed, we cannot anticipate every problem. Please do not hesitate to call for any concern that is not addressed.

FOR EVENINGS, NIGHTS, HOLIDAYS, OR WEEKENDS, PAGE THE PEDIATRIC STEM CELL TRANSPLANT ATTENDING WHO IS ON CALL 24 HOURS A DAY (717) 531-8521. If you are put on hold while the doctor is being paged, please do not hang up. It may take several minutes for the page to go through and the doctor to answer. If there is a long waiting time, the operator will come back on the line.

Between 7:30 am – 4:00 pm, Monday – Friday, please call the BMT staff at the clinic at (717) 531-4904.

FOR EMERGENCIES: CALL 911 and then page the Pediatric Stem Cell Transplant Attending on call 24 hours a day (717) 531-8521.

The following is a discussion of some of the issues and concerns you may encounter when you leave the hospital.

Medications

It is extremely important that your child take prescribed medications as directed. Your child's nurses will teach you the purpose of each drug, how it is given, when it is given, how much is given, and its side effects. You will be given a copy of your child's current medications. You are encouraged to place the list in this section of your notebook and to bring it with you to each clinic visit. Please have one of our team members update it as medications and dosages change. Taking ordered medications as instructed will help prevent and control the complications associated with your child's transplant.

- **Cyclosporine** or **Tacrolimus (FK506)**, or **Mycophenylate (Cellcept)** are given to prevent GVHD, and are usually taken by mouth as a pill or liquid. Failure to take any of these medications is an urgent matter and must be discussed with the SCT Attending immediately.
- **Bactrim (Septrim)**, taken as a pill or liquid, **Dapsone** taken as a pill, or **Pentamidine** (given IV or as an aerosol) will be prescribed to prevent pneumocystis pneumonia.
- **Acyclovir** (given as a pill or liquid) may be prescribed to prevent Herpes infections.
- **Steroids** (Solumedrol) will often be continued outpatient. Doses will be tapered before the medication is stopped. Failure to take steroids as prescribed, as with other immunosuppressants, could lead to serious or fatal GVHD. Discuss this with the SCT Attending on call immediately.
- **GCSF** is continued until your child's white blood cells are sufficiently high. Dosage will be tapered before the medication is stopped.
- **IVIG** will be given as needed depending upon your child's individual situation.

Exercise

Your child is expected to follow a daily routine of exercise that will gradually increase until they are at their pre-transplant level of activity. Exercise is important because it stimulates the blood circulation and strengthens the heart and lungs. Walking, playing and bike riding are good ways to improve physical fitness. Your child should be encouraged to resume the games and outdoor activities they enjoyed prior to diagnosis. If your child's platelet count is low, they should refrain from contact sports and other activities that may cause injury or bleeding. Please discuss exercise limitations with your child's doctor.

Daily Hygiene:

- *Change clothes daily.
- *Continue to bathe or shower daily using antibacterial soap.
- *Wash hands after using the bathroom and before eating or preparing food.
- *Check skin daily for any new rashes, petechiae (small red/purple dots on skin), or bruises.
- *Central line dressing changes should be done as instructed by your home infusion company nurse.
- *Have them clean and dry their peri-rectal area carefully each time they use the bathroom.
- *You may continue any skin or peri-rectal creams given to you in the hospital, as instructed by your child's doctor.
- *Continue rectal care at home, especially if your child has diarrhea. Girls should wipe from front to back to avoid urinary tract infection. Do not use rectal creams or suppositories without talking to your child's doctor.
- *If your child has dry skin, use bath oils, lotions with lanolin or aloe vera and/or a natural soap.
- *Introduce make-up and lotions one at a time. Observe for signs of allergic reactions. Use new bottles that are the same type/brand used prior to SCT.
- *Use electric razors until your child's platelet count reaches 50,000.
- *Use pH balanced shampoos and conditioners on scalp and new hair.
- *Mouth care is addressed under "Frequently Asked Questions about Discharge" (following)
- *No tattoos
- *No body Piercings
- *No Manicures/Pedicures

School and Work

It may take up to one year for your child's immune system to function adequately. Therefore, depending on the type of transplant your child had, we may suggest you wait this amount of time before allowing them to return to school or work. Please discuss this with your child's doctor. You may allow your child to receive homebound instruction or to work in a home office as long as they are not in contact with a lot of people.

Gardening:

Your child should avoid gardening and playing in the soil or sand while immunosuppressed. Please check with his/her doctor before allowing him to resume these activities.

Dental Follow-up

Children post-transplant may have dental problems. Inadequate cleaning/brushing during times of mucositis may also predispose your child to tooth decay. It is, therefore, important that your child see their dentist every 6 months for a mouth evaluation. Special fluoride treatments may be ordered. **The SCT team should be notified before dental visits are scheduled. Your child may need to be put on antibiotics prior to the appointment to prevent infection.** Your child's doctor and dentist should be notified if your child notices excessive mouth dryness, or any mouth lesions, loose teeth or receding gums. Children less than twelve years old who have received total body irradiation should be evaluated periodically for the development of permanent teeth before any baby teeth are removed.

Medic Alert Identification

You will need to make plans to purchase a medic alert identification tag for your child. It can be a bracelet or a necklace. This identification states that your child has had a stem cell transplant. If your child needs an emergency blood transfusion, it tells the kind of blood products to give. This identification tag can be purchased at some jewelry stores, pharmacies, or through medic alert mail order. You will need to get this ID tag around the time of discharge.

Engraving information for **Allogeneic SCT Patients:**

ALLOGENEIC SCT. TRANSFUSE ONLY IRRADIATED AND LEUKO-FILTERED BLOOD PRODUCTS.

Engraving information for **Autologous SCT Patients:**

AUTOLOGOUS SCT. TRANSFUSE ONLY IRRADIATED AND LEUKO-FILTERED BLOOD PRODUCTS.

Please ensure your child's medic alert ID will be available by discharge. It is very important to wear this ID for at least one year after stem cell transplant. Older children may also want to make a medic alert card for their wallet, stating the same information (along with CMV status for allogeneic patients) and physicians name if desired.

Chronic Graft vs Host Disease (GVHD)

Chronic GVHD can occur from 100 days to 2 years post-transplant. It is caused when donor cells recognize that your child's body is foreign and begin to attack it. Symptoms include: dry, painful eyes; dry mouth, mouth ulcerations; hair loss; brittle nails, thin skin and other changes in the texture of the skin; malabsorption of food leading to weight loss; a compromised immune system; a low platelet count; unusual fatigue; chronic low grade fevers and abnormalities in lung, kidney and/or liver functions.

