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Dear Patients/Parents/Legal Guardians/Caregivers,

Welcome to the Bone Marrow Transplantation and Immune Deficiency Program in the Cancer and Blood Diseases Institute at Cincinnati Children’s Hospital Medical Center. Our team understands this can be an extremely difficult time for everyone when caring for a patient who is receiving a transplant. Our team will act as partners with you and we will treat you with respect and care. This binder will help to prepare you and your family for the transplant process. This binder is yours to keep. We encourage you to read this binder, write questions in this binder, and use it as a reference throughout your transplant experience.

This binder provides education on how to keep you healthy, safe, and decrease the risk of infection. This binder also answers many of the commonly asked questions. Throughout this binder, references to “you” may stand for either the patient or for the parents/legal guardians/caregivers if the patient is under 18 years of age.

If the patient is old enough to understand this information, please share it with him/her. To better prepare you for the transplant experience, we will provide you with complete and accurate information. Please ask questions any time about your care and about anything that is confusing or unclear. Our team strives to provide a caring, positive experience throughout the transplant process. Please ask if there is anything our team can do to help you throughout this transplant experience.

Sincerely,

Stella Davies, MBBS, PhD, MRCP
Jacob G. Schmidthiapp Endowed Chair and Professor of Pediatrics
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Cincinnati Children’s Hospital Medical Center
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Bone Marrow Transplantation and Immune Deficiency Program | Patient/Family Education Binder 2015
Cincinnati Children’s, a nonprofit academic medical center established in 1883, is one of the oldest and most distinguished pediatric hospitals in the United States. As an international leader in improving child health, Cincinnati Children’s serves the medical needs of infants, children, and adolescents with family-centered care, innovative research, and outstanding teaching programs. Cincinnati Children’s state-of-the-art facilities provide innovative care and advanced treatment in a number of specialty areas including Cancer and Blood Diseases Institute Bone Marrow Transplantation and Immune Deficiency Program. In the 2014-15 U.S. News & World Report survey of best children’s hospitals, Cincinnati Children’s ranked No. 3 among all Honor Roll hospitals. With nearly 600 registered beds, Cincinnati Children’s had more than 1.1 million patient encounters and served patients from all 50 states and 53 countries in the fiscal year 2013.

About the Bone Marrow Transplantation and Immune Deficiency Program:

The Bone Marrow Transplantation and Immune Deficiency Program within the Cancer and Blood Diseases Institute at Cincinnati Children’s is an international leader. We specialize in using transplant therapies to treat cancer, rare genetic conditions such as immune deficiency disorders, and bone marrow failure syndromes such as Fanconi anemia. Our cancer program was ranked No. 3 in the country in the 2014-15 list of Best Children’s Hospitals published by U.S. News & World Report.

Our multidisciplinary team has performed more than 1,500 transplants since April 1981 making us one of the largest pediatric blood and marrow transplantation programs in the United States. The Bone Marrow Transplantation and Immune Deficiency Program is currently transplanting about 100 patients each year with higher survival rates than the national average. We are also one of the nation’s largest referral centers accepting patients from within the U.S. and around the world. The Bone Marrow Transplantation and Immune Deficiency Program has been a National Marrow Donor Program/Be The Match Transplant Center since 1990. We have been a FACT (Foundation for the Accreditation of Cellular Therapy) accredited Clinical Program and Bone Marrow Collection Facility since 2003.

The director of the Bone Marrow Transplantation and Immune Deficiency Program is Stella M. Davies, MBBS, PhD, MRCP. Dr. Davies and her colleagues have developed disease-specific transplant regimens that have improved outcomes and are now the international standard of care. The team of internationally recognized specialists manages every stage of treatment.

The Bone Marrow Transplantation and Immune Deficiency Program has one inpatient setting and two outpatient settings. Our inpatient unit has 36 beds and is reserved for Bone Marrow Transplant and Immune Deficiency patients (see Inpatient Unit). Our two outpatient settings are the Cancer and Blood Diseases Institute (CBDI) clinic and the CBDI Day Hospital. The clinic has a Pediatric Center and an Adolescent and Young Adult/Survivor Center. Both are used for patient visits. Day Hospital is used for our patients to receive certain IV medications, transfusions, and other treatments.
Emergency Instructions

When in doubt, make the call. We want to hear from you.

Always call 911 if the patient is having trouble breathing, is unconscious, is having a seizure, or has bleeding that will not stop after five minutes of direct pressure. If you are in the Greater Cincinnati area and need 911 services please call 1-877-205-7721 for Arabic or call 1-844-720-6891 for Spanish.

Call the Bone Marrow transplant and immune deficiency doctor right away, day or night, if the patient has any of the problems listed below.

- Dial 513-636-4200 or toll free at 1-800-344-2462
- Ask the operator to page the “Bone Marrow transplant doctor on-call”.
- Please stay on the line until the BMT doctor is on the line.
- If you need an interpreter to assist with this call dial 1-855-________________ and ask the operator to page the “Bone Marrow transplant doctor on-call.”

Signs of Infection:

- Fever of 100.5°F (38.0°C) or higher (the patient will need antibiotics within 60 minutes of the first fever- see handout on fever instructions)
- Chills or shaking with or without a fever
- Redness or swelling around the central line or if the central line has come out

Change in Eating/Drinking Habits

- Loss of appetite or inability to meet fluid and/or food intake goals
- Unable to take or tolerate medications

Trouble with Breathing

- Coughing, sneezing, or runny nose
- Fast breathing or wheezing sound

Bleeding

- Bleeding or bruising
- Nose bleed that does not stop
- Coughing or vomiting blood
- Blood in urine or bowel movement

Changes in Bowel or Bladder:

- New or increased diarrhea, nausea or vomiting
- Trouble urinating or pain with urination

Other Issues:

- New rashes or sores
- Mood changes or sleeping excessively
- Exposure to chickenpox, shingles, or the flu
- If the parents/legal guardians/caregivers become sick
- Any new symptom that concerns you
Instructions for a Fever

A fever of 100.5°F (38.0°C) or higher is an emergency for our patients. They will need antibiotics started within 60 minutes of the fever.

Here are some tips to help your child get the antibiotic they need within 60 minutes.

**Before leaving home:**
- Always call 513-636-4200 (or toll free at 1-800-344-2462) and ask the operator to page the “Bone Marrow transplant doctor on-call” before heading to the CBDI clinic or Emergency Department because of a fever.
- If your child has a port, put numbing cream on it before leaving home.
- Remember to have your child wear the N-95 mask to the CBDI clinic or Emergency Department.
- Have a list of your child’s current medications available for staff.

**At the hospital:**
- Let the hospital staff know if your child has a history of having trouble with getting IV access.
- Your child will get antibiotics before their lab work is back.
- Antibiotics may need to be given as a shot to make sure your child gets the antibiotic within 60 minutes.
Important Phone Numbers

**Bone Marrow Transplantation and Immune Deficiency Doctor:**
For after hours, weekends, holidays, and anytime the patient is sick (see Emergency Instructions)

**Bone Marrow Transplantation and Immunology Care Managers (Monday-Friday 8 AM-5 PM):**
Call the BMT Care Manager directly or call toll free 1-800-344-2462 and ask the operator to page the Care Manager:

**Immunology Care Managers**
Linda Carl 513-803-2603
Mat Goodridge 513-803-0074
Jessica Gray 513-803-7897
Cherie Short 513-803-0340
Linda.Carl@cchmc.org Mathew.Goodridge@cchmc.org Jessica.Gray@cchmc.org Cherie.Short@cchmc.org

**Marrow Failure/Metabolic Diseases Care Managers**
Kathy Ball 513-803-0124
Katie Brooks 513-803-1962
Michelle Harris 513-636-3219
Kathleen.Ball@cchmc.org Katie.Young@cchmc.org Michelle.Harris@cchmc.org

**Malignancies Care Managers**
Suzanne Berger 513-636-7908
Mark Mueller 513-636-7191
Suzanne.Berger@cchmc.org Mark.Mueller@cchmc.org

**Inpatient Care Managers**
Wendy Engel 513-636-9774
Debbie Maas 513-636-3217
Wendy.Engel@cchmc.org Debbie.Maas@cchmc.org

**Search Coordinators**
Angie Bonavita 513-636-4258
Christine Sper 513-636-5430
Danielle Fohl 513-803-4676
Angie.Bonavita@cchmc.org Christine.Sper@cchmc.org Danielle.Fohl@cchmc.org

**Social Workers for Immunology**
Nancy Delaney 513-803-1782
Elizabeth Smith 513-636-9919
Nancy.Delaney@cchmc.org Elizabeth.Smith@cchmc.org

**Social Workers for Marrow Failure/Metabolic Diseases/Malignancies**
Carrie Breitwieser 513-803-1781
Krista Mann 513-636-5578
Carrie.Breitwieser@cchmc.org Krista.Mann@cchmc.org

**Inpatient Unit**
513-636-4071
Ronald McDonald House
513-636-7642

**CBDI Clinic**
513-636-8790
CCHMC Home Care Services
513-636-4663

**Day Hospital**
513-803-2500
CCHMC Outpatient Pharmacy
513-636-8808

**Guest Services**
1-888-894-1374 or 513-636-5009
guestservices@cchmc.org

**Family Resource Center**
513-636-7606
frc@cchmc.org
Our Team Members

All Bone Marrow Transplantation and Immune Deficiency team members are trained in the care of pediatric transplant (allogeneic and autologous) patients in the inpatient and outpatient settings. You will meet most of these team members during your pre-transplant evaluation.

Attending Physicians: Attending Physicians are pediatricians who are board certified in pediatric Hematology/Oncology or have completed specialist training as a fellow. You will have a primary Attending Physician who is responsible for your care throughout the transplant process. Your Attending Physician will see you before, during, and after the transplant.

Fellows: Fellows are pediatricians obtaining specialized training in Hematology/Oncology, Immunology, and hematopoietic progenitor cell transplantation.

Hospitalists: Hospitalists are pediatricians who work under the direct supervision of the Attending Physician to care for you.

Consulting Physicians: Consulting physicians are specialists who are capable of assisting the BMT team in the management of your care. Examples of consulting physicians include gastroenterology, pulmonary medicine, surgery, intensive care, and infectious disease.

Clinical Directors: Clinical Directors are advanced practice nurses who are responsible for overseeing the clinical operations. There is a Clinical Director for the Bone Marrow Transplantation and Immune Deficiency unit, the Cancer and Blood Diseases Institute Clinic and the Day Hospital. The Clinical Directors provide support to patients, families, and staff to help meet your needs on an ongoing basis.

Care Managers: Care Managers are experienced BMT nurses who are your main contact before, during, and after your transplant. You will have a primary Care Manager who will work with you and your Attending Physician to provide clinical care education, coordination of your appointments, and discharge planning throughout your BMT. There are outpatient and inpatient Care Managers. Your Care Manager will also keep all members of the BMT team, including your referring physician, informed of your health status throughout your BMT.

