Your Blood and Marrow Transplantation

University of Michigan
C.S. Mott Children’s Hospital
Pediatric Blood and Marrow Transplant Program Patient Guide
**The Transplant Hospital stay** Once the pre-admission testing is completed and your child is ready for transplant, they will be admitted to the transplant unit at C.S. Mott Hospital. This unit (7E) specializes in the care of bone marrow/blood stem cell transplant patients.

**The Hospital Room**
Patients receiving a transplant will be placed in a private room.

Each room on the transplant unit includes a small refrigerator, a bedside stand with small drawers, a closet and shelves for storage, a television, a telephone and a private bathroom. The 46” flat panel monitors displaying the GetWellNetwork System in the patient rooms will enable clinicians, Child and Family Life program staff, and other members of the care team to interact and communicate with their patients and families. The Internet, on-demand movies, familiar games and music channels available through this system help to make kids feel a little more normal. This service is available at no charge.

**Family Facilities**
Families and visitors can use the transplant unit loungeduring the day. One adult family member or caregiver is allowed to stay overnight in the patient room. Only overnight guests are allowed to use the patient's bathroom. There are several public restrooms close by. Overnight guests need to coordinate with the nurse before using the shower in the patient’s room. Family caregivers may ask for delivery of meal to the room for a small fee that will be added to the hospital bill. Contact the unit clerk or the dietary aide to make these arrangements.

**Visiting Guidelines**
Visiting hours are flexible for patients in private rooms.

**Sick Siblings, family members or visitors**
All visitors must wash their hands when entering and leaving a patient room. Because this is a transplant unit where patients are at risk when exposed to any illness, we ask that visitors and family members wait to visit until they are well. During flu season (or other epidemics) the rules for visitors may change. Visit [www.med.umich.edu/flu](http://www.med.umich.edu/flu) for details on current restrictions.
Visitors under the Age of 14
To protect patients, visitors under age 14 are required to undergo an infection control screening at the Badging Stations in C.S. Mott Hospital. Children found to be ill are not allowed on the transplant unit. In general, children may visit if they are healthy and have not been exposed to contagious diseases (such as chickenpox, measles, colds or flu) within the previous 48 hours. We recommend taking the visitor’s temperature prior to visiting.

Visitor Check-in and Badging at Mott Hospital
For the safety of your child, all family members and visitors must wear an ID badge at all times. ID badges are provided at Security Welcome Desks throughout the hospital. When getting your ID badge, please be prepared to provide the following information;

- Full name of patient
- Relationship to the patient
- Photo identification
- Parking ticket for validation stamp

Telephone Service
There is no charge for calls using the patient telephones. All rooms have standard telephone jacks for personal phones, answering machines or fax machines.

Patient Mail
While your child is in the hospital, your child can receive mail at the following address. It is important to include your exact room number and hospital unit in the mailing address to ensure the mail gets to you. Also, write the word "patient" in the lower left-hand corner to ensure quick delivery of your letter or card.

Mott Patients:
Patient Name
C.S. Mott Children’s Hospital
Bone Marrow Transplant Unit
Patient Unit 7EMott / Room #
1540 E Hospital Dr.
Ann Arbor, MI 48109
Computer Resources, Internet Access and CarePage Updates
Access and update your CarePages using the room computers on the Blood and Marrow Transplant Unit. Computers with Internet access are also available in the Family Center, and the hospital provides personal computers and independent network connections at every bedside. All of these are provided at no cost to the patient, through the GetWellNetwork. The Mott Family Center (open from 8am to 6pm) has wireless Internet, two plasma TVs, five computers, three digital cameras, photo printer, and X-box 360 game stations. Families and patients are welcome to bring in their own personal laptops to use the wireless Internet access.

Plants/Flowers
Transplant patients are susceptible to infections until their white blood cell count returns to normal. During this time, fresh-cut flowers and plants are not permitted because they may carry a large number of germs in their water and soil. Fresh fruit baskets also are not permitted. Artificial flowers and cards are welcome.

Meals
Our dietary staff will deliver and serve your child’s meals in his room. While your child is in the hospital there will be some restrictions in their diet in order to reduce the chance for infection. You can serve your child food from home but please ask your dietitian or nurse about food safety guidelines, restrictions and nutrition options. You may store food you brought from home in refrigerators that are available on the unit.