Please notify your doctor immediately if you notice any of these changes. They will be able to perform tests to determine whether your child's symptoms are due to chronic GVHD. If so, several medications can be prescribed to alleviate or control these symptoms.

Frequently Asked Questions about Discharge

1. How long do we need to stay in town after transplant?
 - This is dependent upon your child's resilience for complications, and will be discussed with you individually.
2. How long does my child have to wear a mask?
 - Check with your pediatric stem cell transplant attending physician. Factors such as chronic graft-vs-host disease, immunosuppressive drugs or slowly recovering immune systems all affect how long a patient needs to wear a mask. Generally, autologous transplant patients should wear a mask for 100 days post-transplant. Allogeneic transplant recipients should wear a mask until their immune function studies show nearly normal results.
3. Can we drive around in the car without a mask?
 - Yes, if the air conditioner or heat is set on "fresh air circulating" and windows are up. A mask should be worn if you will be driving through dust or a construction area.
4. When can my child go to other outdoor areas?
 - Anytime that dust and pollen are not blowing in the air. Remember that young children may not be able to avoid touching dirt, rocks, plants, etc., so you may want to consider having your child wear gloves and cleaning their hands thoroughly (take wipes along!) after your visit **or** avoid outdoor areas altogether until your physician gives you the okay.

Remember also, that your child is susceptible to sunburn after chemotherapy and /or irradiation. Sun irritation may also activate GVHD. Limit your child's outside exposure to 30-60 minutes in the early morning or evening. Avoid direct sun between 10:00 am and 4:00 pm. Your child should wear a hat and sunscreen with an SPF of at least 50 when outside. Remember to cover the backs of the hands, ears, neck and scalp. Reapply sunscreen often.

Limit evening hours outside during warm weather to avoid insect bites.

5. When can my child return to school?
 - Check with your child's SCT physician

6. When can my child go to church, movie theater, mall, grocery store, etc.?
 - Check with your child's SCT physician

7. When can my child go swimming in a private, chlorinated pool?
 - Check with your child's SCT physician. You child's central line must have been removed prior to swimming. **Remember Sunscreen! Avoid** swimming/wading in lakes/rivers/streams/the ocean until your child's physician says it is okay to do so. Your child will be allowed to swim in a pool before they are allowed to swim in other bodies of water.

8. When can my child be around pets?
 - Cats Avoid kittens. Older cats are okay if they are kept inside. Avoid litter boxes.
 - Dogs Avoid puppies. Older dogs are okay. Avoid face licking, and sleeping in bed with the child. Avoid feces.
 - Birds **Avoid**
 - Reptiles **Avoid**

Encourage your child to not tease pets, so as to avoid scratches and bites.

9. When can my child's friends and relatives come to visit?
 - Visitors who are important, support people for you or your child and who are **HEALTHY** can visit anytime. **Remember** to avoid babies/children who have received live vaccines (chickenpox, MMR, oral polio) for 30 days. Avoid anyone who has received the intra-nasal flu vaccine.

10. When can my child drink well water?
 - Water should be tested for bacteria and toxins. If found to be safe, then it is okay for them to drink 6 months after transplant, if chronic GVHD is not present.

11. Will my child need immunizations repeated after transplant?
 - Autologous transplant patients may not need repeat vaccination. Studies done at one year post-transplant will help decide the need for re-vaccination. Allogeneic transplant patients will need re-vaccination, but not before one year post-transplant. Check with your child's SCT physician to find out when this will be necessary.

12. Should my child or other family members get the flu shot?
 - All close family members should get the flu shot if they can safely receive it. The **patient** should **not** get the vaccine if they are still on immunosuppressive therapy or IVIG. Patients and family members/contacts may not receive the intranasal vaccine.

13. How should the house be cleaned before my child returns home?
- Thorough cleaning of all carpets, curtains, bed linens and clothes. Anything saturated with water during cleaning (e.g. carpets) should be cleaned at least two weeks prior to the child returning home to allow for sufficient "airing out".

14. What about smoking in the home/car?

- **Absolutely not allowed!**

15. What are the dietary restrictions after transplant?

- Continue to follow the Neutropenic diet until your child's SCT physician says that it no longer needs to be followed. Foods containing lactose should be added back to your child's diet slowly. Consult your child's SCT physician for guidance.

To help members of our team to assess your child's nutritional status and need for TPN, please keep a record of what your child is eating and drinking. **Bring this "food log" to each clinic visit.**

16. How long should mouth care continue?

- You should finish your open bottle of chlorhexidine rinse and then this step can be stopped. If old enough, your child should go back to brushing their teeth 2-3 times/day with a soft toothbrush and toothpaste. Continue to use lip balm or petroleum jelly on the lips as needed.

HOME HOME! !

After your child completes treatment, you will return to your own community to gradually resume normal activities. The physician who referred your child to our transplant program will continue to monitor your child's progress and will notify us with any changes. Contact them as soon as you arrive home. Members of our transplant team will also be available to address your questions or concerns.

Remember that full strength and fitness may take up to a year to achieve. Tell your child not to be discouraged if they are persistently tired. Recovery is a slow process; tell them to be patient with themselves and have them continue to get plenty of rest, exercise, and good nutrition.

As a parent, remember to take care of you! Accept help from friends and relatives and get adequate sleep and nutrition. You have been through a stressful and intensive medical treatment with your child. You must maintain your health in order to continue giving them and your family good care, attention, and support.

Many transplant recipients and their parents feel vulnerable after they return home. It is important for your child and you to return to normal activities and to resume friendships. Your experience and your child's experience may have changed your role within relationships as well as your outlook on life. It may take some time before relationships are back to "normal". Be patient with your family and friends.

Some transplant patients and their family members may feel guilty because they have done well after transplant while other patients that they met on the unit did not have good outcomes. Discuss this issue with a trusted family member, friend, minister, or transplant team member. They can help you to put things in perspective.

Many children respond to an extensive hospitalization by regressing to the behavior of a much younger child. They may become aggressive and rebellious or withdrawn and passive. Young children may use baby talk, wet the bed or have temper tantrums. They may develop unusual fears or have nightmares. Once the child returns home to a familiar environment and is stronger, the regression usually reverses. Try to be understanding and encourage your child to talk, act out, or use drawings, stories or other forms of play to show you their feelings.