Social Workers: Social workers assist families in problem solving, obtaining internal and external resources, and provide emotional support throughout the transplant process. By learning about the needs and desires of your family, the social worker assists the BMT team in providing the best clinical care experience for you. The social workers offer a weekly parent/caregiver support group.
Nurse Practitioners: Nurse Practitioners (NP) are advanced practice nurses who collaborate with the Attending Physicians to provide care for you. The Nurse Practitioner communicates your condition, treatment plan, and medication changes to the primary Care Manager and the primary Attending Physician.

Transplant Financial Manager and Specialist: Transplant Financial Manager and Specialist will assist you in evaluating the financial issues surrounding your transplant. They also work with your insurance company to determine the level of benefits your current insurance plan provides.

Search Coordinators: Search Coordinators are experienced BMT nurses who work with your Attending Physician and the National Marrow Donor Program/Be The Match to find unrelated donors and/or unrelated cord blood unit(s) for your transplant. Search Coordinators also act as an advocate for you with the National Marrow Donor Program/Be The Match.

Charge Nurses and Safety Coaches: Charge Nurses and Safety Coaches are experienced BMT nurses who are responsible for the daily functions on the Bone Marrow Transplantation and Immune Deficiency Unit. They manage daily staffing and assignments of RN's, HUC's and PCA's. They also coordinate admissions, discharges, transfers, and talk to families and staff if there are concerns or conflicts. They will assist all staff members in care delivery activities. They are a resource for all staff on the unit as well as for consults and other disciplines coming to the unit to see you. They maintain a safe environment and update the Clinical Director.

Primary Nurses: Primary Nurses are experienced BMT nurses who coordinate your daily care, act as a liaison with the BMT team, and assist in meeting your needs.

Patient Care Attendants: Patient Care Attendants (PCA) assist your nurse with carrying out activities of daily living. They gather supplies for your care, assist in recording all oral intake and output, record vital signs, obtain equipment for your use, set up rooms for admission, and break down rooms at time of discharge. The PCA also covers for the Health Unit Coordinator, attends to call lights, offers breaks for parents/legal guardians/caregivers, assists with the admission process, gives tours of the unit, and contacts resources to help with your care under the direction of your nurse. The PCA is also utilized to help maintain a safe environment. PCA’s are utilized on the BMT unit, the CBDI clinic, and the Day Hospital.

Pharmacists: Pharmacists are specially trained and licensed in the preparation and use of medications, therapeutic drug monitoring, therapeutic interventions, drug information, and chemotherapy administration.

Dietitians: Dietitians assess and monitor your nutritional status. Working with the BMT team, the dietitian ensures optimal nutritional intake and promotes growth and development.
**Pediatric Palliative and Comfort Care Team:** Pediatric Palliative and Comfort Care Team provides support to patients who develop significant comfort issues (i.e. mucositis) related to the BMT process. Once involved, these team members will see you on a daily basis until your comfort issue(s) has/have resolved.

**Child Life Specialists:** Child Life Specialists (CLS) are certified trained professionals with expertise in helping patients of all ages and their families overcome life’s most challenging events. Child Life Specialists promote effective coping through play, preparation, education, and self-expression activities. They will provide age-appropriate toys, games, crafts, and movies. Your CLS can arrange private time for you in the A5 Playroom and Adolescent/Young Adult (AYA) Activity Room, if your Attending Physician feels you are well enough. CLS provide emotional support for families, encourage optimum development of children, and advocate for the unique needs of adolescents and young adults. They practice patient and family centered care. CLS provide information, support and guidance to parents/legal guardians/caregivers, siblings, children of patients, and other friends/family members.

**Fertility Specialist:** A Fertility Specialist will meet with you during the pre-transplant evaluation as part of the Oncofertility Program. The fertility specialist will discuss ways to protect fertility from the effects of chemotherapy or radiation.

**Behavioral Health and Clinical Psychology:** Behavioral Health and Clinical Psychology works with you and your family to adjust to the mental demands of transplant. They can help the family figure out how to fit treatments and medication schedules into their busy lives. They can also work with you to use relaxation techniques to help reduce pain and other physical symptoms associated with transplant.

**Recreational Therapists:** Recreational Therapists seek to improve not only your physical functioning as it pertains to play but social, emotional, and cognitive functioning as well.

**Occupational/Physical Therapists:** Occupational/Physical Therapists help you work on strengthening muscles needed for daily activities, feeding, and development.

**Speech Pathologist:** Speech Pathology Services include comprehensive diagnostic evaluations, consultations, parent counseling, and treatment for patients with communication disorders. Treatment programs include a wide range of specially designed services to fit your needs.

**Patient Attendant:** Patient Attendants actively observe patients to ensure their safety. They also assist with activities of daily living.

**Health Unit Coordinators:** Health Unit Coordinators (HUC) greet you as you enter the unit and coordinate daily activities for patients.

**Chaplains:** Chaplains from many different denominations are available to provide spiritual support for you and your parents/legal guardians/caregivers.
**Research Coordinators:** Research Coordinators are specially trained nurses or research professionals who may discuss special research studies that you might be eligible to participate in at Cincinnati Children’s.

**School Intervention Program Educators:** The CBDI School Intervention Program provides re-integration services for eligible patients. The School Intervention Program works with families, schools, and school districts to provide in-services and initiate home instruction or private tutoring. Teachers are available to assist you. Students can range from 3-25 years old. All patients are eligible to receive education sessions from teachers while on the Bone Marrow Transplantation and Immune Deficiency Unit.

**Customer Service Representatives:** Customer Service Representatives work to schedule clinic visits and evaluations. They are a resource for facilitating any scheduling changes that may be necessary.

**Holistic Health Practitioners:** Holistic Health Practitioners offer the following services:
- Therapeutic Massage: provided by licensed medical massage therapists for soothing, comforting touch to promote well-being.
- Healing Touch: practitioners use the gentle movements of their hands to smooth and balance the energy field surrounding the body.
- Guided Imagery: a relaxation technique.

**Home Care Liaisons:** Home Care Liaisons assist with education to prepare for your discharge from the hospital. Parents/legal guardians/caregivers are educated on how to care for your central line and any other ordered home therapies (ie: feedings and medications). Education will continue outside the hospital with the assistance of a Home Care Primary Nurse.

**Music Therapist:** Music Therapists provide music therapy.
Pre-Transplant:
The pre-transplant phase begins as soon as you are referred to Cincinnati Children's for consideration of a hematopoietic cell transplant (HCT). Your Care Manager will work closely with you and your referring physician to gather information and determine if HCT is medically appropriate. The Care Manager will also arrange a consultation with you, your Attending Physician, and other team members.

The search to find a donor may begin at this time. Your attending physician may ask for lab samples from your parents and siblings to help with this matching process of finding a donor. The Search Coordinator may meet with you to discuss the donor search process in more detail.

If a transplant is medically appropriate for you, your Care Manager will schedule a pre-transplant evaluation. The pre-transplant evaluation involves testing, procedures, and blood work which are usually done as an outpatient and often take up to 2 weeks to complete at our hospital. If you do not live locally, your social worker will help you identify local housing options. Once the evaluation is complete, your primary attending physician and care manager will meet with you to discuss the results. The pre-transplant evaluation focuses on:

- Testing your vital organ function
- Determining your current disease status
- Planning for a special type of intravenous (IV) catheter
- Meeting with consulting physicians
- Drawing blood work
- Introducing you to BMT team members
- Touring our facility
- Planning your hospital admission for the transplant

You will receive a consent form with detailed information about the transplant process and the planned treatment preparations for you. The consent also describes the purpose, procedures, benefits, risks, and discomforts of the transplant along with the precautions that will be taken. Your primary Attending Physician will discuss the consent form with you. Read the consent form carefully and ask any questions that you might have. Before the transplant phase can begin, you will need to give consent, letting us know that you agree to the described treatment plan. You will get a copy of the signed consent(s) to keep in this binder for your records (see Copies of Consents).
Transplant:
During the transplant phase, you will receive medications to prepare your body for the transplant. The preparation regimen you receive is discussed in the consent. Once admitted to the BMT unit, you will be placed in Strict Contact Precautions and must remain in your hospital room the majority of the time you are admitted (see Infection Control).

The day you receive the stem cells is called “Day 0” or the transplant date. On Day 0, you will receive the stem cells as an infusion through a central venous catheter. We will watch you carefully before, during, and after the stem cell infusion. For more detailed information about the transplant, please refer to the consent.

Recovery:
The recovery phase is a critical time after the stem cell infusion when you receive supportive care. Before the stem cells start growing (engrafting) your blood counts will be very low and you could experience the symptoms described in the consent (poor appetite, diarrhea, fever/infections, fatigue, etc.). During this time of low blood counts you have little to no ability to fight infections. Infection Control Guidelines, such as thorough hand washing, contact precautions and daily care routines, are used to minimize the risk of infections (see Infection Control). The length of time it takes for the stem cells to engraft and the body to begin healing varies with each patient. Your attending physician will discuss the anticipated engraftment time frame with you.

Discharge:
When your blood counts are recovering and your physical condition has stabilized the planning for discharge increases. You and your caregiver’s involvement in the preparation for discharge are especially important. The goal of discharge planning is to ensure that you and your caregiver are comfortable and confident in caring for your needs outside the hospital. This includes basic things such as bathing, toileting, and preparing food as well as medical things such as giving medications, feeding, and taking care of the IV catheter.

If you do not live locally, you will be required to stay near Cincinnati Children’s (within 30 minutes of the hospital) for several weeks and even months following your discharge. During this time, you will visit the outpatient clinic/day hospital several times a week for physical exams, infusions, blood product support, and routine medications. Your Care Manager will work very closely with you to help coordinate these visits. Please be aware that re-admission after discharge is common for further control of side effects and complications from the transplant. It is a good idea to keep a note pad where you can document your symptoms and questions to discuss at follow up visits (see To Take Notes).

It is very important after discharge from the hospital that you and your caregivers continue to limit your exposure to infections as it may take up to 2 years for your immune system to fully function. This is why it is very important to follow the Infection Control Guidelines after discharge (see Discharge Instructions).
Long Term Follow Up:

After the initial post BMT follow up is complete, your attending physician will begin the process of returning your care to your original primary care providers. The attending physician will also discuss the desired frequency of follow up here at Cincinnati Children’s to check for long term complications associated with a transplant. It is important to keep follow up appointments with all medical team members who care for you (ie: primary care physician, dentist, endocrine, ophthalmologist, BMT Attending Physician, physical therapy, etc.) and to share any symptoms that you are experiencing.

Once your immune system has recovered, your attending physician will discuss the need to begin the process of repeating childhood immunizations with your new immune system.
Definitions

Afebrile: Without a fever

Alopecia: Hair loss. This can occur as a side effect of the preparative regimen.

Anemia: Decreased red blood cells. This can occur as a side effect of the preparative regimen. Anemia causes tiredness (fatigue) and decreased oxygen delivery to tissues and organs.