Bringing Food to Transplant Patients
Transplant patients are on a special diet throughout the transplant admission. Follow these guidelines if you want to bring your child food from the outside

Food Preparation Guidelines:
- Always wash your hands and a surface the food will touch before handling food. If you are handling raw meat you must wash your hands after handling the meat and before touching another food substance.
- If a plate, cutting board, or utensil was used for pre-cooked food, do not use again for cooked food.
- Use separate cutting boards for meats and vegetables.
- Do not thaw food at room temperature. Thaw frozen foods appropriately as follows:
  a. In the refrigerator
  b. In the microwave on the defrost setting
  c. By running cold water continuously over meat until thawed
- Cook foods thoroughly. Fresh vegetables must be cooked, patients may not eat them raw. Your child may eat fresh fruits with a thick peel (such as oranges, bananas) or those that can be eaten once peeled (such as apples). Canned and cooked fruit sauces are allowed. Cook meats until well done.
- Add seasoning (ex. pepper, herbs, and spices) prior to cooking. Only salt may be added after cooking.
- Portion food into individual servings in tightly sealed containers and cool in the refrigerator or freezer prior to transporting to the hospital.
- Do not leave food in a large cooking pot or let it cool on the counter, this leaves food in the "danger zone" temperature of 40 to 140 degrees which is prime temperature for bacteria to grow.

**Food from a Restaurant or Grocery Store:**
If purchasing food from a restaurant or the cafeteria, follow these guidelines:

- Check “sell by” and “use by” dates and do not buy out of date items
- Do not buy damaged, bulging, or deeply dented cans
- Make sure that frozen foods feel solid and refrigerated foods are cold
- Store groceries promptly after shopping
- Do not buy bulk foods from self-service bins
- Avoid lunch meats from a delicatessen. Prepackaged ham and turkey slices are OK. Avoid bologna, salami, olive loaf.
- Avoid cold deli salads, salad bars or smorgasbords.
- Avoid fountain pop/soda, milkshakes, frosties, frozen yogurt or soft serve ice cream from bulk serving machines.
- Avoid unpasteurized and gently pasteurized honey, cider or juices
Avoid unpasteurized milk or dairy products. Pasteurized milk and dairy products, including yogurt, are acceptable.

Avoid aged cheeses or cheeses with molds (brie, Camembert, bleu, Roquefort, stilton, gorgonzola, feta, farmer’s cheese).

Avoid raw nuts. Roasted nuts without shells are acceptable (i.e. roasted peanuts)

Avoid raw or undercooked meats, poultry, fish and shellfish. Well-cooked meats, poultry, fish and shellfish are acceptable.

Avoid selecting an item that has been held in a food warmer. Request that the item be freshly prepared.

Request the item be prepared without condiments (i.e. ketchup, mustard, mayonnaise, and tarter sauce). Ask for individual packages instead.

Request that sandwiches be prepared without lettuce, tomatoes and raw onions.

Bakery items with cream and custard fillings as well as baked custard are only allowed if they have been refrigerated, or are fresh out of the oven. Shelf stable bakery items (Twinkies) are allowed.

Transporting Food to the Unit:
- Transport refrigerated or frozen food items in a cooler with ice.
- You don’t need to use a cooler or ice if you bring freshly made food from home or from a restaurant and transportation time is less than 10 minutes. If transportation will take longer than 10 minutes, cool the food thoroughly in the refrigerator or freezer and then place on ice in a cooler for transport to the unit.

Food Storage and Preparation on the Unit:
- Place food either in the room refrigerator or in the Family Lounge and label with the patient’s last name and the date.
- Reheat food in the microwave until hot (steaming) and serve promptly.

The Medical Center Smoking Policy
The University of Michigan has a no smoking policy for the entire Medical Center. Smoking is not allowed in buildings or parking structures.
The Transplant Process

Conditioning
Conditioning is the first phase in the transplant process. At the start of the hospital stay the patient receives high doses of chemotherapy and/or radiation therapy in order to eliminate cancer cells that are present, to make room for the new stem cells, and to suppress the immune system. Your child’s immune system needs to be suppression to prevent rejection of the new donor cells. This conditioning phase can take from one to 10 days and is typically completed a day or two before the infusion of the stem cell product.