Expect good behavior from your child and use appropriate discipline when necessary. This gives children a sense of security and hope that things are back to "normal". Continue to be open and honest.

Siblings often resent all of the special attention the transplant patient is receiving or may have trouble coping with all of the changes in their life because of the disruption of the family. They may exhibit regressive or behavioral changes similar to those of the previously hospitalized child or they may be anxious, depressed, have trouble sleeping, or have increased physical complaints like

headaches or stomachaches. A change in school performance commonly occurs. Try to be understanding. It is important to continue to be open and honest and to explain why you have to spend extra time with their brother or sister. Involve them in their sibling's care whenever possible. Give them appropriate responsibilities so they feel of value and part of the "team". Spending time with each child individually and recognizing their achievements is critical. It is a good idea to talk with your children's teachers so that they will understand the situation and give support to siblings.

Remember that you and your family have been through a very stressful medical treatment. Each person will have different levels of understanding and coping. Each person will have to assume unfamiliar roles within the family unit. Try to recognize, respect, and be tolerant and understanding of where each family member is in their acceptance of what has happened. The challenge created by a child having undergone a transplant can be overwhelming to even the strongest family. Do not be afraid to seek professional guidance to help you understand and cope with the stressful events that have occurred in your life. You deserve help! Many families have sought some form of assistance. Please contact a member of the transplant team if you need help in finding an appropriate counselor or support group to meet your needs.

And *finally*, please remember to take one day at a time. Enjoy being reunited with family and friends. Enjoy life! Be proud of the fact that you and your child have endured a stem cell transplant!

Please keep in touch. Everyone on the unit and in the clinic loves to receive updates on your child through cards, letters, e-mail and pictures! Please come visit on the unit when you are in town for check-ups! We would love to see you!

Stem Cell Transplant Glossary

ABMT: Autologous bone marrow transplant

Absolute Neutrophil Count (ANC): A common blood cell count measured after stem cell transplant. Neutrophils are responsible for much of the body's protection against infection.

Acute: Having severe symptoms and a short course

Adjuvant Therapy: Additional drug or other treatment designed to enhance the effectiveness of the primary treatment

Alkaline phosphatase: An enzyme produced by the liver or bone. An elevated level of alkaline phosphatase in the blood may indicate a liver or bone problem

Allogeneic: Transplant in which stem cells (bone marrow or cord blood) from a donor, rather than the patient's own marrow or blood, is infused

Allogeneic Stem Cell Transplant: A type of transplant where the bone marrow or peripheral blood stem cells are obtained from another person, usually of the same or very similar tissue (HLA) type. The donated cells can come from a related or unrelated donor.

Allograft: Bone marrow removed from a donor to be used in an allogeneic BMT

Alopecia: Loss of hair

Anaphylaxis: Acute allergic reaction (shortness of breath, rash, wheezing, low blood pressure)

Anemia: A condition where not enough oxygen gets to the tissues and the organs due to a decreased number of red cells. In severe form it results in weakness and fatigue or even fainting.

Antibiotic: A drug used to fight bacterial infections

Antibody (antibodies): Any of various proteins in the blood that are created by the immune system to neutralize foreign substances in the body. The immune system creates antibodies in response to substances in the body that contain foreign antigens, such as viruses.

Antiemetic: A drug used to control nausea and vomiting

Antigen: A foreign substance that causes your immune system to create an antibody or cells that will, in turn, attack the foreign substance.

Apheresis: A method of obtaining and separating specific blood components, such as white blood cells (called leukopheresis), platelets, plasma, or stem cells. The process is similar to donating a unit of blood. During apheresis, a portion of the donor's blood travels through a closed, sterile tubing system through a machine that separates out the targeted cells and returns the remainder of the cells back to the donor.

Aplasia: A failure to develop or form. In bone marrow "aplasia", the marrow cavity is empty.

Ascites: Abnormal buildup of fluid in the abdomen

Ataxia: Loss of balance

Autograft: Bone marrow removed from the patient to be used in an autologous BMT

Autologous Stem Cell Transplant: A transplant where the patient's own bone marrow or peripheral blood stem cells are removed, stored, treated, and returned to the patient at a later time

Bacteria: Microscopic organisms that invade human cells, multiply rapidly, and produce toxins that interfere with normal cell functions

Baseline test: Test which measures an organ's normal level of functioning. Used to determine if any changes in organ function occur following treatment

Bilirubin: A pigment produced when the liver processes waste products. A high bilirubin level causes yellowing of the skin

Biopsy: Removal of tissue for examination under a microscope, sometimes required to enable the doctor to make a proper diagnosis

Blast: An immature or imperfectly developed blood cell.

Blast cell: Immature cell

Blast crisis: In patients with chronic myelogenous leukemia, the progression of the disease to an acute advanced phase, evidenced by an increased number of immature white blood cells in the circulating blood. Sometimes loosely used to describe a rapid increase in the white blood cell count of any leukemic patient

Blood Stem Cells: Cells found in the blood that can grow into a red blood cell, a white blood cell or a platelet. Also called hematopoietic stem cells.

Bone Marrow: A spongy tissue found in the cavities of your body's bones. It resembles blood and contains stem cells, which produce your red cells, white cells, and platelets. Marrow for transplant is usually collected from the back-side of the pelvic bone, specifically the iliac crest.

Bone marrow aspiration: Procedure used to remove a sample of bone marrow, usually from the rear hip bone, for examination under the microscope

Bone Marrow Harvest: Removal of a portion of a person's bone marrow from their pelvic bone using a needle for use in autologous or allogeneic transplantation.

Bone Marrow Transplant: A procedure in which doctors use high doses of anticancer drugs or radiation to destroy the patient's diseased marrow and then give the patient healthy marrow as a replacement. In an autologous transplant, the patient's own marrow or – more often – blood stem cells are harvested, possibly treated, and then transplanted. In an allogeneic transplant, another person donates the healthy marrow or blood stem cells. On occasion, the allogeneic stem cell collection is treated to reduce the number of T-lymphocytes.

Bone Scan: A test to create images of your bones on a computer screen or on film. A small amount of radioactive material is first injected into your vein and then travels through your blood-stream. It collects in your bones (especially abnormal areas of the bone) and is then detected by a scanner. This examination can detect tumors of the bone.

Cardiac: Pertaining to or having to do with the heart

Catheter: Small flexible plastic tube inserted into a portion of the body to administer or remove fluids

CAT Scan: This test combines x-ray and computer technologies to produce highly detailed cross sectional tissue views.