Loss of Appetite: Can be a side effect of the preparative regimen or other BMT complications. Close monitoring with assistance from our dieticians can assist with this complication. You may require being fed through a nasogastric tube (NG) or being fed through your veins using your central line catheter.

Bone Marrow: A soft, spongy tissue located inside bones and is the site of blood cell production such as white blood cells, red blood cells, and platelets. These blood cells grow in the bone marrow and then leave to enter the blood stream.

Central Venous Catheter (CVC): Central Venous Catheters are a thin, plastic, flexible tube inserted into the large vein ending just above the heart. This catheter can be used to infuse medications, intravenous fluids, nutrition, and blood products as well as other things. It can also be used to withdraw blood for lab testing. These catheters need to be cleaned and flushed regularly to prevent infections and blood clots. There are four types of CVC’s used here at CCHMC: CVC, mediport, peripherally inserted central catheter (PICC), and apheresis catheter. You will require a CVC for transplant and your Attending Physician will decide which CVC is best for you.

**CVC:** A CVC has an “exit” site on the skin of your chest or neck. These catheters can be tunneled under the skin for long term use and are placed in the Operating Room under general anesthesia.

**Mediport:** A mediport is similar to a CVC. A mediport is under the skin of the chest and is accessed by using a special needle. Mediports can remain with you for years, if needed.

**PICC:** A PICC has an “exit” site on the skin of the upper arm. This catheter is placed in Interventional Radiology and is used for short term treatments.

**Apheresis Catheter:** An apheresis catheter is a larger sized catheter used for procedures such as peripheral blood stem cell harvest, photopheresis, or dialysis. An apheresis catheter has an “exit” site on the skin.
**Complete Blood Count (CBC):** Complete blood count refers to the lab used to place a numerical result on the amount of each blood cell type in a patient’s blood sample. These numbers will fluctuate throughout the transplant process and include white blood cells, red blood cells, and platelets.

**Complications to Heart, Liver, Lungs, and Kidneys:** It is possible that treatment with a transplant can cause damage to multiple organs of the body. The most common organs are the heart, liver, lungs, and kidneys. These organs will be monitored closely throughout transplant and Consulting Physicians will assist the BMT team in the management of your care.

**Diarrhea:** Diarrhea is a potential side effect of the Preparative Regimen, certain medications, and GVHD. This can lead to decreased absorption of food or medications from the gut, excess fluid loss (dehydration), and skin breakdown.

**Engraftment/Chimerism:** These are terms used to describe what percent of a patient’s blood sample are donor cells and what percent are patient (recipient) cells after transplant.

**Fatigue:** Fatigue can be the most challenging side effect. Fatigue can be both mental and physical. It is important for you to have activities to stimulate the muscles as well as your mind and allow time for you to rest.

**Febrile:** Febrile is a fever of 100.5°F (38.0°C) or higher.

**Graft versus Host Disease (GVHD):** GVHD is a risk with allogeneic HCT. GVHD is when the immune cells (white blood cells called T cells) from the donor (graft) recognize your body (host) as foreign and cause a reaction. GVHD causes damage to tissues or organs in your body and affects their ability to function normally. The effects to these organs can be anywhere from mild to life-threatening and may be fatal. GVHD can occur early or late in the transplant process. Medications are started during the Preparative Regimen to prevent this complication and continue post-transplant. These medications suppress your immune system and cause you to be at increased risk for infections. GVHD symptoms can include skin rash or peeling, yellowing of the skin, poor liver function, poor appetite, nausea, vomiting, stomach/abdominal pain, diarrhea, or blood in the stool. Your Attending Physician will evaluate your symptoms and start GVHD testing or treatment, if needed.

**Human Leukocyte Antigen (HLA):** HLA typing is used for allogeneic HCT. Antigens are proteins found on the surface of white blood cells called leukocytes. HLA typing is used to determine how well a donor matches you. You inherit your HLA typing from your parents. Blood samples or cheek swab samples are used to determine HLA typing.

**Immune Compromised or Immunocompromised:** Immunocompromised is used to describe you when your immune system is weakened. This means you have little to no ability to fight infections and are at risk for infections.
Infection: You are at a high risk for infections (bacterial, viral, and fungal) related to your weakened immune system. These infections can come from out in the community or from within your own body. You will be on medications to prevent infections. You will require close monitoring and a quick response to infectious symptoms such as fever.

Mucositis: Mucositis is a potential side effect of the Preparative Regimen where your mucous membranes have died off causing inflammation, pain, and sometimes bleeding. This can occur in the mouth, throat, and gastrointestinal (GI) tract. This side effect typically resolves when your white blood cell count increases.

Nausea/Vomiting: Nausea and vomiting are potential side effects of the Preparative Regimen, medications, or GVHD. Nausea/Vomiting can be acute (quick onset), delayed, or anticipatory (ie: nausea at the thought of having to take medicine).

Neutropenia: Neutropenia is used to describe when your absolute neutrophil count (ANC) is low. The lower the ANC and the longer the ANC is low, the greater the risk is for infection because you have little to no ability to fight infections.

Neutrophils: Neutrophils are a type of white blood cell which help to fight infections. They can be seen on a CBC.

Pancytopenia: Pancytopenia is used to describe when your white blood cells, red blood cells, and platelets are low. This could be a side effect of your disease, the Preparative Regimen, or the medications used during transplant.

Photopheresis: Photopheresis is a procedure used to prevent and/or treat GVHD. A special apheresis catheter is used for this procedure. This procedure separates the white blood cells from the other parts of the blood. The separated white blood cells are mixed with a medicine and exposed to ultraviolet light before they are returned to you. The whole procedure takes about 3-4 hours. The procedure affects the cells responsible for GVHD and decreases its harmful damage.

Platelets: Platelets are a part of your blood that help your body to stop bleeding. They can be seen on a CBC.

Preparative Regimen: Refers to the medications used to destroy the cells in your bone marrow that produce your blood and immune cells. Examples include chemotherapy, monoclonal antibodies, or radiation. These medications help to prepare for the new stem cells. Your Attending Physician will discuss these medications with you during the consent signing.

Prophylactic: Describes a treatment or a medication used to prevent a complication from occurring such as an antibiotic used to prevent a bacterial infection.

Red Blood Cells: Red blood cells deliver oxygen to your tissues and organs. They can be seen on a CBC along with your hemoglobin (Hgb) and hematocrit (Hct) to evaluate function.
Skin Changes: You may experience changes in your skin as a result of transplant. Sun sensitivity, increased pigmentation (color), fingernail or toenail changes, and dry skin are included in these changes. Most of the time these skin changes are temporary.

Stem Cell: A stem cell has the ability to develop into any cell type that makes up the tissues and organs of the body. Stem cells are self-renewing and/or multi-potent. Hematopoietic stem cells develop into white blood cells, red blood cells, and platelets.

Thrombocytopenia: Thrombocytopenia is used to describe when your platelet count is low. This results in a high risk for bleeding.

Thrombotic Microangiopathy (TMA): A complication involving the vascular system as a result of chemotherapy, infection, or GVHD. The blood vessels become inflamed and small blood clots can form. This causes kidney injury, protein leaking in urine, and high blood pressure. The lungs, heart, and gut may also be affected.

Types of Stem Cells used for Hematopoietic Cell Transplant (HCT): The stem cells for a HCT can come from three stem cell sources. Stem cells can be collected from peripheral blood using an IV and a special machine (peripheral blood stem cell harvest), from the bone marrow in the Operating Room (bone marrow harvest), or from cord blood collected after delivery of a baby. There are risks and benefits associated with each source and the chosen source of stem cells for you will be discussed with you by your Attending Physician.

Types of Hematopoietic Cell Transplant (HCT): There are three types of HCT: allogeneic, autologous, and syngeneic. Allogeneic HCT uses stem cells from a donor who is an acceptable HLA match for you. This can be from a related donor or an unrelated donor. Autologous HCT uses your own stem cells with the purpose of giving them back to you after receiving an intense Preparative Regimen. Syngeneic HCT uses stem cells from your identical twin. Your Attending Physician will discuss with you which type of HCT is best for your type of disease.

Veno-Occlusive Disease (VOD): Veno-occlusive disease is a complication involving the liver as a result of high doses of chemotherapy or radiation as part of the Preparative Regimen. The blood vessels in the liver become blocked and the liver can no longer process medications and waste products in the blood. This causes swelling and may lead to other organ failure.
Identifying Caregivers/Caregiver Selection

Bone marrow Transplantation and its treatment course can be challenging. You will need to identify a primary caregiver, or a small group of caregivers (a primary caregiver plus 2-3 more caregivers), to provide support and encouragement throughout this long process. Reliable caregivers can have a positive impact on the outcomes and recovery after transplant. In most cases, the primary caregiver is a parent/legal guardian or a spouse.

It is very important for caregivers to remember to care for themselves as well during this time. As a caregiver, you need adequate rest and nutrition in addition to regular healthcare follow up exams. Our Attending Physicians strongly recommend parents/legal guardians/caregivers and other family members receive the annual influenza vaccine. Talk to the patient’s Attending Physician before parents/legal guardians/caregivers or other family members receive other vaccinations.

Primary Caregiver:

- Attend all appointments (appointments last several hours)
- Required to be present with the patient 24 hours a day while inpatient if the patient is unable to care for him/herself (ie: infants, toddlers, and school age patients). Arrangements can be made with team members to allow breaks for caregivers to eat, shower, etc.
- Give/monitor all prescribed medications as you feel comfortable
- Prepare food/meals
- Watch and report any symptoms or side effects to the team members
- Assist with personal care, if needed (ie: bathing, toileting, dressing, etc.)
- Assist with medical care, if needed (ie: central line dressing changes, IV medication administration, tube feedings, etc.)
- Will need to be available to the patient 24 hours a day during certain times in the transplant process
- Can provide transportation during an emergency and to all appointments

Other Caregivers can:

- Assist with household activities (grocery shopping, laundry, house cleaning, pet care, lawn care, etc.)
- Control finances (paying bills, managing bank account, etc.)
- Care for the family’s other children
- Provide transportation
- Act as the designated contact person for family and friends to gain updates on the patient (via social media websites, phone, or email)
- Provide emotional/spiritual support for the family
- Ensure the primary caregiver is getting adequate rest, nutrition, taking breaks, and is accepting of help, when needed
CCHMC Resources for Caregivers

Amenities on the Bone Marrow Transplantation and Immune Deficiency Unit
(see Inpatient Unit)

Family Resource Center
(see CCHMC Services)

Assistance with FMLA
The Family Medical Leave Act (FMLA) gives you the right to take time off of work without losing your job in response to illness or the need to care for an ill dependent. Your Social Worker, Care Manager, and Transplant Financial Manager/Specialist can assist you with completing required documentation requested by your employer.