Conditioning: Chemotherapy
The chemotherapy doses and timing are planned by your doctor and written in a carefully outlined plan called a "protocol.” The protocol outlines the medications your child will receive, as well as blood tests, X-rays and other procedures. The protocol was written by a doctor who is an expert in the field of bone marrow transplant. Before your child’s admission you will review and sign an informed consent that outlines the treatment protocol. This document assures that we gave you important information, including the risks and benefits about the treatment and the transplant process.

The chemotherapy is an important part of the protocol and will consist of one or more different types of medications, depending on the type of disease your child has and the type of transplant your child is receiving. Your child will receive the chemotherapy according a special schedule that is thought to be best for killing your cancer cells (if present). We will tell you exactly what days your child will receive chemotherapy and how we expect them to to feel. Your child will receive the medications directly into the vein (intravenously or IV). The doses of chemotherapy used in a transplant are often much higher than those your child may have received before. To kill cancer cells, it is often necessary to use the highest doses possible. Because of this, there is a possibility that your child may have more severe and different side effects than the ones they may have had in the past.

Chemotherapy may kill or damage cells other than cancer cells. It can damage normal, fast-growing cells in the mouth, throat, bowels, skin, hair and bone marrow. Your child may have mouth or throat sores, nausea and vomiting, diarrhea, a rash or change in the color of the skin, and hair loss. The blood
counts will become very low.

Your child will also receive medications to reduce the nausea and vomiting. If your child develops sores in the mouth or throat he will receive pain medications. All transplant patients must follow good oral hygiene including frequent mouth-care to help limit the number of mouth or throat sores. A nurse will help your child develop a mouth-care plan. A nutritional supplement called Glutasolve® (a glutamine powder) is recommended for all patients to help prevent or reduce the severity of these issues. If your child develops diarrhea or constipation, we will use medications to correct the problem. It is very likely that your child will lose their hair during the treatment. If they lose their hair, they may wear a cap, scarf, wig or turban. Body heat is lost through the head, so your child may feel colder after they lose their hair. In most cases, the hair loss is temporary and should start to grow back within 2-3 months.

Chemotherapy may also affect organs of the body such as the brain, kidneys, liver, heart and lungs. Even though severe side effects are uncommon, they can progress and cause more serious problems. It is impossible to predict who will experience these side effects. You will receive information to explain each chemotherapy medication, how it works and the potential side effects.

**Reduced Intensity Conditioning**

In some cases, the doctors may recommend a less intensive or “reduced intensity” conditioning regimen. Reduced intensity transplants are typically performed either for adult patients older than 50 years, or for those patients who are noted to have abnormal organ function (such as the heart, liver, lungs or kidney) prior to the transplant. In such cases, the transplant doctor may not feel that your child’s body can tolerate the full dose of chemotherapy that most transplant patients receive. In a reduced intensity transplant, chemotherapy works to suppress the immune system, thereby allowing the new stem cells to take hold and start growing. As the chemotherapy is less intensive, the complications your child may have in the first 2-4 weeks after transplant, such as mouth sores, infections, kidney or liver problems, are often much less. However, since a lower dose of chemotherapy is used, reduced intensity transplants do not immediately kill as many cancer cells as full dose transplants. Patients undergoing reduced intensity transplants should be in remission (or close to remission) before starting transplant. In some cases, this may not be possible. Your transplant doctor will tell you if a reduced intensity
transplant is possible for your child.

**Radiation**

Radiation therapy (or irradiation therapy) is a part of some transplant conditioning regimens. There are three types of radiation that can be given to patients:

1. Total body irradiation (TBI) given to the entire body
2. Total lymphoid irradiation (TLI) given to major-lymph nodes
3. A boost of radiation directed at certain body parts. Radiation is given by a machine that sends rays of high energy into the body. The cells in the body are prevented from growing and multiplying when they receive these high energy rays.