CBC: Complete blood count. Determines whether the proper number of red blood cells, white blood cells and platelets are present in the patient's blood

Central line: See central venous catheter

Central venous catheter: Small, flexible plastic tube inserted into the large vein above the heart, through which drugs and blood products can be given, and blood samples withdrawn painlessly (also called central line, Broviac catheter)

Chemo- responsive: Responds to chemotherapy, e.g., a tumor is chemo-responsive if it shrinks in size following chemotherapy

Chemotherapy: A treatment that destroys cancer cells with drugs to prepare the patient for a blood stem cell transplant. Selected forms of chemotherapy work by inducing the differentiation of the cancer cell to a mature normal cell.

Chronic: Lasting a long time

Clinical Trial: A study that uses new treatments to care for patients. During clinical trials, more information is collected about new treatments, their risks, and how well they do or do not work. If clinical trials show that the new treatment is better than the treatment currently being used, the new treatment may become the “standard” treatment.

CNS: Central nervous system

Collection Center: National Marrow Donor Program-accredited hospitals with experience and facilities to collect stem cells and care for stem cell donors before and after the stem cell donation procedure.

Colony-Stimulating Factors (CSF): Substances that stimulate the production of blood cells. Treatment with CSF can help the blood-forming tissue recover from the effects of chemotherapy and radiation therapy.

Conditioning: The process of preparing the patient to receive stem cells for transplant. The chemo- therapy and/or radiation that is given to patients before the marrow or blood stem cell transplant. The purpose is to kill diseased cells so the new cells can grow.

Confirmatory Typing: A repeat tissue typing test to confirm the compatibility of a volunteer or related donor with a patient. To determine if the relative or volunteer is interested in proceeding with testing, they are contacted by a member of the donor center. Arrangements are then made by the donor center for the drawing and shipping of the blood sample. The blood sample is tissue typed using DNA technology and is tested for infectious diseases.

Conjunctivitis: Eye inflammation

Contracture: Shortening of muscle, skin and other soft tissue, usually in the limbs. May occur in patients with chronic graft-versus-host disease

Coordinating Center: The NMDP Coordinating Center, office located in Minneapolis, Minnesota, establishes standards, policies, and procedures for its Network of Transplant, Donor, Apheresis and Collection Centers, Cord Blood Banks, Recruitment Groups and Cooperative Registries. From this office, Network Centers performance is monitored; patients’ searches for compatible unrelated donors are coordinated; and communication between Network members is facilitated. The scheduling, coordination, transport and tracking of unrelated stem cell collections are managed by the Coordinating Center.

Cord Blood: The blood of newborns found in the umbilical cord and placenta. It contains large numbers of blood stem cells. For this reason, blood stem cells from the placenta and umbilical cord are collected after birth and stored for transplant.

Cord Blood Bank: An organization that helps to collect and store umbilical cord blood for transplant.

Cryo- preservation: To preserve by freezing. Bone marrow harvested for an autologous BMT, for example, is cryopreserved

CSF: See colony stimulating factor

CT (or CAT) Scan: A test that takes a series of detailed pictures of areas inside your body. The pictures are created by a computer linked to an x-ray machine. Also called coputed tomography scan or computed axial tomography scan.

Cytomegalovirus (CMV): A virus that lies dormant in many persons' bodies and frequently causes infection post-transplant. Patients who have been exposed to and still carry the virus are CMV-positive

Dermatitis: A skin rash

Differential: The percentages of each type of WBC in the blood

DNA: Deoxyribonucleic acid. The protein that carries genetic information. Every cell with a nucleus contains a strand of DNA. DNA determines the unique characteristics of each person.

DNA Based HLA Typing: Determining a person's HLA type by direct examination of the DNA, DNA-based typing is favored by the NMDP because it is very accurate and efficient.

Donor: A volunteer who has donated stem cells for a patient.

Donor Center: An NMDP-accredited organization with the experience, staff and facilities to recruit and manage interaction with volunteer stem cell donors listed on the Registry.

Donor Workup: The process that a closely matched potential donor undergoes to determine whether he or she is healthy and prepared to donate stem cells. Workup includes a detailed information session with a donor center coordinator, a thorough physical examination, a donation of additional blood samples for testing and research and usually a donation of autologous blood. During the donor workup two questions need to be answered after the volunteer has been fully educated about stem cell donation:

- Does the volunteer want to donate their stem cells?
- Is the volunteer medically able to donate their stem cells?

Dysplasia: Alteration in the size, shape and organization of cells or tissues

-ectomy: Surgical removal

Edema: Abnormal accumulation of fluid, e.g., pulmonary edema refers to a build-up of fluid in the lungs

EKG: Test to determine the pattern of a patient's heartbeat

Electrolyte: Minerals found in the blood such as sodium and potassium that must be maintained within a certain range to prevent organ malfunction

Emesis: Vomit

-emia: Of the blood, usually refers to a blood disorder, e.g., leukemia or anemia

Encephalopathy: Abnormal functioning of the brain

Engraftment: Return of the normal production and maturing of blood cells, following stem cell transplantation. Engraftment is characterized by an increase in white blood cells and/or platelets in the peripheral blood and the presence of donor cells in the bone marrow.

Enzyme: A protein that is capable of facilitating a chemical reaction

Eosinophil: A type of white blood cells that protects against infection

Febrile: Feverish

Filgrastim: The generic name for a growth factor produced by recombinant DNA technology that occurs naturally in humans and stimulates production of white blood cells called granulocytes. A protein that helps bone marrow make more white blood cells. Filgrastim is also known as G-CSF (granulocyte-colony stimulating factor) or by the trade name Neupogen®. It is given to donors who have agreed to donate peripheral blood stem cells. This moves blood stem cells from the marrow into the bloodstream so that they can be collected by apheresis. It is also given to patients to help increase their white blood cell count after the transplant.

Foley catheter: Flexible plastic tube inserted into the bladder to provide continuous urinary drainage

Formal Search: The stage in a search for a matched unrelated stem cell donor when our Search Coordinator requests blood samples on one or more potential donors for confirmatory typing.

Fungus: A primitive life form that can cause infection in the body. Fungi that sometimes cause post-transplant infections are the Candida and Aspergillus fungi

Gastritis: Inflammation of the stomach

Gastrointestinal: Refers to the stomach and intestines

G-CSF: Granulocyte colony stimulating factor. A protein that stimulates the growth and maturation of a wide variety of white blood cells

Genetic Factor: A characteristic or trait that is influenced or encoded by one or more genes.