Inpatient & Outpatient Support Groups- Contact your Social Worker for more information about these programs:

1. Let’s Chat- A support group for inpatient caregivers on the Bone Marrow Transplantation and Immune Deficiency Unit. It is held on the 1st and 3rd Thursday of every month from 1:00-2:00pm in the Parent Lounge. Let’s Chat is an opportunity for caregivers to come together, receive support, ask questions, share advice on managing life on this unit, receive new information on support services and share a meal together.

2. Caregiver’s Lunch- Caregiver’s Lunch is sponsored by the Leukemia Lymphoma Society (LLS). The lunch is held on the 3rd Friday of each month. The Caregiver’s Lunch is an opportunity for all our caregivers on our inpatient units (A5N, A5S, and A5C) to enjoy an hour of pampering and relaxation with volunteers from LLS.

3. Munch & Mingle- A support group for inpatient caregivers from all of our inpatient units (A5N, A5S, and A5C). It is held on the 2nd and 4th Friday of each month on A5. Munch & Mingle is an opportunity for caregivers to come together, receive support, ask questions, share advice on managing life, receive new information on support services, and share a meal together.

4. Coffee & Dessert by Max’s Meals- Provides an opportunity for caregivers to connect with other caregivers who have experienced a similar healthcare journey. It is open to all Cancer and Blood Diseases Institute (CBDI) caregivers. Coffee and Dessert is held one or two times per month on a Sunday afternoon or Friday evening by a wonderful team of parent volunteers.
5. **Max's Meals & More** - Strives to nourish CBDI inpatients and their families, through meals, comfort items, and support activities. Max’s Meals & More regularly provide specialty catered meals for special occasions (such as holidays) and special events throughout the year.

6. **Hispanic Parent Support Group** - Meetings held several times per year

7. **Katie Linz Foundation** - Dedicated to improving both the lives of children diagnosed with cancer and their families. Katie Linz Foundation provides funding for the Patient & Family Wellness Center to purchase the continental breakfast food items available in all of the A5 CBDI inpatient unit Parent Lounges.

8. **Family to Family** - A parent caregiver support group program created by CCHMC. The program matches families with a parent volunteer who has experienced a similar health care journey. The program is designed to empower patients and families by bringing them together for extended support.
Financial/Insurance Concerns

We understand that financial and insurance issues associated with transplant can be complicated. In addition to the hospital charges, you may have other costs like physician charges, prescriptions, follow-up care, home care, and personal expenses including travel, meal, and lodging expenses or time lost from work. Below are some practical tips you might wish to use when dealing with insurance companies:

- **Be informed** about your treatment options.

- **Get organized.** Dedicate a space or a box on your desk or countertop to hold all transplant insurance documents as you receive them. You will receive additional insurance paperwork with the transplant because it is such an expensive procedure and is often managed by a different area within your insurance company. Keeping transplant insurance information separate is helpful when trying to resolve issues with the insurance companies.

- **Examine your health insurance benefits booklet.** If you cannot find your copy, call and get a new copy from your human resources department. Know the limitations and restrictions of your policy. Because your employer ultimately determines the details of the policy, it might be helpful to speak with your employer’s benefits specialist.

- **Document every single telephone conversation and keep a copy of every letter when speaking/writing to your insurance company.** Include in your documentation the name of the person(s) you spoke with, the phone number, the time and date of the conversation, and the nature of the conversation. Hopefully you will never need this information, but it’s useful when trying to resolve issues with the insurance company.

- Often you will be assigned a transplant case manager by your insurance company in addition to the transplant financial manager or specialist you are assigned at Cincinnati Children’s. The insurance company’s transplant case manager is an insurance based nurse who will oversee your care by monitoring hospitalizations, pre-authorizations, and pre-certifications. If you belong to a Health Maintenance Organization (HMO), most procedures will require prior authorization by your insurance company.

- **Transplant is one aspect of your health care.** After transplantation, there will be additional follow-up appointments and prescription medications both here in Cincinnati and at home. It is important to know what types of coverage your insurance policy contains. For example, you will want to know what the lifetime maximum dollar coverage is for you and at what age you are no longer covered under your policy. Some knowledge right now allows for better financial planning.
- During your Pre-Transplant Evaluation, your Transplant Financial Manager and/or Specialist will work closely with your insurance to obtain transplant approval. Your health history, current disease evaluation, recent test results, and the need for transplant are sent to your insurance company. Approval for transplant can take approximately two weeks.

- **Bureau for Children with Medical Handicaps (BCMH)**
  - CCHMC will assist you in securing financial assistance through all available sources. BCMH is for families who reside in Ohio. The patient must be under 21 years of age, have an eligible medical condition, and see a BCMH approved physician. All our Attending Physicians are BCMH approved.

  - Most patients in the Bone Marrow Transplant and Immune Deficiency Program are eligible for assistance. BCMH always pays after insurance or Medicaid. The bureau can help you meet co-payments and deductibles. It is important that you apply within 30 days of the patient being identified as having disease criteria that meet the guidelines. If you are interested in more information about this program, please see your Social Worker or the Transplant Financial Manager or Specialist.

- There are many financial resources available at Cincinnati Children’s. If you have questions, please call our Transplant Financial Manager at 513-636-8908 or our Transplant Financial Specialist at 513-636-7949. We will do our best to help you find the answers.
Clinical Research Studies

Cincinnati Children’s conducts research to improve the quality of pediatric care. The Bone Marrow Transplantation and Immune Deficiency Program is involved in clinical research studies that may result in new ways to prevent, diagnose, and treat children with cancer, blood, and immune disorders.

All clinical research studies use plans, called protocols, that spell out who may participate, exactly what the procedures are, and how long the study will last. These studies have hospital and federal regulations to make sure all the participants understand what they agree to do and that the possible benefits of participation are greater than the risks. The requirements, as well as your other treatment options, will be explained to you by BMT team members.

Who Can Participate?

- The patient, their immediate family, and/or their BMT donor may be invited to participate in one or more clinical research studies.
- **Participating in the clinical research studies is always voluntary and you may decline and/or terminate your participation at any time.**
- Your Attending Physician will decide which clinical research studies you are eligible for and each of these studies will be explained to you in detail.

More about Clinical Research Studies:

- Clinical research studies involving treatments for certain diseases measure a treatment’s safety, its possible side effects, and its ability to affect a disease.
- Clinical research studies involving data gather clinical and/or personal information about patients diagnosed with certain disorders or patients who are undergoing similar types of treatment.
- Clinical research studies may ask to collect lab samples (blood, bone marrow, urine, tumor biopsies, stool, etc.). These lab samples are often collected during your normal clinical care. For example, while blood is being drawn for routine clinical tests your Attending Physician or a BMT team member may ask your consent to use any remaining specimen(s) for research purposes.

Deciding whether to participate in a clinical research study is an important decision. We appreciate your interest and encourage you to ask questions as you decide. Almost daily, researchers discover new information about medical conditions and possible therapies which improve the quality of health care.
Medication Information

Medications used during and after transplant are very important to the success of the transplant. It is very important that you always take all your medications. Notify us if medication doses are missed or if you are unable to take a certain medication.

Infections during Transplant:
- Infections can be life threatening during the transplant process because the immune system is weakened and you have little to no ability to fight infections.
- Your Attending Physician may start you on medications prior to your transplant to prevent certain infections.
- Medications are prescribed to prevent infections from bacteria (Staphylococcus), viruses (herpes-HSV, cytomegalovirus- CMV, adenovirus- ADV, Epstein-barr virus- EBV, varicella zoster virus-VZV), fungus (Candida) and parasites (pneumocystis jirovecii- PJP, toxoplasmosis).
- You may need to continue taking these medications after transplant for months or even years until your new immune system is fully recovered.
- If you develop a fever, you will be started on an antibiotic.
- The amount (level) of some drugs (vancomycin, gentamicin) is measured in the blood. This level helps us adjust the amount of medicine taken so it is safe for your body.

During Transplant Hospitalization:
- The preparative regimen includes medications given to prepare your body for the new stem cells. Your Attending Physician will determine your preparative regimen and discuss this with you during the pre-transplant evaluation.
- The preparative regimen contains monoclonal antibodies (alemtuzumab) and/or chemotherapy agents (busulfan, fludarabine, melphalan, cyclophosphamide, and methotrexate).
- These medications can cause side effects including upset stomach (nausea), vomiting, sore mouth and throat, hair loss, and make your body more susceptible to infections.
- You will receive medications to help prevent or control some of the side effects listed above. These medications are given either orally (by mouth) or intravenously (IV).
- Another medication you may receive is filgrastim (G-CSF) which is used to speed up the recovery of your blood counts.
- Female patients who have periods may receive hormonal therapy (birth control pills) to prevent bleeding when their platelet counts are low.
Eating during Transplant:
- You may develop a very sore mouth and throat (called mucositis) from the medications.
- Mucositis decreases the body's ability to prevent infection so it is very important to clean your mouth at least three times a day.
- Pain medications are given to help make the mucositis more tolerable and increase the ability to eat and talk with this pain.
- Swishing and spitting a medication called chlorhexidine (Peridex) can help clean the mouth and provide a soothing effect.
- You may not be able to eat or drink after transplant for a period of time. You can receive nutrition through a naso-gastric (NG) tube or intravenously (called hyperalimentation or TPN).
- You may still need these feedings after you leave the hospital until you can eat and drink enough on your own.
- Multivitamins are prescribed during the first several months following a transplant to make sure you get the daily required vitamins.

Immunosuppressive Drugs:
- If you are having an allogeneic transplant, we will give you immunosuppressive drugs to help prevent Graft Versus Host Disease (GVHD).
- These medications are often continued for many months after the transplant.
- The amount (level) of some drugs (Cyclosporine, Tacrolimus) is measured in the blood. This level helps us adjust the amount of medicine being given so it is safe for your body.
- It is very important to always follow the directions for taking these medications.
- The medications used to suppress your immune system can often result in having high blood pressure or electrolyte imbalances. We may give you additional medications to help correct these side effects.

Medications to Avoid during Transplant:
- It is extremely important that certain medicines NOT be taken before or after the transplant process, due to their effects on platelets or interactions with other prescribed drugs.
- Medications to avoid include: aspirin, ibuprofen (Advil, Motrin), and other drugs that contain these drugs (cough and cold preparations).
- There are many cough and cold preparations that contain these drugs. Always check with a team member before giving the patient any drug, vitamin, or herbal medication not prescribed by a team member as these can have unwanted side effects or may interact harmfully with other agents the patient is receiving.
- If you are seen by other physicians, be sure to tell them about your transplant status and any other medications you are currently taking.
- If you are allergic or have had any adverse reactions (side effects) to any medications, please inform a team member so other forms of therapy may be used.
Medication Examples

Below is a list of frequent medications used with our transplant patients grouped by category. While you may not be on all of these medicines, you may hear about them during the transplant process. Please let us know of any questions or concerns about any of the medications you may be taking.