Your transplant doctor and radiation oncology team will talk to you about the type of radiation your child may receive. If radiation is planned, your child will meet with the radiation oncology team before the transplant admission. The team consists of the radiation oncology doctor (who is in charge of the radiation treatments), the radiation technologist (who administers the treatments), and the radiation nurse (who will monitor for side effects).

Your child may receive radiation as an outpatient or (following admission) during the transplant hospital stay. The radiation is given 1-2 times per day on the B2 level of University Hospital. The special machines in this department require the temperature to be cold. Your child may want to wear a robe and bring an extra blanket. Your child should take off all metal (jewelry, safety pins, clips, etc.) before their appointment.

The radiation therapy procedure often takes 30 to 60 minutes. During this time your child will remain in a certain position (lying down, standing or sitting). Some children need anesthesia for radiation. Your child will be alone in the treatment room, but the technologist can hear them, talk to them, and see them on a video monitor. The machine makes a humming sound while the treatment is being given, but your child will not feel anything.

Radiation may affect both cancer cells and normal cells. The side effects from radiation are due to its effects on normal cells. Initially, your child may have
nausea, vomiting and diarrhea. They will receive medications to prevent and treat these side effects.

After the radiation treatments your child may have other side effects, such as:

- red, dry skin, which may develop into a suntan look
- dry mouth, which occurs from the effect of the radiation on your salivary glands
- parotitis which is swelling of the parotid glands in front of your ears
- infertility
- lung-changes
- cataracts

The doctors and nurses will be monitoring your child very closely for these side effects. Some of these are easily treated, while others may require long-term follow-up. If you have questions regarding these treatments, ask a member of your transplant or radiation team.

**Stem Cell Infusion - "Transplant"**

After the conditioning chemotherapy, your child is ready to receive their transplant. The infusion, or transplant, is done very much like a blood transfusion. If they are receiving stem cells from a donor (an allogeneic transplant), the infusion is given soon after the stem cells are collected. The transplant is given through the IV catheter much as other blood transfusions.

If your child receives their own stem cells (an autologous transplant), a blood bank technologist will bring the frozen product to the room for thawing immediately before infusion. Your child may have some side effects from DMSO, a preservative used to protect the cells during the freezing and thawing process.

Your child may notice a garlic-like or creamed corn-like taste in their mouth that will remain on their breath for two or three days. Their urine may become red-colored for 24 hours. In rare cases, the DMSO can cause other problems, such as shortness of breath, wheezing and stomach pains. However, these side effects occur rarely and the nurse and doctor will monitor your child closely during the transplant.

**Recovery**

Within 1-2 weeks after starting the conditioning therapy, your child’s white
blood cell count will decrease and may remain low until the new bone marrow cells begin to grow. During this time, your child is at great risk for developing an infection, since they will not have white blood cells to fight bacteria, viruses or fungi.

If your child develops an infection during the time when the blood counts are low, she will start antibiotics immediately. To help identify an early infection it is important to let the nurse or doctor know how your child is feeling. Some of the symptoms of an infection are:

- fever (over 38°C; or 100.4° degrees Fahrenheit)
- skin tenderness
- chills/sweating
- a burning feeling when urinating
- rectal pain/tenderness
- a cough, sore throat or mouth pain
- loose bowels
- general feeling of tiredness

If these symptoms appear, notify the nurse or doctor immediately.

**Blood Products / Transfusions**

During the recovery period, your child's body will require support through transfusions of red blood cells and platelets. Blood products are provided by the American Red Cross and are coordinated by the UMHS blood bank. It is not possible for your child's family and friends to supply all their blood product needs.

Platelets are also made in the bone marrow and help prevent bleeding. Your child’s platelet count will be checked often during their transplant admission, and they will be watched for signs of bleeding. Your child will receive platelet transfusions if his platelet levels get too low or if he shows signs of bleeding.

It will take several weeks to months for your child’s red blood cells to return to their normal levels after conditioning therapy. During this time your child will require red blood cell transfusions to maintain their red blood cell count.
Your child may also receive immunoglobulins (antibodies) through their IV. Immunoglobulin infusions are a boost of antibodies that can kill bacteria, fungi, or viruses. Infusions of immunoglobulin are a type of transfusion, as the immunoglobulins (antibodies) have been collected from healthy donors. The transfusion of antibodies takes several hours and may also be given as an outpatient after discharge.