GI: Gastrointestinal

Graft Failure: A condition that may happen after a stem cell transplant where the donated stem cells are present, but function very poorly or not at all.

Graft Rejection: A condition that may happen to people who receive someone else's blood stem cells or marrow in a transplant. The patient experiences a loss of donor cells through an active (often the recipient's immune system) process. It is most often seen in patients with aplastic anemia.

Graft vs. Host Disease (GVHD): A complication of stem cell transplantation in patients receiving stem cells from another person. The newly transplanted immune system identifies the patient's body as foreign and attacks it, resulting in varying degrees of damage to three target organs: the skin, gastrointestinal tract, and liver. GVHD can be mild or serious and is sometimes life-threatening.

Graft vs. Leukemia Effect: A condition where the transplanted bone marrow (the graft) destroys the recipient's residual leukemic cells and thus prevents a relapse.

Granulocyte: A type of white blood cell also called a neutrophil. These cells are important in fighting bacterial and fungal infections.

Granulocyte-macrophage-colony stimulating factor (GM-CSF): Sold as Sargramostim or Leukine, this growth factor is used like G-CSF to speed the recovery of the granulocyte count following the administration of chemotherapy.

Growth Factor: Another term used when referring to medications that stimulate the production of blood cells. Filgrastim is an example of a growth factor that stimulates granulocyte production. (See Filgrastim).

Guaic Test: A chemical test to detect blood in the stool

GVHD: See graft-versus-host disease

Hematocrit: The percentage of the blood made up of red blood cells

Hematology: The study of blood and its disorders

Hematopoietic: The process of forming blood cells: red blood cells, white blood cells, and platelets.

Hematopoietic Stem Cells: Blood forming stem cells capable of producing all the components of blood and marrow. These cells are capable of both replacing themselves and maturing to white blood cells, red blood cells, and platelets.

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

Hemorrhage: Bleeding

Hemorrhagic cystitis: Bladder ulcers

Hepafilters: Air filters that remove very small particles, including bacterial or fungal agents but not viruses, from the air.

Hepat(o): Pertaining to the liver

Hepatitis: Inflammation of the liver

Hereditary: Traits that are passed down to children from their parents.

Hickman catheter: See central venous line

Histocompatibility: The state of similarity between tissues of the donor and the patient (recipient). The level of histocompatibility describes how well a patient and donor are matched. The major histocompatibility determinants in humans are called human leukocyte antigens (HLA). The closer the match, the less likely the donated stem cells and the patient's body will react against each other (see GVHD).

HLA: See human leukocyte antigen

HLA Typing: The process used to determine a person's HLA, A, B, C, and DR proteins.

Human Leukocyte Antigens (HLA): A series of antigens found on white blood cells and most other cells of the body that are used to determine tissue type. Your HLA allows your immune system to recognize self from non-self. When these proteins are the same for both donor and recipient, an allogeneic stem cell transplant is much more likely to be successful. In stem cell transplantation, the HLA antigens routinely typed for are HLA-A, B, and DR.

Hyper-: Excessive, increased

Hyperalimentation: Intravenous feeding that provides patients with all essential nutrients when they're unable to feed themselves. Also called hyperal, TPN or total parenteral nutrition

Hyperpigmentation: Darkening of the skin

Hypertension: High blood pressure

Hypo-: A deficiency, less than usual

Hypotension: Low blood pressure

Iliac crest: The hip bone in which a large quantity of bone marrow is concentrated

Immune System: The complex group of organs and cells that defends the body against infection or disease; the body's defense network against infection and foreign particles.

Immunocompromised: A condition in which the immune system is not functioning normally

Immunoglobulin: An antibody

Immunosuppression: A condition when the body's natural immune system responses have been weakened or are prevented from working.

Immunosuppression may be deliberate, such as in preparation for stem cell transplantation to prevent rejection of the new stem cells by the recipient's immune system; or a side effect that often results from chemotherapy for the treatment of cancer.

Immunotherapy: A treatment that stimulates the body's immune system to fight cancer. Alternatively, antibody or cells administered to patients that have direct or indirect anti-cancer effects.

Infectious Disease Markers: Elements, generally in the form of antibodies, in a person's blood which indicate if a person has had an infectious disease.

Infectious Disease Testing: The method to determine if a person has or did have an infectious disease. Potential stem cell donors have infectious disease testing done at the time of confirmatory typing. Infectious disease testing is also done on all potential stem cell donors during the workup phase at their physical examination. These tests must be repeated within 30 days of the donation.

Informed Consent: The process by which a patient receives a written explanation of the risks and benefits to a medical treatment involving research, so they can make an informed decision on whether or not to participate. If a patient chooses to participate, they will indicate in writing that they understand and agree to the information provided. The written document used in this process is called a consenting document. The consenting document has been reviewed and approved by an Institutional Review Board or human use committee to ensure that it accurately reflects what the research protocol states will be done and is understandable to the average lay-person. A person must be at least 18 years of age before they can provide informed consent.

Intravenous: Through a vein

Irradiate Blood Products: Red blood cells or platelets that have been exposed to radiation to inactivate the lymphocytes, which could potentially cause graft-versus-host disease.

-itis: Inflammation

IVIG: Intravenous Immunoglobulins

Jaundice: A yellowish discoloration of the skin and body tissues and fluids caused by an increased level of bilirubin in the blood stream.

Karnofsky Score: A measure of the patient's overall physical health following a transplant, judged by his or her level of activity

Laminar Air Flow (LAF) Room: A hospital room on the AB&MT Transplant Unit that is reserved for patients receiving a donor cell transplant. This is a room-within-a-room with one wall of the interior room being a high efficiency filter providing the cleanest air possible for stem cell transplant patients.

Leukocyte: Another name for white blood cells. A leukocyte is a type of cell in the blood which helps defend the body against diseases caused by bacteria, virus, or parasites. There are three types of leukocytes: monocytes, granulocytes, and lymphocytes.

Leukocytosis: An increase in the total white blood cell count.

Leukopenia: A low number of white blood cells or a decrease in the total white blood cell count.

Leukophoresis: The process of separating some of the white blood cells from the rest of the blood. Blood is taken from the vein and some of the leukocytes are removed. The remaining blood cells are returned.