Antiemetics
- Ondansetron (Zofran®)
- Granisetron (Kytril®)
- Promethazine (Phenergan®)
- Diphenhydramine (Benadryl®)
- Lorazepam (Ativan®)

Antifungals
- Fluconazole (Diflucan®)
- Itraconazole (Sporanox®)
- Voriconazole (Vfend®)
- Posaconazole (Noxafil®)
- Amphotericin B (Ambisome®)
- Nystatin (Nilstat®, Mycostatin®)
- Caspofungin (Cancidas®)
- Micafungin (Mycamine®)

Antibiotics
- Piperacillin/Tazobactam (Zosyn®)
- Meropenem (Merrem®)
- Gentamicin (Garamycin®)
- Vancomycin (Vancocin®, Lyphocin®)
- Pentamidine (Pentam®)
- Sulfamethoxazole/Trimethoprim/Co-Trimoxazole (Bactrim®, Septra®)
- Metronidazole (Flagyl®)

Antivirals
- Acyclovir (Zovirax®)
- Ganciclovir (Cytovene®)
- Foscarnet (Foscavir®)
- Cidofovir (Vistide®)
Blood Pressure Medications
- Amlodipine (Norvasc®)
- Enalapril (Vasotec®)
- Chlorothiazide (Diuril®)
- Clonidine (Catapres®)
- Nicardipine (Cardene®)
- Nifedipine (Procardia®)

Pain Medications
- Morphine
- Fentanyl
- Oxycodone (Oxycontin®)
- Methadone
- Hydromorphone (Dilaudid®)

Chemotherapy Agents
- Cyclophosphamide (Cytoxan®)
- Busulfan (Myleran®)
- Etoposide (VP16® VePesid®)
- Carboplatin (Paraplatin®)
- Melphalan (Alkeran®)
- Fludarabine (Fludara®)

Graft Rejection & Graft Versus Host Disease Medications
- Cyclosporine (Neoral®)
- Lymphocyte Immune Globulin (ATG®, Atgam®)
- Thymocyte Globulin (Thymoglobulin, Anti-thymocyte Globulin (Rabbit))
- Tacrolimus (Prograf®)
- Methotrexate
- Prednisone (Deltasone®)
- Infliximab (Remicade®)
- Mycophenolate (MMF, Cellcept®)

Other Medications
- Mesna (Mesnex®)
- Filgrastim (GCSF®, Neupogen®)
- Ranitidine (Zantac®)
- Chlorhexidine Gluconate (Peridex®)
- Immunoglobulin (IVIG®, Cytogam®)
- Rituximab (Rituxan®)
- Pantoprazole (Protonix®)
- Alemtuzumab (Campath®)
- Alefacept
- Basiliximab
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Checked by:
BMT Food Safety Guidelines

The following pages describe the BMT Food Safety Guidelines (also called the BMT diet) used to protect the patient from infections. Bone Marrow Transplantation and Immune Deficiency Program patients should follow these BMT Food Safety Guidelines until after your transplant recovery period and you have discussed diet recommendations with your Attending Physician. When you are admitted to the hospital for the start of the preparative regimen, this BMT Diet will start.
BMT Food Safety Guidelines

Using basic food safety guidelines keeps food clean and safe to eat. People with a weakened immune system are at a greater risk for getting sick when they eat foods that are not kept safe. Using the ideas in this guide can help keep food safe for you and your child after having a Bone Marrow Transplant.

Cleaning

- Clean the refrigerator often (do not overfill).
- Wash kitchen surfaces and wipe up spills right away.
- If you use washcloths, wash them daily after use.
- Dishwasher- use only on the highest temperature to clean all dishes.
- If washing dishes by hand, use hot/warm water to clean dishes.
- Wash your hands with warm soapy water before cooking and before and after handling raw meats.
- Wash cutting boards and food surfaces with warm soapy water before and after each raw food/meat.
- Clean lids of canned items before opening.

Shopping

- Avoid fruits/vegetables with bruises and cuts.
- Check expiration dates and plan to eat foods before they expire.
- Avoid buying dented/rusted cans.
- Do not buy foods in packaging that is torn or leaking.
- Do not buy foods from open bin containers (i.e. nuts/candy scoped into bags filled by customers).
- Avoid buying loose spices from Farmer’s Markets, etc.

Foods to Avoid

- Dishes with meats that are not cooked all the way through (i.e. smoked meats, sushi with raw fish such as raw salmon, raw tuna, raw red snapper)
- Foods made with raw eggs (i.e. egg nog, some homemade salad dressings)
- Soft Cheeses made from unpasteurized milk (i.e. brie, feta, etc.)
- Raw sprouts
- Unpasteurized dairy products
- Honey
- Unpasteurized juices
Deli Counter
- Avoid any sides made at the grocery store (for example: potato salad, egg salad, macaroni salads that are made in the grocery store where it was purchased or at the deli counter).
- Avoid any sliced meats/cheeses from deli counters (packaged meats are okay).

Separating Items
- Separate raw meats when shopping at the grocery store by putting them in a separate bag to prevent juices from cross contaminating.
- Package fruits/vegetables away from raw foods when taking them home from the market.
- DO NOT use recyclable bags for meats, vegetables, fruits (may use these bags for dairy, grain, and pre-packaged products).
- Buy two cutting boards (one for raw meats and one for raw fruits/vegetables).

Cooking
- Do not thaw frozen foods at room temperature (foods can be thawed in the refrigerator, microwave or in cold water).
- Cook refrigerated raw meats within 1-2 days of purchase.
- Frozen meats must be cooked within 3-4 months.
- Use a meat thermometer to test the temperature of the cooked foods.
- Cook all raw meats to an internal temperature of 165 degrees.
- Microwave foods evenly by turning often.
- No leftover foods for patients.

Egg Safety

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<th>Eggs to AVOID</th>
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<td>Soft Boiled</td>
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<td>Quiche</td>
<td>Sunny Side Up</td>
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</table>
Patients cooking

- Patients may not handle/bake with raw yeast.
  - Patients may eat foods already prepared with yeast (breads, etc.).
- Patients cannot eat raw cake or cookie batter.
  - Patients may eat baked cookies and cakes.

Food temperature

- Patient must eat a prepared meal within 2 hours.
- Do not let ready to eat foods sit out at room temperature for more than 2 hours (if it is above 90°F, foods can only sit out for 1 hour).
- Maintain a refrigerator temperature at or below 40°F.

Dining Out

- Do not eat:
  - Lettuce/tomato/onion on sandwiches
  - Community ketchup, mustard, mayonnaise (single serving is best; single bottle on a table is also okay)
  - Raw appetizers (i.e. raw sushi, raw fish, shrimp cocktail)
  - Food from salad bars (i.e. soups, salads, vegetables, fruit, breakfast bar)
  - Foods from buffet restaurants
  - Restaurant salads
  - Soft serve ice cream/frozen yogurt (including Graeters/UDF)
  - Fruit/vegetable trays sitting out for the party to eat

- Do not drink:
  - Raw lemon added to water
  - Slushies’ from movie theaters/gas stations
  - Honey added to drinks

Always ask for your meal to be prepared fresh.

If you have questions, please ask your dietitian.

Dietitian: _____________________________ Phone: ___________________________
Inpatient Unit Description

The Bone Marrow Transplantation and Immune Deficiency Inpatient Unit is a dedicated, 36 bed, critical patient-care area with highly skilled staff members who are committed to providing the best care for you and your family. Our Family-Centered Care approach is evident at CCHMC. We hope that you will feel free to ask questions and actively participate in the patient's care.

For Infection Control and to decrease the flow of traffic onto our unit, the unit is locked-down to staff and visitors. To gain access onto the unit, you will need to contact the nursing station by using the black phone located at the entrance to the BMT unit or by using an access card provided for use by parents/legal guardians/caregivers.

When you are admitted to the unit, your nurse will go over an Admission Checklist and tell you about the unit. For your safety, you must wear your identification (ID) bracelet at all times. It is also important to minimize distractions when your nurse is at the nurse server, giving medications, and during sterile procedures (ie: dressing changes).

Each patient room is private and has a telephone, access to Wi-Fi, a TV with a DVD player, a bathroom for patient use, and a closet. There is also a "sleeper chair" for one parent/legal guardian/caregiver to stay 24 hours a day. Down the hall from the inpatient unit, you will find a washer, dryer, partial kitchen, exercise equipment/room and shower facilities.

On the unit, we have a Parent Lounge. Depending on the patient's precautions, the Parent Lounge is where parents/legal guardians/caregivers can eat, drink, socialize, and relax with other parents/legal guardians/caregivers while remaining close to the patient's room.

We also have an A5 Playroom and Adolescent/Young Adult (AYA) Activity Room. Your Attending Physician must approve you to go to these places and you must be afebrile (without a fever). Your Child Life Specialist can arrange a private time for you to go to the A5 Playroom and AYA Activity Room, if needed.

For more information on the things mentioned about see the sections labeled Visitation Guidelines and Inpatient Infection Control.
Family Presence/Visitation Guidelines

We recognize the positive impact visitors have on the mental well-being of the patient but, due to the high risk of infection in the transplant patient, we have to set restrictions on visitors during this time. For Infection Control, visitation by family/friends other than parents/legal guardians/caregivers is strongly discouraged. **Visitation should be scheduled and approved in advance by special agreement.** Each request will be reviewed on a case-by-case basis.

Visiting hours are 8:30am until 8:30pm.

**Visitation List:**
- Patients/parents/legal guardians/caregivers will be asked to identify a list of no more than ten people to visit the patient during their hospitalization.
- Of the ten identified visitors, four can be designated as primary support visitors, including the parent, guardian, and/or primary caregiver.
- Of the ten identified visitors, six can be designated as secondary support visitors, including a grandparent, relative, sibling, and/or significant person in the patient's life.
- Any changes to this list need to be discussed with the patient’s social worker.

**Who can Visit:**
- Parents/legal guardians/caregivers will be given 24 hour access to the unit until the patient is discharged (CCHMC provides a name badge and access card).
- Visitors, other than immediate family members, should be 14 years of age or older.
- Visitors under 18 years of age must be accompanied by an adult.
- Sibling visitors must be older than 18 months, not been exposed to any contagious illness, and pass the Health Screening.
- No visitors under 14 years of age are permitted for patients in Strict Protective Precautions, unless approved by the Attending Physician.
- Everyone who spends time on the unit is expected to be well and free from any illness symptoms in the last 48 hours. Illness symptoms include: fever, runny nose, cough, vomiting, diarrhea, eye infection, rash or skin infection.