**Patient Responsibilities**
Throughout your child's recovery process, the most important members of the “team” is your child and your family. You play an important part in your child's care and will have many things to do every day. All of these are important for recovery. You know your child best, and your child’s transplant team depends on your input and cooperation.

**Nutrition**
Nutrition has a vital role in helping your child achieve the best result from medical treatment. Good nutrition helps prevent infections from developing and also helps maintain a sense of well-being.

It is often difficult to stay well-nourished during chemotherapy. The dietician will offer your child nutrition supplements and make suggestions for nutritious foods she may tolerate in order to meet her nutrient requirements. This is very important for recovery after the transplant. If your child is unable to eat, he will receive nutrition through an intravenous solution, called total parenteral nutrition (or TPN), or by a feeding tube.

Another aspect of nutritional care is a low microbial diet. This means avoiding foods that may contain bacteria or molds. This helps decrease the risk of infection. The diet allows only well-cooked foods and restricts food that may be high in bacteria, such as fresh fruits and vegetables that are unable to be peeled. The dietitian will instruct you on the guidelines and principles of the diet.

**Mouth Care**
This is an area where your child can make a difference. Good oral hygiene will be important before, during and after the transplant. Mouth sores and
infections can be painful and life threatening.

The therapy your child receives before your transplant affects the cells lining the inside of the mouth and throat. As a result, your child may develop sores. If the mouth is not kept clean, an infection can occur that can quickly spread to other parts of the body. Your child will receive medications to help prevent infections if the sores develop. However, the most important part will be keeping the mouth clean. Your child will need to brush their teeth and tongue at least four times a day during the transplant process.

**Hygiene**
It is necessary for your child to take a bath or shower every day. The nurse will give a special soap to use that will kill bacteria on the skin. Always remember to wash hands after using the bathroom, after touching sores on the body, and before performing mouth care.

**Activity**
There are many reasons why we stress exercise and physical activity. Your child will feel better mentally and physically, keep his skin, muscles, heart and lungs in shape, and sleep better at night if he follows a regular exercise program.

Your child will work with a physical therapist to develop a personalized exercise program based on their experience, habits, interests and physical condition. Exercise bicycles are available for use in the patient rooms and walking as much as possible in the hallways is also recommended. Caregivers age 18 years and older, will have access the exercise room on the 7th floor of the C.S. Mott Hospital for their own use.

It is important that the child to stays out of bed during the day as much as possible. Distracting activities are a good way to keep busy and decrease boredom. These include games, puzzles, listening to music and other hobbies. If you have questions about an activity, ask your nurse, doctor or physical/occupational therapist.

**Engraftment**
Engraftment is when the donated cells start to grow and make new blood cells. Approximately two to four weeks after the transplant, the bone marrow should
show signs that it is engrafting. Blood draws help us measure how well the marrow is engrafting. The first sign of engraftment is the production of white blood cells called neutrophils (ANC). Platelets often take a little longer to begin developing. The child will be discharged from the hospital once the ANC has recovered, transfusions are infrequent and her condition is stable

**Discharge**

Although each person varies in how long he or she takes to recover, the following are general criteria used for discharge from the hospital:

- Infections or graft versus host disease (GVHD) are absent, stable or under control.
- Not requiring daily transfusions (especially platelet transfusions)
- Able to tolerate oral medications, food and fluids
- Active enough to function outside the hospital
- Completion of discharge teaching for the child and caregiver

**Complications**

There are many potential complications of transplant. The high doses of chemotherapy, prolonged periods of low blood counts, and effects from the donor cells themselves can all lead to serious complications. These can occur at any time during or after transplant. Many of these complications can be treated with medications and careful monitoring. Some of them, however, can lead to life-threatening situations. There may be a time when we will need to monitor your child very closely in an intensive care setting. If this occurs, the transplant team will continue to care for your child together with the intensive care staff.