Lumbar Puncture (LP): A test in which a sample of the fluid surrounding the brain and spinal cord is removed to check for cancer cells or infection (Also called a "spinal tap")

Lymph: A clear fluid that contains mostly lymphocytes and circulates through the body in the lymphatic system. It is drained from tissue spaces by the lymphatic system and can transport bacteria, viruses and cancer cells. The lymph channels eventually dump the lymph back into the blood stream.

Lymph Nodes: Small, oval-shaped glands distributed throughout the body that contain the vast majority of lymphocytes. These glands house lymphocytes and filter microorganisms and other particles from lymph. The function of these nodes is to fight infection.

Lymphatic System: The tissues and organs that produce, store, and carry white blood cells that fight infection and disease. This system includes the bone marrow, spleen, thymus, and lymph nodes and a network of thin tubes that carry lymph and white blood cells. These tubes branch, like blood vessels, into all the tissues of the body.

Lymphocyte: One of the major groups of white blood cells. The three main kinds of lymphocytes are T-cells, B-cells, and Natural Killer cells. T-cells attack and destroy virus-infected cells, foreign tissue and cancer cells. B-cells help produce antibodies or proteins that help destroy foreign substances. Natural Killer cells destroy cancer cells and virus-infected cells. T-cells are a kind of lymphocyte that causes GVHD.

Macrophage: A type of white blood cell that assists in the body's fight against bacteria and infection by engulfing and destroying invading organisms

Magnetic Resonance Imaging (MRI): A diagnostic procedure which uses magnetic fields instead of radiation to produce images of the body.

Malabsorption: Failure of intestines to properly absorb oral medications or nutrients from food

Marrow Donation: A surgical procedure by which a person donates a portion of their bone marrow for a patient who had diseased marrow and needs a marrow transplant.

Match: In stem cell transplantation, the word “match” relates to how similar the HLA tissue typing is between a donor and a recipient. When a donor and a recipient’s HLA A, B and DR typing are the same they are said to be an “identical match”, a “6 of 6” or a “perfect match.”

Matched Unrelated Donor (MUD): Donor is not related to recipient. (See unrelated stem cell transplant).

Mentation: Thinking

Metabolite: A by-product of the breakdown of either food or medication by the body

Metastasis: The spread of cancer cells from the original site to other areas of the body.

Mixed Lymphocyte Culture (MLC): A lab test in which patient and donor lymphocytes are studied to determine whether they react. Often used to determine the most suitable donor.

Molecular Typing: A term used interchangeably with DNA-based typing or genotyping.

Monoclonal antibody: Antibodies that are all identical, derived from a single "clone". Sometimes used in "purging", a process by which certain cells are removed from bone marrow before infusion into patients

Monocyte: A type of white blood cell that assists in the fight against bacteria and fungi that invade the body

Morbidity: Sickness, side effects and symptoms of a treatment or disease

MRI: Magnetic resonance imaging. A method of taking pictures of body tissue using magnetic fields and radio waves

Mucositis: Inflammation of the lining of the mouth, the throat, the gastrointestinal tract, the genital or urinary tracts. Mouth sores.

MUD: See Matched Unrelated Donor

Myeloblast (Myeloblastic): Immune non-lymphocyte type white blood cells. It is normally seen only in the bone marrow. In some diseases, such as leukemia, myeloblasts may appear in the blood. Healthy myeloblasts will develop into granulocytes.

Myelodysplastic Syndromes (MDS): Also called pre-leukemia or “smoldering” leukemia. A group of disorders in which the bone marrow does not function normally and not enough normal blood cells (platelets, red blood cells, and white blood cells) are made.

Myelosuppression: A decrease in the production of red blood cells, platelets and some white blood cells by the bone marrow.

Nadir: Lowest point, usually used in reference to blood counts related to chemotherapy.

Natural Killer Cells: A type of lymphocyte normally present in the body. Their responsibility is to kill cells that are infected with viruses. Rarely these cells can transform to a form of leukemia or lymphoma.

Neuro: Pertaining to the nervous system

Neutropenia: A decreased number of neutrophils, a type of white blood cell.

Neutrophil: The most common type of white blood cell in the blood stream. It fights bacterial infections. Also called segmented neutrophils or segs. If your neutrophil or seg count is less than 1,000, you are at great risk for infection. The number of neutrophils present in the blood stream is often used as a measure of stem cell engraftment.

Nodule: A small group of cells, a small solid mass.

NPO: Do not take anything by mouth

Oncologist: A physician who specializes in the study and treatment of cancer.

Oncology: The field of study and treatment of tumors (cancer).

Osteopetrosis: A disease of the bones where the bones get very hard and the bone marrow cannot grow.

Osteoporosis: disease in which bones become weaker and more likely to break.

Oto-: Pertaining to the ear

Packed red blood cells : Red blood cells collected from an individual that are packed into a small volume for transfusion into a patient

Palliative: Provides relief

Pancytopenia: A condition where there is a reduction in red blood cells, white blood cells and platelets.

-pathy : Disease

-penia: Deficiency, e.g., neutropenia means a deficiency of a type of white blood cell called a neutrophil

Peripheral Blood Stem Cells: The cells originating in the bone marrow from which all blood cells develop. These cells may divide to form more stem cells or mature into a variety of different blood cells. The stem cells may be collected from the blood system through a procedure called apheresis.

Peripheral Blood Stem Cell (PBSC) Donation: Hematopoietic stem cells are collected from a donor's circulating blood through an apheresis procedure following mobilization from the marrow with Filgrastim. The stem cells are then transplanted into a recipient.

Peripheral neuropathy: Injury to the nerves that supply sensation to the arms and legs

Petechiae: Small areas of bleeding that appear on the skin. This can be due to low platelet counts.

Philadelphia Chromosome: An abnormal arm of genetic material that is often present in some leukemia.

Phlebitis: Inflammation of a vein

-plasia: Development, formation

Plasma: The liquid portion of unclotted blood. (Serum is the liquid portion of clotted blood).

Plasmapheresis: Blood is taken from a vein and circulates through a machine, which separates the cells and the plasma. The plasma is removed and replaced with a substitute, which is returned to the body along with the blood cells.

Platelet: A blood cell that assists in blood clotting. Also called thrombocytes. Patients are at risk to bleed excessively from surgery or trauma if the platelet count is less than 50,000. An increased risk of spontaneous bleeding occurs with platelet counts less than 20,000.

Platelet Count: The number of platelets in a blood sample.