**During the Visit:**
- Only two visitors are permitted in the patient’s room at any time.
- Visitors must stay in the patient’s room during the visit (not allowed to gather on the unit, go into another patient’s room, or in the Parent Lounge).
- Visitors are not allowed to eat or drink in a patient’s room.
- Visitors are not allowed to use the patient’s bathroom (must use public bathroom).
- One caregiver is permitted to sleep overnight in the patient’s room using the “sleeper chair.” This caregiver must be over 18 years of age.
- No individuals under 18 years of age can sleep at the patient’s bedside even with an adult present. Infant visitors who are breastfed by the patient’s primary caregiver may stay overnight with the primary caregiver.
What to do When Visiting:

- All visitors need to check-in at the A Welcome Desk and obtain a Visitor Sticker. The visitor must be listed on the “Family Approved Patient Visitation List” before a Visitor Sticker will be given. If the visitor is not on the visitation list, and there are fewer than ten names on the list, the visitor will be instructed to contact the parent/legal guardian/caregiver about being added to the list before they will be allowed on the unit.
- If the visitor is 16 years of age or older, they must provide a photo ID.
- Wash your hands before entering the unit at the sink station with soap and water for 15 seconds (or about as long as it takes to say the ABC’s), rinse well, and use a paper towel to turn off the faucet. Hand washing is the most important way to prevent the spread of infection.
- All individuals are required to use appropriate hand hygiene (ie: wash hands with soap and water or approved hand gel) each time you enter and exit the patient’s room.
- All visitors must be screened before entering the unit (Health Screening). Based on the Health Screening, a nurse may need to further evaluate before approving the visit. A physician’s approval must be given if the Health Screening is questioned.
- All visitors must follow the same infection control precautions as the staff (ie: wear gown, gloves, and mask)

The above Family Presence/Visitation Guidelines can change if the patient is transferred to the Pediatric Intensive Care Unit (PICU) or the team decides it is unsafe.
What to Bring

For Patients:
- Several sets of very comfortable clothing (oversized T-shirts, pull-on pants, socks, underwear, shoes, slippers, nightshirts, and pajamas/onesies with snaps/buttons). If you choose not to bring your own clothing, hospital clothing will be provided.
- Favorite blanket or comforter that can be machine washed regularly
- Favorite toy that can be safely cleaned and disinfected by machine washing or using a disinfecting cleansing wipe (Child Life can provide other toys, crafts, books, games, etc.)
- Plush toys/stuffed animals should be avoided. Otherwise, they must be machine washed and dried in an automatic dryer once a week.
- iPad, iPod, laptop computer, cell phone, camera (don’t forget the chargers)
- Favorite CD’s and DVD’s (Child Life has a lending library)
- Family photographs, pet photos, posters
- List of phone numbers and addresses of family and friends
- Electronic handheld games and game system (PlayStation, Xbox, Wii). It is hospital policy that all electronic equipment is checked and cleared for use by Clinical Engineering.

For Parents/Legal Guardians/Caregivers:
- Prescription medications
- Health insurance identification card
- Proof of guardianship (if appropriate)
- iPad, iPod, laptop computer, cell phone, camera (don’t forget the chargers)
- List of phone numbers and addresses of family, friends, employer, neighbors, and the patient’s medical care providers in your hometown
- Comfortable clothing, shoes, and umbrella
- Laundry detergent and dryer sheets (you will have access to a washer and dryer)
- A few good books/small craft projects
- Cards and stamps to send to relatives
- Favorite CD’s, DVD’s (your room will have a TV with a DVD player)
- Journal/log book to write down everything
- This Patient/Family Education Binder

Special Considerations:
- To keep the patient safe and to decrease clutter, patients/parents/legal guardians/caregivers should only bring personal belongings/toys which can be contained in one bin.
- For Infection Control, no live plants or flowers.
- For Infection Control, do not bring toys that soak up water or retain water.
- There is minimal food storage in the Parent Lounge which is cleaned out weekly.
- Please clean and mark all items brought to the hospital with the patient’s name.
- For fire/safety/Infection Control reasons, please do not bring in coffee pots, crockpots/hot plates, refrigerators, or decorative/holiday lighting.
Bone Marrow Transplantation and Immune Deficiency Patient Daily Routine

12 AM-1 AM
Nursing Physical Assessment, Vital Signs, Mouth Care

4 AM-5 AM
Physical Assessments by Team Members, Vital Signs, Mouth Care

7 AM-9 AM
Physical Assessments by Team Members, Vital Signs, Mouth Care

12 PM-1 PM
Nursing Physical Assessment, Vital Signs

4 PM-5 PM
Nursing Physical Assessment, Vital Signs, Mouth Care

8 PM-9 PM
Nursing Physical Assessment, Vital Signs

6 AM
Input And Output Totals

2 PM
Input And Output Totals

5 PM
CHG Bath, Linen Change, Lead Change, 1 Time Out of Bed, and 2 Mouth Care should be done

10 PM
Input And Output Totals

8 AM-2 PM
Family Centered Rounds


1 Time
- CHG Bath
- Linen Change
- Lead Change

Before 5 PM

2 Times
- Out of Bed

Every 8 Hours

3 Times
- Mouth Care
- Change Pulse Ox Location
Infection Control Guidelines While in the Hospital

Please follow these Infection Control Guidelines to keep the patient safe and decrease the risk of infection.

General Guidelines:

- Anyone spending time on the unit is expected to be well and free from any illness symptoms within the last 48 hours. Illness symptoms include: fever, runny nose, cough, vomiting, diarrhea, eye infection, rash, or skin infection.
- Hand washing keeps the patient healthy and is the most important way to prevent the spread of infection.
- Everyone is required to wash their hands before entering the unit at the sink station with soap and water for 15-20 seconds (or about as long as it takes to sing the ABC’s). Dry hands well and use the paper towel to turn off the faucet.
- All individuals (including the patient) should wash their hands before and after eating, drinking, handling food, bathing, toileting, changing diapers, blowing their nose, and covering a cough or sneeze.

Precaution Guidelines:

- Upon admission, the patient will be placed in Strict Contact Precautions. They are screened for infections at admission and then weekly. If tests are positive for certain infection(s), they will remain in Strict Contact Precautions. The BMT team will notify you when Strict Contact Precautions are no longer needed and your child is placed in Contact Precautions, Protective Precautions, or some other type of precautions.
- In Strict Protective, Contact, or Strict Contact Precautions, everyone must wash their hands and then put on the required personal protective equipment (i.e.: gown, gloves, and/or mask) before entering the patient’s room. Put the personal protective equipment in the trash and wash your hands before leaving the patient’s room.
- Parents/legal guardians/caregivers are not required to gown, glove, and mask while in the patient’s room.
- If the patient is in Strict Contact, Contact, or Strict Protective Precautions, parents/legal guardians/caregivers are not allowed to gather on the unit or in the Parent Lounge. Parents/legal guardians/caregivers may use the Parent Lounge but limit your time there (eat and leave).

Food & Drink Guidelines:

- Only patients are allowed to eat and drink in the patient’s room.
- The BMT Food Safety Guidelines should be followed for the patient (see BMT Diet)
- Food and drinks should not be stored in the patient’s room. A separate kitchen area is provided.
- Parents/legal guardians/caregivers may have one covered beverage in the patient’s room.
- Parents/legal guardians/caregivers may eat and drink in the Parent Lounge.
- If approved, parents/legal guardians/caregivers may eat and drink in the patient’s room.
Room Guidelines:

- Everyone is required to use appropriate hand hygiene (i.e.: wash hands with soap and water or approved hand gel) each time you enter and exit the patient’s room.
- The safest place for the patient is in the patient’s room. Locations used by multiple people may be contaminated with the germs of others.
- Your hospital room should only be visited by designated members of your family/caregivers. It is NEVER allowed for other patients and/or their family members/caregivers to visit your room, handle supplies, or participate in your care.
- All rooms are private rooms and the door must remain closed.
- Rooms are double HEPA filtered with positive airflow. For some infections, you may be placed in a double HEPA filtered room with negative airflow.
- You must remain in your room. Approval must be given for you to leave the room for any reason other than testing (i.e. CT scans, X-rays).
- You must wear a half-face N95 mask when outside of your room.
- It is recommended that parents/legal guardians/caregivers do not sleep in the patient’s bed. Each room has a “sleep chair” for one parent/legal guardian/caregiver to stay 24 hours a day.
- A clean mat or blanket will be placed on the floor when the patient plays or has physical therapy on the floor. The mat or blanket must be re-cleaned before re-use.
- Every patient room is cleaned daily. Please decrease clutter so we can effectively clean the room (keep personal belongings/toys contained in one bin). Also, keep counters and floor space clear so surfaces can be cleaned properly. It is preferred for extensive cleaning to occur once a month. If the patient’s stay has been longer than a month, you can expect to be moved to another room in order to accommodate this extensive cleaning process, if a room is available. The patient cannot be in the room during the extensive cleaning process.
- Please do not put any personal items on the nurse server or IV pole.
- No live plants, flowers, latex balloons, or items with standing water (i.e.: fish bowls, coffee makers, humidifiers, etc.)

Toy/Movie/Electronic Device Care Guidelines:

- Only toys that can be safely cleaned and disinfected by machine washing or using a disinfecting cleansing wipe should be used.
- Toys that have the potential of retaining water are not allowed.
- Plush toys/stuffed animals should be avoided. Otherwise, they must be washed and dried in an automatic dryer once a week.
- Disinfecting cleansing wipe should be used to wipe down surfaces the patient comes in contact with (i.e.: computer, cell phone, TV remote).
- The patient should be the only one playing with the toys/electronics/activity items and they should remain in the patient’s room (single patient use).
**Bathroom Guidelines:**

- Only patients are allowed to use the bathroom in the patient’s room.
- Parents/legal guardians/caregivers may use the bathroom in the Parent Lounge.
- Parents/legal guardians/caregivers may use the bathroom in the patient’s room **ONLY IF** the patient is in diapers full-time, has not started toilet training prior to admit to the unit, and there is no expectation the patient will start toilet training while admitted to the unit, and/or if the patient is in Strict Contact Precautions.
- For parents/legal guardians/caregivers who are allowed to use the bathroom in the patient’s room, the following rules apply:
  - Parents/legal guardians/caregivers must flush the toilet after each use
  - Parents/legal guardians/caregivers must wash their hands after each time using the bathroom
  - Parents/legal guardians/caregivers should lock the bathroom door when in use
  - No personal care items are allowed near the diaper scale
  - Personal care items must be put away after each use and not left out. Bathrooms must be kept free of clutter so daily cleaning of the bathroom can occur by Environmental Services staff.
  - Parents/legal guardians/caregivers must place dirty clothing, towels, and washcloths in personal wash. If hospital issued towels/washcloths are used, then place in dirty linen hamper
  - If bathroom becomes visibly soiled, please clean up area with hospital disinfecting wipes or have Environmental Services contacted

**Parent Lounge Guidelines:**

- When entering and exiting the Parent Lounge, hands should be washed with soap and running water for at least 15 seconds or use alcohol gel.
- Patients are not allowed in the Parent Lounge.
- The Parent Lounge is for inpatient parents/legal guardians/caregivers only (no visitors or siblings).
- Please clean up after yourself (wipe down area after use, do not leave dishes in the sink).
- The refrigerator is cleaned out weekly.
Discharge

Your Attending Physician will work closely with the BMT team and your caregivers to decide when you are well enough to be safely discharged from the hospital after BMT. Education is a large part of the discharge process to increase your comfort level in caring for the patient outside of the hospital. Please feel free to ask any questions at any time.