Remember that all patients are unique and not every patient will develop these complications. We will watch your child closely for the following possible complications. In general, we divide potential complications into four phases; each phase is separated by an approximate time point post-transplant. Day 0 is the actual day of transplant.
This diagram serves only as a general reference. It provides a general overview of common transplant complications, and when they are likely to occur following transplant. It is not meant to be all-inclusive. Likewise, the diagram does not mean that your child will develop each of these complications, or that the complications (if developed) will always be severe. Some complications, such as GVHD (graft versus host disease) typically do not occur in autologous transplants. On the other hand, patients who receive a transplant from a partially matched donor are more likely to develop graft versus host disease. Your child’s doctor will review the common complications that your child may experience with transplant, based on the particular transplant type, the intensity of the chemotherapy your child will receive with the transplant, and the degree of match your child has with their donor. This diagram can simply serve as a guide or reference to help discuss your child’s particular risks.

**Infections**
During and after your transplant, your child will be at risk for developing many
different types of infections. Immediately after transplant your child is at risk for bacterial and fungal infections, as well as for reactivation of certain viruses that reside in the body (for example, the chicken pox or herpes simplex virus). Even the slightest infection can become life threatening. Your child will receive a number of preventive antibiotics during the transplant. These antibiotics are intended to lower the risks for developing certain viral, bacterial or fungal infections during the process.

During the first several months after transplant your child will continue to be prone to infections, especially viral infections. Cytomegalovirus (CMV) is a virus that may cause severe infections of the lungs, gastrointestinal tract or liver. Patients at risk for this infection will have regular blood draws to monitor their condition and will receive special medications to treat CMV if present. Pregnant women must avoid contact with patients who have an active CMV infection.

Your child's immune system may remain weakened for approximately one year (or more) following their transplant. Even though your child can return to an active life, it is important for them to be more cautious and report lingering illness to the transplant team. A common event for patients is to have shingles (herpes zoster), a reactivation of the chicken pox virus, in the year following transplant. Approximately 1 year after transplant, your child will need to have all of their childhood vaccinations repeated.

**Veno-Occlusive Disease (VOD)**

This is a complication that typically affects the liver. It is caused by the high doses of chemotherapy that may be used during the transplant. When VOD occurs, it becomes very difficult for the liver and afterwards the lungs and kidneys to function normally. The signs and symptoms of VOD may include jaundice (yellow skin and eyes), a swollen and tender belly (especially where the liver is located), and weight gain. Treatment for VOD may include various medications, blood transfusions, careful monitoring of the liver and kidney function, and blood tests. If veno-occlusive disease occurs, your child may be transferred to an intensive-care unit for monitoring. In some cases, their lungs may require extra support to breathe, requiring the use of a machine called a ventilator or breathing machine. In other cases, their kidneys may require the support from a dialysis machine to remove extra fluid from their body.
Lung and Heart Complications

Pneumonias are common following transplant. Approximately 30-40% of patients undergoing an allogeneic transplant and approximately 25% of patients undergoing an autologous transplant will develop pneumonia at some point during their transplant course. The pneumonia may be severe, even life threatening in some cases. Not all pneumonias are caused by infections. Approximately half of all pneumonias following transplant are not caused by infection. A condition called Idiopathic Pneumonia Syndrome (IPS) is a particularly dangerous condition that may occur in the lungs following a transplant. It is most likely to occur in patients who receive a transplant from a mismatched donor. However, it can occur in any type of transplant. Typical signs and symptoms of IPS include shortness of breath, cough, and the need for oxygen support. There are special medications to treat IPS. In addition, many patients need a breathing machine to help them breathe when they have IPS. A test called a bronchoscopy helps to determine if your child has an infection in their lungs. A bronchoscopy is a special tube (a type of periscope) that is passed into the lungs to see how they look. Lung fluid can be collected during the bronchoscopy procedure, and then tested to determine if an infection is present or not. Other tests, including Chest X rays and CT scans are often done to monitor the appearance of the lungs.

Since lung problems are common with transplant, your child will typically have tests done before, during and after the transplant to monitor the condition of their lungs.