Polycythemia: An increase in the total number of red blood cells in the bloodstream

Preleukemia: A condition in which the bone marrow does not function normally. It does not produce enough blood cells. This condition may progress and become

acute leukemia. Preleukemia also is called myelodysplastic syndrome or smoldering leukemia.

Preliminary Search: The process by which a patient's HLA type is sent to the NMDP and entered into the computer where it is compared to the HLA types of all volunteers listed in the Registry at the time. The patient's demographic information and basic disease status are also submitted at preliminary search. The preliminary search becomes formal when specific donors are requested for further testing on behalf of the patient.

Preparative Regimen: The chemotherapy and/or radiation given to transplant patients prior to transplant to kill diseased cells and/or make space for healthy new marrow and/or suppress the immune system so graft rejection does not occur

Pre-Transplant Conditioning: A regimen of chemotherapy with or without radiation therapy that destroys a patient's underlying cancer and bone marrow. The marrow is then restored by transplanting stem cells.

Prognosis: The predicted or likely outcome

Prophylactic: Preventive measure or medication

Prospective HLA DR Typing: A National Marrow Donor Program typing program that selects stored samples from donors who have been HLA-A, B typed, but not HLA-DR typed, and submits them for HLA-DR typing in advance of the donor being identified as a potential match for a specific patient. The goal of this program is to increase the number and diversity of fully HLA typed volunteer stem cell donors on the NMDP Registry, thus reducing search times and costs for patients.

Protocol: The outline or plan which specifies times and dosages for treatment methods such as surgery, chemotherapy or radiation therapy. Various tests at specific times may also be part of the protocol.

Pulmonary: Pertaining to the lungs

Purging: Process by which certain types of cells are removed from bone marrow prior to infusion into the transplant patient. In autologous BMT's, marrow may be purged to remove cells that cause graft-versus-host disease

Rad: Unit of measurement for radiation dose

Radiation Therapy: Treatment aimed at eliminating cancer cells, shrinking tumors or suppressing the immune system by using high-energy radiation from x-ray machines or other sources.

Red blood cell (RBC): Cells that pick up oxygen from the lungs and transport it to tissues throughout the body.

Refractory: Resistant to therapy.

Registry: A confidential national database of potential volunteer stem cell donors established and maintained by the National Marrow Donor Program.

Relapse: A reappearance of cancer after it had disappeared for a period of time after treatment. The disease is active again and causing symptoms.

Remission, Complete: Complete condition in which no cancerous cells can be detected by a microscope, and the patient appears to be disease-free

Remission, partial: Partial generally means that by all methods used to measure the existence of a tumor, there has been at least a 50 percent regression of the disease following treatment

Renal: Pertaining to the kidney

Research Sample: A sample of a donor's or recipient's blood that is used in research studies. Typically, blood samples are collected for research studies but sometimes a marrow sample is requested at the time of donation.

Scans: Pictures are taken of organs in your body to be used in diagnosing, staging, and monitoring cancer. These pictures include liver scans, bone scans, position emission tomography scans (PET) and computed tomography (CT) or computer axial tomography (CAT) scans. In PET scanning, liver scanning and bone scanning, radioactive substances are injected into your blood stream and collect in these organs. You are then placed through a scanner that detects the radiation and creates a picture. In CT scanning, an x-ray machine is linked to a computer and is used to make detailed pictures of organs inside your body.

Search Process: The process of identifying a suitable donor for a patient in need of a stem cell transplant. The first step is to test family members. If a suitable donor is not found, the patient's HLA antigens are then compared to those of the volunteer donors listed in donor registries (preliminary search). Potentially matched donors are then contacted and asked to participate in further testing (formal search). Blood cells on the volunteers arrive at the transplant center and are tested to identify the best donor for the patient (confirmatory typing). The search process may take from several weeks to over a year.

Sepsis: The presence of organisms in the blood

SGOT: An enzyme produced by the liver. Elevated levels of SGOT in the blood indicate a liver problem

SGPT: An enzyme produced by the liver. Elevated levels of SGPT in the blood indicate a liver problem

Solid tumor: A cancer that originates in organ or tissue other than bone marrow or the lymph system

Spleen: The organ located in the left side of the abdomen, near the stomach which helps to fight bacterial infections

Stem Cell: A common word for any of the cells in the body that can grow into other kinds of cells. In blood stem cell transplants, blood stem cells are given to the patient after they are treated for the disease of the bone marrow. (See also Blood stem Cells and Hematopoietic Stem Cells).

Stem Cell Transplant: The process of infusing healthy stem cells into persons who have undergone high-dose chemotherapy for one of many forms of leukemia, immunodeficiency, lymphoma, anemias, or metabolic disorders. There are three types of stem cell transplants: autologous, allogeneic and syngeneic. Healthy stem cells are collected from bone marrow, peripheral blood, and umbilical cord blood. Once the healthy stem cells are infused into the patient's blood stream, the cells move from the blood vessels to the center of the bones, where they begin making new blood cells.

Steroid: In bone marrow transplantation, a drug commonly used in combination with other drugs to prevent and control graft-versus-host disease

Stomatitis: Mouth sores

Subclavian catheter: See central venous catheter

Syngeneic Stem Cell Transplant: A type of transplant where the bone marrow or peripheral blood stem cells are obtained from someone genetically identical to the patient; an identical twin.

Systemic Disease: Disease that reaches and affects all areas of the body.

TBI (Total Body Irradiation): This type of radiation therapy is often given to patients undergoing a stem cell transplant and is effective in killing cancer and normal bone marrow/immune tissue.

T-Cell: A type of white blood cell that can distinguish which cells belong in a person's body. T-cells are responsible for GVHD.

T-Cell Depletion: The removal, usually in part, of T-cell lymphocytes, a type of white blood cell, from bone marrow donated by another person to prevent or reduce the risk of severe graft vs. host disease.

Thrombocytes: Platelets or cells needed for the blood to clot. (See Platelets)

Thrombocytopenia: An abnormally low number of platelets. If your platelet count gets too low, bleeding may occur.

Thrombocytosis: An abnormally high number of platelets that can be associated with either excessive bleeding or blood clotting.

Tissue Typing: Another term for HLA-typing. (See Human Leukocyte Antigens)

Total parenteral nutrition (TPN): Intravenous feeding that provides patients

with all essential nutrients when they're unable to eat/feed themselves. Also called TPN, hyperalimentation or hyperal

Toxin: Poison

Transplant Center: NMDP- accredited, hospital-based programs with experience, staff and facilities to perform allogeneic stem cell transplantation.