Members of the team who will be helping with the discharge teaching are:

- **Care Manager**
  - Will meet with you to teach these discharge instructions
  - Answer questions about discharge
  - Review emergency phone numbers and when to call
  - Will give you a schedule of follow-up appointments
  - Review Infection Control Guidelines while outpatient

- **Home Care Nurse**
  - Will show you how to care for your central line with “hands-on” demonstrations
  - Will show you how to give home infusions (IV medications, IV fluids, enteral feeds) with “hands-on” demonstrations
  - Teach other home care needs
  - Set up home care nursing visits, delivery of central line supplies and home infusions.

- **Pharmacist**
  - Will meet with you to review the medications you will need outside the hospital and give you the “Medication Record”.
  - Will bring your filled prescription oral medications to you on the day of discharge or will give you the prescriptions to be filled at an outpatient pharmacy prior to discharge (depending on insurance).
  - Will review medication information with you.

- **Dietician**
  - Will meet with you to review goals for your oral intake

- **Social Worker**
  - Will meet with you to review housing and transportation after discharge. You will need to stay within 30 minutes of CCHMC.

- **Physical Therapist, Occupational Therapist, Recreational Therapist, and Speech Therapist**
  - Will discuss any concerns you have about your child’s developmental milestones
What to Expect After Discharge

Leaving the hospital can be scary for some patients/parents/legal guardians/caregivers. You will be closely monitored after discharge by our team and we encourage you to express any concerns you have with us. Below are guidelines to follow as an outpatient:

CBDI Clinic or Day Hospital visits:
- It is very important for you to keep all follow up visits and be on time.
- Be aware it is common for you to be re-admitted to the hospital after discharge.
- You should expect to come to the clinic and/or Day Hospital 3-5 times a week.
- Depending on your needs, these visits could last 2 to 8 hours.

What to Bring to Clinic or Day Hospital for Every Visit:
- Bring any oral medications you may need to take while you are away from home.
- If the patient needs to receive tube feeds or formula while in Clinic or Day Hospital, please bring these and any necessary supplies from home.
- All IV medications and/or IV fluids will be given by your nurse in Clinic or Day Hospital (i.e. do not bring your IV medications).
- Bring your Medication Record for review.

At Home:
- Check the patient’s temperature under the arm if the patient feels warm or if you are concerned.
- Follow your Medication Record. Do not stop or change medications on your own. Work your medication schedule into your daily routine.
- Check the central line site with every dressing change.
- Look for rashes or skin breakdown anywhere on the body.
- Monitor the patient’s stool(s) for blood and/or diarrhea.
- Bathe with mild soap daily (Aveeno, Dove).
- Apply skin cream approved by your Attending Physician. If getting radiation therapy, please check with your Attending Physician before applying skin cream.
- Do not use a standard toothbrush to brush your teeth unless it’s approved by your Attending Physician.

Home Health Care:
- A home care nurse will visit soon after discharge and as often as needed.
- The home care company will deliver supplies and home infusion supplies as often as needed.
Infection Control Guidelines While Outpatient

Please follow these Infection Control Guidelines to keep the patient safe and decrease the risk of infection.

**General Guidelines:**

- Hand washing keeps the patient healthy and is the most important way to prevent the spread of infection.
- Everyone is required to wash their hands before and after coming in contact with the patient. Use soap and water for 15-20 seconds (or about as long as it takes to sing the ABC’S’s), dry hands well, and use the paper towel to turn off the faucet.
- Everyone (including the patient) should wash their hands before and after eating, drinking, handling food, bathing, toileting, changing diapers, blowing their nose, and covering a cough or sneeze.

**Visitor Guidelines:**

- Everyone spending time with the patient is expected to be well and free from any illness symptoms within the last 48 hours. Illness symptoms include: fever, runny nose, cough, vomiting, diarrhea, eye infection, rash, or skin infection.
- The patient should only be visited by designated members of your family/caregivers. It is still NEVER allowed for other patients and/or their family members/caregivers to visit the patient, handle supplies, or participate in your care.
- Continue to limit visitors.

**Guidelines Outside of the Home:**

- The safest place for the patient is in your home/apartment/hotel
- You should remain in your home/apartment/hotel
- You must wear a half-face N95 mask when outside your home/apartment/hotel
- You must wear sunscreen SPF 30 when outside. Reapply at least every 2 hours. All skin surfaces not covered by clothing should have sunscreen applied. Wide brim hats are encouraged.
- No smoking (tobacco free) around the patient, in the patient’s home/apartment/hotel, or in cars where the patient may ride.
- Avoid public areas that are crowded with people (grocery stores, places of worship, malls, movie theaters, restaurants)
- Avoid areas of construction
- Avoid smoke rooms and fumes
Home Preparation & Maintenance Guidelines:

- Any place that you will be staying as an outpatient should be approved by a team member.
- Thoroughly clean your home/apartment/hotel.
- Recommended cleaning agents are a solution of bleach with water and disinfectant wipes.
- Carpets should be cleaned and dried thoroughly prior to patient discharge.
- Dust with a damp cloth.
- The patient cannot be in a room that is being vacuumed. Patient should not return to the room for one hour after vacuuming.
- Change furnace filters regularly.
- Home renovation projects should be avoided.
- Wood burning fireplaces are not recommended.
- Humidifiers are discouraged.
- Live Christmas trees are discouraged.

Food and Drink Guidelines:

- The BMT Food Safety Guidelines should be followed for the patient (see BMT Diet).

Toy/Movie/Electronic Device Care Guidelines:

- Only toys that can be safely cleaned and disinfected by machine washing or using a disinfecting cleansing wipe should be used.
- Toys that have the potential of retaining water are not allowed.
- Plush toys/stuffed animals should be avoided. Otherwise, they must be washed and dried in an automatic dryer once a week.
- Disinfecting cleansing wipe should be used to wipe down surfaces the patient comes in contact with (i.e., computer, cell phone, TV remote).
- The patient should be the only one playing with the toys/electronics/activity items and they should remain in the patient's room (single patient use).

Bedding/Towels/Washcloths Guidelines:

- The patient should bathe and change clothes at least once a day.
- Bedding should be washed in hot, soapy water at least once a week and whenever visibly soiled.
- Bedding, towels, and washcloths should be thoroughly dried before using again.
- Bedding, towels, and washcloths should not be shared with other family members.
- It is still recommended that parents/legal guardians/caregivers do not sleep in the patient bed (patient should sleep in his/her own bed).

Bathroom Guidelines:

- If possible, please designate one bathroom for use by the patient only.
- Bathroom should be wiped down with disinfecting cleansing wipe prior to being used by the patient.
Pets/Animal Guidelines: If approved by your Attending Physician

- Patients should not be involved in routine pet care
- Patient should wash his/her hands after any contact with pets
- Patient and parents/legal guardians/caregivers should not have any contact with reptiles (turtles, snakes, iguanas, etc.)

Activity Guidelines:

- No swimming until approved by your Attending Physician
- School work should be performed at home/apartment/hotel until your Attending Physician approves for the patient to return to school
- Your Attending Physician will approve of you to return to work when appropriate
- No working in the yard (no cutting grass, mulching, gardening)
- Driving or operating heavy machinery is not allowed.

Vaccine Guidelines:

- Please ask your Attending Physician before other family members are immunized
- Your Attending Physician will tell you when the patient can begin to be re-immunized
- All patients and family members should get the Flu shot annually
- If the patient is less than 12 months old, the Attending Physician may decide to give the patient Synagis

Additional Guidelines for Teenage and Adult Patients:

- Patients of reproductive age will have specific challenges and restrictions after transplant. Sexual intercourse will need to be avoided with low platelets and when one partner has a contagious illness. Proper birth control should be used. Males should wear condoms to avoid infections. You may experience a decreased sex drive, vaginal dryness, or an inability to keep an erection. Females should not use tampons or douche.
- Please talk to a team member if you are experiencing any of these symptoms
Cincinnati Children’s Hospital
Medical Center (CCHMC) Services

Educational Videos about Transplant
Please visit http://www.cincinnatichildrens.org/service/b/bone-marrow/videos/ to watch educational videos on the topics below:

- What to Expect as a BMT Recipient
- What to Expect from your BMT Workup
- What to Expect as a BMT Donor
- How to Collect and Prepare Buccal Swab Samples
- How to Take a Temperature
- What to Eat on the BMT Unit
- How to Call about a Fever

Family Resource Center
The Family Resource Center is a one-stop destination for families in need of assistance with navigating their visit. The Family Resource Center provides patient & family advocates as well as Guest Services staff members to assist with your individual needs. The Family Resource Center has a multipurpose gathering space with a fireplace, TV, and couches, an outdoor landscaped patio, two private office spaces, and a resting room with recliners. The Family Resource Center provides books and activities for all ages, computers, internet access, fax, scanner, printer, and educational reading materials related to medical conditions. This peaceful environment provides a relaxed retreat. The Family Resource Center is located on the first floor of Location A. Hours of Operation are 7:30am-8:30pm Monday-Friday and 11:00am-3:00pm on weekends and holidays. The Family Resource Center phone number is 513-636-7606.

Guest Services
Please contact your social worker for resources and assistance with navigating Guest Services. Guest services will help you schedule clinic appointments, transportation, lodging accommodations, services, local restaurants and entertainment when you need to travel to CCHMC and stay for the patient’s medical care. Guest Services phone number is 513-636-5009.

Complimentary Shuttle Runs
There is a shuttle provided by CCHMC Guest Services that picks up on the first floor of Location B. This shuttle runs to Target, Meijer, Walmart, CVS, Kenwood Mall, Biggs, Walgreens, and Kroger at specific times throughout the week. For the shuttle schedule and to reserve a seat please contact Guest Services at 513-636-5009.

Parking and Protective Services
Parking is free for patients, families and visitors. Please remember to have your ticket validated at any Welcome Desk. Your safety is important to us. The Visitor Parking lots are regularly patrolled by Protective Services officers on foot and by bike. Protective Services can help you to your car or to the Ronald McDonald House by calling Protective Services at 513-636-4204.
Smoke-free Environment
In an effort to support a healthy environment, all buildings, grounds and property, including vehicles, owned or operated by CCHMC are tobacco free.

Safe Environment
In an effort to support a safe environment, CCHMC has a badging system. To gain access to the 2nd floor or higher in Location A or B, you must first go to a Welcome Center.

Latex-Free Environment
In an effort to support a safe environment, CCHMC is latex-free. No latex balloons are allowed. Mylar balloons are accepted.

Food Services
Location D: A full-service cafeteria is arranged in a food court style and is located on the first floor. Food choices range from comfort foods, fresh soups, specialty cuisine, LaRosa’s pizza, Cincinnati-style chili, salad bar, deli, and grill items. Vending machines are located outside the BMT unit.