Heart and blood pressure problems are also common during transplant, especially in people who already have a history of high blood pressure, high cholesterol or triglyceride levels, blood clots, heart attacks, strokes or blocked arteries. In addition, patients with a history of diabetes are at higher risk for developing blood clots or heart problems during transplant. Heart related complications following transplant may include high blood pressure, irregular heart beat / arrhythmias, heart failure, or even heart attacks. Tests (blood tests, echocardiogram or MUGA test) that your child will have prior to transplant will help determine your child's risk for developing such problems during transplant.
Bleeding
Bleeding after transplant is common, especially when the platelet levels are very low. Platelet transfusions help to prevent severe bleeding. The medical team will monitor your child’s platelet count and for signs of bleeding during her transplant stay. Blood in the urine (called hematuria) is also common after certain types of transplant, and is often caused by a specific virus that infects the bladder. The doctors will monitor your child for such complications and treat your child with specific antibiotics, if required.

Graft Versus Host Disease: (GVHD)
Graft versus host disease (GVHD) is a complication that occurs when the new stem cells (the graft) react against your body (the host). It can range from a very mild complication, or may progress to a life-threatening one. It is common in allogeneic transplants and rarely occurs in autologous transplants. There are two general forms of GVHD: acute GVHD and chronic GVHD.

When does GVHD typically occur?
Acute GVHD typically occurs within the first 100 days after transplant. Chronic GVHD typically occurs after the first 100 days post-transplant. This is not a hard and fast rule. There are cases in which acute GVHD starts after day 100, and cases in which chronic GVHD starts before day 100 post-transplant.

What does Acute GVHD look like?
Acute GVHD often starts as a skin rash on all or part of your child's body. The rash associated with GVHD is red, but generally not painful or very itchy. The rash often starts on the cheeks, ears, upper neck, shoulders, palms and soles of the feet. The rash can spread to the entire body surface. GVHD can also involve the intestines (causing diarrhea) and the liver (causing jaundice). GVHD of the intestines is typically associated with a crampy belly pain plus watery diarrhea. The diarrhea is often described as watery green, but it may be yellow or brown in color also. The belly cramps may be severe and require pain medications.

What does Chronic GVHD look like?
Chronic GVHD typically develops between three to 12 months after transplant. Sometimes it occurs after a patient has already had the acute type of GVHD. In other cases, chronic GVHD may occur on its own. Chronic GVHD can affect the
skin, mouth eyes, gut, liver, lungs, genitals and joints. Patients diagnosed with chronic GVHD do not usually have involvement in every organ, but skin, mouth and eye involvement are quite common.

The skin rash associated with chronic GVHD is different than the rash seen with acute GVHD. With chronic GVHD, the skin may develop an eczema type appearance, may become dark (or very light) in appearance, or may develop tightness (called scleroderma).

The lungs can also be affected by chronic GVHD, with scar tissue forming in the lungs. If this were to happen, your child’s lung capacity would decrease and they would become short of breath more easily with exertion. Your child would be at greater risk for developing pneumonia if the chronic GVHD involved their lungs. Special tests call Pulmonary Function Tests (PFT’s) will be done at specified times after an allogeneic transplant to monitor for GVHD of the lung. It is VERY important that your child does not skip these PFT tests.

Chronic GVHD may cause dryness of the eyes and mouth. It is very important that patients undergoing allogeneic transplants take eye drops prescribed during transplant and see an ophthalmologist (eye doctor) on a regular schedule. The transplant team will help you schedule these appointments with an ophthalmologist. Your transplant coordinator will schedule an appointment for you to see an ophthalmologist at the University of Michigan prior to your transplant admission. Routine follow-up appointments with an ophthalmologist after transplant will be necessary.

Finally, it is not uncommon for chronic GVHD to cause significant dryness to the vaginal area in females. For females 16 years in age or older, the transplant coordinator will schedule an appointment in the OB-GYN (Obstetrics and Gynecology) clinic at the University of Michigan, prior to transplant. Your child will also have follow up appointments with the OB-GYN service after transplant.

**How are acute or chronic GVHD diagnosed?**
The diagnosis of acute GVHD is based on symptoms such as skin rash, crampy diarrhea, and yellow jaundice. If the clinician is not sure of the diagnosis, he will order biopsies of affected areas such as the skin. Likewise, biopsies of the stomach or intestinal tissue are often done by a procedure called an endoscopy or colonoscopy to make the GVHD diagnosis.
The diagnosis of chronic GVHD is made by exam of the skin, eyes, mouth, and lungs. Tests such as PFT’s (see above) are routinely performed to monitor for chronic GVHD of the lungs. Like acute GVHD, biopsies of tissue (skin, mouth, intestines) are often required to confirm the diagnosis of chronic GVHD.