Trauma: Injury

Tumor: An uncontrolled, abnormal growth or mass of body cells that serves no purpose. It may be either benign or malignant.

Tumor burden: The size of the tumor or number of abnormal cells in the organ or tissue

Ultrasound: A test that bounces high-frequency sound waves (sonar) off internal body parts to create images. Tissues of different densities reflect sound waves differently. Echoes are turned into picture (sonograms).

Umbilical Cord Blood Stem Cell: A stem cell from the blood of the umbilical cord and placenta. These cells have the potential to produce all the components of blood in the same manner as stem cells derived from marrow.

Unrelated Stem Cell Transplant: Any stem cell transplant between two individuals who are not directly related. Healthy stem cells are collected from bone marrow, peripheral blood, and umbilical cord blood.

Veno-Occlusive Disease (VOD): A disease that can occur in the blood vessels that carry blood through the liver causing the liver to become swollen or clogged. This sometimes occurs following high-dose chemotherapy &/or radiation.

Virus: A very small particle of DNA or RNA that can infect cells and change how the cells of the body function. Infection with a virus can cause a person to develop symptoms. The disease and symptoms that are caused depend on the type of virus and the type of cells that are infected.

Volunteer Donor: A person who has agreed to donate marrow or stem cells for transplant. Volunteer donors are listed in the NMDP Registry.

White Blood Cells (WBC): A type of blood cell that helps the body fight infection and disease. These cells begin their development in the bone marrow and then travel to other parts of the body. White blood cells also play a role in inflammation and allergic reactions.

Whole blood: Blood that has not been separated into its various components

Workup: The process that a closely matched potential donor undergoes to determine whether he or she is healthy and prepared to donate stem cells. Workup includes a detailed information session with a donor center coordinator, a thorough physical examination, a donation of additional blood samples for testing and usually a donation of autologous blood. During the donor workup two questions need to be answered after the volunteer has been fully educated about stem cell donation:

- Does the volunteer want to donate their stem cells?
- Is the volunteer medically able to donate their stem cells?

Xerostomia: Dryness of the mouth caused by malfunctioning salivary glands

X-Ray: High-energy radiation used in low doses to produce images or pictures of internal body structures to diagnose. X-rays are used in high doses to treat cancer.

Abbreviations

Abbreviations are often used in the hospital setting. Below is a list of commonly used abbreviations that you may find helpful.

ABC	Augmented blood count
ABG	Arterial blood gas
Abx	Antibiotics
ANC	Absolute neutrophil count
bid	Twice a day
BM	Bone marrow (or bowel movement)
BMT	Bone marrow transplant
C	Centigrade
Ca	Calcium
CBC	Complete blood count
cc	Cubic Centimeter 1cc = 1mL
CMP	Chemistry panel (lab test) Complete Metabolic Panel
CMV	Cytomegalovirus
CNS	Central nervous system
CTX	Cytosan (cyclophosphamide)
CXR	Chest X-ray
CYA	Cyclosporine
ECG/EKG	Electrocardiogram
drsg	Dressing
GVHD	Graft-versus-host disease
Hct	Hematocrit
Hgb	Hemoglobin
HLA	Human leukocyte antigen
HSV	Herpes simplex virus
ICU	Intensive care unit
I/O	Intake and output
IV	Intravenous
K	Potassium
Mg	Magnesium
mL	Milliliter
NPO	Nothing by mouth
NS	Normal saline
O2	Oxygen
OR	Operating room
OT	Occupational therapy
oz	Ounce

PFT's	Pulmonary function tests
PICU	Pediatric intensive care unit
plts	Platelets
po	By mouth
PRBCs	Packed red blood cells
PSCTU	Pediatric stem cell transplant unit
PT	Physical therapy
QD	Every day
QID	Four times a day
QOD	Every other day
RBC	Red blood cell
TBI	Total body irradiation
TID	Three times a day
UCB	Umbilical cord blood
WBC	White blood cells

Metric Conversions

Temperature: Your child's temperature will be recorded in Centigrade (C.) while you are probably much more familiar with Fahrenheit (F.). This table will help you convert between the two.

<u>Centigrade</u>	<u>Fahrenheit</u>
36.0	96.8
36.5	97.7
37.0	98.6
37.5	99.5
38.0	100.4
38.5	101.3
39.0	102.3
39.5	103.1
40.0	104.0
40.5	104.9
41.0	105.8

Volume: we measure liquid volumes in ml's (milliliters), cc's (cubic centimeters) and oz (ounces). Below are some of the conversions for these measurements.

1cc = 1 mL
5 mL= 1 teaspoon
15 mL= 1 tablespoon
30 mL= 1 ounce
1000 mL= 1 liter = approximately 1 quart

Weight: We record weights in kilograms (kg). To convert a weight from kilograms to pounds (lb.), multiply by 2.2. For example a 60-kg child would be 132 lbs.

$$\begin{array}{r} 60 \\ \times 2.2 \\ \hline 132 \end{array}$$

To convert from pounds to kilograms, just do the opposite; divide by 2.2. See the weight conversion table below for some help.

<u>Kilograms</u>	<u>Pounds</u>
20	44.0
21	46.2
22	48.4
23	50.6
24	52.8
25	55.0
26	57.2
27	59.4
28	61.6
29	63.8
30	66.0
31	68.2
32	70.4
33	72.6
34	74.8
35	77.0
36	79.2
37	81.4
38	83.6
39	85.8
40	88.0
41	90.2
42	92.4
43	94.6
44	96.8
45	99.0
46	101.2
47	103.4
48	105.6
49	107.8
50	110.0
51	112.2
52	114.4
53	116.6
54	118.8
55	121.0
56	123.2
57	125.4
58	127.6
59	129.8

<u>Kilograms</u>	<u>Pounds</u>
60	132.0
61	134.2
62	136.4
63	138.6
64	140.8
65	143.0
66	145.2
67	147.4
68	149.6
69	151.8
70	154.0
71	156.2
72	158.4
73	160.6
74	162.8
75	165.0
76	167.2
77	169.4
78	171.6
79	173.8
80	176.0
81	178.2
82	180.4
83	182.6
84	184.8
85	187.0
86	189.2
87	191.4
88	193.6
89	195.8
90	198.0
91	200.2
92	202.4
93	204.6
94	206.8
95	209.0
96	211.2
97	213.4
98	215.6
99	217.8

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