**How often do patients get acute or chronic GVHD?**

Patients who undergo transplant from a fully matched sibling donor typically have a 33% chance of developing some form of acute GVHD after transplant. Patients who receive transplant from an unrelated donor may have a 50-60% chance of developing acute GVHD after transplant. If there is a mismatch between the patient and donor, then the chances for developing GVHD are even higher.

The chances of developing chronic GVHD depend upon several factors, including the donor source (sibling or unrelated donor), and the type of process used to collect the stem cells (peripheral stem cell harvest or a bone marrow harvest). Patients who undergo transplant from a matched sibling donor have a lower chance of developing chronic GVHD than patients receiving transplant from an unrelated donor. In addition, patients receiving bone marrow, rather than peripheral stem cells, have a lower chance of getting chronic GVHD. For many transplants, the chances of developing chronic GVHD range from 40-50% after transplant. Your transplant doctor will discuss your child’s risks of developing chronic GVHD, based upon the type of transplant (bone marrow or peripheral stem cell), and how well matched the donor is to the patient.

**How do we treat GVHD?**

If your child is undergoing an allogeneic transplant he or she will receive several medications to prevent severe GVHD from occurring. It is essential that they take all of these medications when they are scheduled. Prevention is the best way to fight GVHD. Typically, some of the GVHD medications (tacrolimus or cyclosporine) are started prior to the stem cell infusion, so that the body can start fighting GVHD as soon as the new stem cells are infused. In addition, the University of Michigan has developed or participated in a number of clinical research studies designed to lessen the severity of GVHD. The transplant doctor will tell you if your child may be eligible for these clinical research studies.
How long does GVHD last?
Unfortunately, we cannot answer this question. Every patient is different. Some cases may last several weeks, others several months, whereas others may last for several years.

Does GVHD serve a useful purpose?
GVHD may not only attack certain sites in the body (skin, liver, intestines), but may also attack cancer cells that remain in the body after transplant. Thus, patients who develop GVHD often have lower rates of relapse of their cancer, than patients who do not develop GVHD after transplant. We call this a “graft versus leukemia” (GVL) effect.

Lack of Engraftment
There is a possibility that the new stem cells will fail to develop or mature after the transplant. If this occurs, it is called rejection or non-engraftment. For the majority of transplants, the risk of rejecting the new bone marrow or stem cells is less than 5%. There are various reasons why your body may reject the bone marrow or stem cells from a donor, including development of some of the complications listed above. There are medications (such as Neupogen®) that can help to stimulate the new bone marrow or stem cells to grow in your body. If the blood counts fail to recover following a transplant, the doctors will talk with you about the potential need to perform a second transplant.

Relapse and Secondary Cancers
Unfortunately, transplant does not guarantee that your child will be cured of their cancer or underlying disease. Even with transplant, the disease could still return or relapse.

In a small number of patients, a different type of cancer can occur after transplant. Such secondary cancers may be caused from the chemotherapy or radiation given prior to transplant. Graft versus host disease occurring after transplant may also cause a secondary cancer. Secondary cancers may include skin or mouth cancer, or other types of leukemia. In general, the lifetime risk of developing a secondary cancer is approximately 10% following many transplants. If this occurs, the doctor will discuss available treatment options with you.
Intensive Care Unit (ICU)
There may be a time during the transplant procedure when your child’s condition becomes more serious. At this time the child will be transferred to the ICU for closer monitoring. This is an intensive care unit with nurses and doctors who are trained and experienced in caring for patients needing intensive and specialized treatment. The bone marrow transplant team works very closely with the staff of the ICU and will continue to follow your child’s care after transfer.

There are different visiting hours and family guidelines than those on the transplant unit. The staff of the ICU will meet with your family to review these soon after transfer.

For more information and other patient and family resources, visit [http://www.mottchildren.org](http://www.mottchildren.org).

Disclaimer: This document is for informational purposes only and is not intended to take the place of the care and attention of your personal physician or other professional medical services. Talk with your doctor if you have Questions about individual health concerns or specific treatment options.

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