Meal Cards can be purchased for $6 at Welcome Desk A in person or over the phone (Guest Services 513-636-5009 option 2) from 8:30am-5:00pm Monday-Friday and 11:00am-3:00pm on weekends and holidays. These cards can be picked up in person or delivered to the patient’s room. This is a service provided by the cafeteria in which the Meal Card provides one meal for a parent/legal guardian/caregiver that can be redeemed via a phone order and delivered to the inpatient unit.

Best Upon Request Concierge Service
The CCHMC Concierge Service, managed by Best Upon Request, can perform just about any service or errand you can think of. They can arrange oil changes or washing/detailing for your car, sell you stamps, coordinate and pick up lunches, grab grocery items, receive discounted tickets to the movie theater or area attractions, buy flowers or a birthday gift, or even pick up a replacement battery for your watch. Errands are limited to a 5 mile radius of CCHMC and are on a first come, first served basis. Employees, patients, and families pay only the cost of any items or services purchased, plus fuel ($0.56 per mile) for the errand. There is no mark up. Their hours are Monday through Friday, 7:30 a.m. to 4:30 p.m. and are located at the D Welcome Desk or you can call 513-803-4871 or e-mail concierge@cchmc.org.
**Ronald McDonald House**
The Ronald McDonald House is a “home away from home” for the families of children undergoing treatment at CCHMC. Patients must be 21-years-old or younger and be seen a minimum of twice per week. You must also live greater than 40 miles from CCHMC. Families apply online when appointment times are given to request a room at [http://www.rmhcincinnati.org/](http://www.rmhcincinnati.org/). At that point, background check information is collected for all adults in the family to verify there have been no felonies or violent crimes committed. If approved, the staff will put your name on the waiting list 24-hours prior to the first appointment. In addition, the Ronald McDonald house also has “short-stay” rooms that may be requested a month in advance if available. This is useful for patients discharged to home and needing to return for follow-up visits. They encourage, but do not require, a minimum donation of $25 per night. The inability to pay this fee does not make you ineligible to stay at their facility. Some insurance companies may even assist with payment. Contact your Social Worker for more information or call the Ronald McDonald House at 513-636-7642. They are located right across the street from CCHMC at 350 Erkenbrecher Avenue, Cincinnati, OH 45229.

**Hope Lodge**
The American Cancer Society Hope Lodge is a local option for free lodging for adult patients undergoing cancer treatment. When patients travel to Cincinnati for cancer treatment, the Hope Lodge offers a comfortable environment in which to stay. To stay at our lodge, download our [Musekamp Family Hope Lodge Request Form](http://www.cancer.org/treatment/supportprograms/services/hopelodge/cincinnati/index) at [http://www.cancer.org/treatment/supportprograms/services/hopelodge/cincinnati/index](http://www.cancer.org/treatment/supportprograms/services/hopelodge/cincinnati/index) and fax it to 513-618-5586 or mail it to 2806 Reading Road, Cincinnati, OH 45206. You may also contact your Social Worker to assist with this process.

**Pastoral Care**
Our experienced pastoral care team offers spiritual guidance in all faiths—or simply emotional support—to the hospitalized patient, to you as a parent/legal guardian/caregiver or to other members of your family who are affected by your illness. Our Chaplains and Bereavement Specialists are available to assist on-site, 24 hours a day. Pastoral Care can provide sacred texts and rituals. Pastoral Care also provides worship services and has 3 chapels open 24 hours a day for prayer and reflection in Location A & Location B. Call Pastoral Care at 513-636-4376.

**Gift Shop**
The Gift Shop is located in the hallway connecting Location B and Location C on the first floor. It has toys, books, greeting cards, seasonal gifts, candy, personal items, and other items specifically for patients.

**Bank Services**
There is a full-service US Bank with a notary located in the Kasota Building across from CCHMC main campus.
ATM Locations, Postal Services, Fed Ex, and UPS
Several money stations are available on the second floor of Location D. Stamps are available for purchase from the Gift Shop. Letters may be mailed outside Location B lobby. If you need directions to the post office, please ask at the Location B Welcome Desk. Fed Ex and UPS drop off boxes are located on the second floor of Location C.

Newspaper Stands
Newspaper stands are located at the front door of Location B, outside of the cafeteria, and on the first floor of Location C.

Seacrest Studios
The Ryan Seacrest Foundation partnered with Cincinnati Children’s Hospital to launch our very own Seacrest Studio, right across from the cafeteria! Being one of eight locations throughout the United States, the studio is part of an entertainment initiative to help patients explore the creative realms of radio, television and new media. Cincinnati Children’s patients can participate in the on-air activities in the studio and from their rooms by conducting celebrity interviews, watching live performances, and playing game shows. Talk to your Child Life Specialist for more information!

Family Pet Center
In September 2013 CCHMC, in working with CancerFree KIDS and Impact 100 officially opened the Family Pet Center. It was the first and believed to still be the only Pet Center at a pediatric hospital in the U.S. Patients who stay five days or more may be eligible to have their pet visit, if medical staff approves. Dogs and cats may visit, however, Infection Control must clear requests for other types of animals. Pets should be current on vaccinations and bathed before a visit. Child Life will schedule and coordinate the visit. Once families request a visit and medical staff approves, families will receive a confirmation by phone or e-mail with instructions. On the day of the visit, a Child Life Specialist will bring the child to the Family Pet Center. A volunteer will meet the parent/legal guardian arriving with the pet and escort them to the center. One adult family member must escort the visiting pet. Pets are not allowed to enter CCHMC buildings or patient rooms, and cannot be left unattended. Speak to your Child Life Specialist for more information.
Resources Available Outside of CCHMC

Please contact your Social Worker with questions regarding these resources.

- **The Dragonfly Foundation**  
  Phone: 1-513-494-6474  
  Website: [www.thedragonflyfoundation.org](http://www.thedragonflyfoundation.org)  
  Local agency specific to BMT and CCHMC that provides support, resources, and activities. They also have a place to visit.

- **Blood & Marrow Transplant Information Network**  
  Phone: 1-847-433-3313  
  Toll Free: 1-888-597-7674  
  Website: [www.bmtinfonet.org](http://www.bmtinfonet.org)  
  Provides BMT specific information and support

- **The Bone Marrow Foundation**  
  Phone: 1-212-838-3029  
  1-800-365-1336  
  Website: [www.bonemarrow.org](http://www.bonemarrow.org)  
  Provides financial aid, education, resources, and support groups

- **National Marrow Donor Program (NMDP)/Be The Match**  
  Phone: 1-800-627-7692  
  Toll Free: 1-888-999-6743  
  Website: [www.marrow.org](http://www.marrow.org)  
  Donor registry, financial aid, BMT specific information, resources, support, newsletter, and caregiver education  
  NMDP also has a patient app with care guidelines before and after transplant.

- **Immune Deficiency Foundation**  
  Phone: 1-800-296-4433  
  Website: [www.primaryimmune.org](http://www.primaryimmune.org)  
  Provides education, resources, and support

- **Aplastic Anemia & MDS International Foundation**  
  Phone: 1-301-279-7902  
  1-800-747-2820  
  Website: [www.aamds.org](http://www.aamds.org)  
  Provides education, resources, and support
• Fanconi Anemia Research Fund, Inc.
  Phone: 1541-687-4658
  Toll Free: 1-888-326-2664
  Website: www.fanconi.org
  Provides education, resources, and support

• American Cancer Society
  Phone: 1-800-227-2345
  Website: www.cancer.org
  Provides education and support groups

• Leukemia & Lymphoma Society
  Phone: 1-914-949-5213
  Website: www.lls.org
  Southern Ohio has a local chapter. Provides financial aid, education, resources, and support groups

• National Children's Cancer Society
  Phone: 1-314-241-1600
  Website: www.children-cancer.org
  Provides financial aid and education

• Cancer Care, Inc.
  Phone: 1-800-813-4673
  Website: www.cancercare.org
  Provides financial aid, education, resources, and support groups

• Cancer Family Care
  Phone: 1-513-731-3346
  Website: www.cancerfamilycare.org
  A local agency that provides support for individuals and families, resources, and a newsletter

• Cancer Support Community
  Phone: 1-202-659-9709
  Toll Free: 1-888-793-9355
  Website: www.cancersupportcommunity.org
  Provides education, resources, caregiver resources, and support groups

• Caring Bridge
  Website: www.caringbridge.com
  Free personalized websites that connect family and friends during a serious health event to share updates and receive messages of support
- **Kid’s Konnected**
  Phone: 1-949-582-5443
  Website: [www.kidskonnccted.org](http://www.kidskonnccted.org)
  For children/teens who have a close family member in treatment for cancer. Provides age appropriate education, support, and activities

- **Super Sibs**
  Toll Free Phone: 1-888-417-4704
  Website: [www.supersibs.org](http://www.supersibs.org)
  Provides financial aid, education, and support for siblings of patient

- **A Kid Again**
  Phone: 1-513-232-5104
  Website: [www.akidagain.org](http://www.akidagain.org)
  Activities and gifts for children and their parents

- **Make-A-Wish**
  Website: [http://wish.org](http://wish.org)
  Grants wishes to children

- **A Special Wish Foundation**
  Phone: 1-800-486-9474
  Website: [www.spwish.org](http://www.spwish.org)
  Grants wishes to children

- **Children’s Wish Foundation**
  Phone: 1-800-323-9474
  Website: [www.childrenswish.org](http://www.childrenswish.org)
  Grants wishes to children

- **Hem/Onc Kids Camp**
  CCHMC hosts an annual week-long summer camp for CBDI patients at Joy Outdoor Education Center.

- **Songs of Love**
  Phone: 1-800-960-7664
  Website: [www.songsolove.org](http://www.songsolove.org)
  Provides a personalized CD for a child

- **Caregiver Action Network**
  Phone: 202-772-5050
  Website: [www.caregiveraction.org](http://www.caregiveraction.org)
  Provides support and education to caregivers
• Alex's Lemonade Stand  
  Website: www.alexslemonade.org  
  Provides financial aid  

• Needy Meds  
  Phone: 1-800-503-6897  
  Website: www.needymeds.org  
  Financial assistance with medications  

• B Positive Foundation  
  Phone: 1-302-654-6207  
  Website: www.bepositive.org  
  Provides financial aid  

• Children's Organ Transplant Association (COTA)  
  Phone: 1-800-366-2682  
  Website: www.cota.org  
  Assists families with fundraising for transplant-related expenses  

• Colburn & Keenan Foundation  
  Phone: 1-800-966-2431  
  Website: www.colkecn.org  
  Provides financial aid  

• First Hand Foundation  
  Phone: 1-816-201-1596  
  Provides financial assistance  

• Home Away From Home  
  Provides assistance with hotel stays through the National Foundation for Transplants (NFT)  

• Kelly Carol Foundation for Children with Cancer  
  Website: www.kellycarolfdn.org  
  Provides financial assistance  

• Matthew & Andrew Akin Foundation  
  Website: www.matthewandandrew.org  
  Provides financial aid  

• Patches of Light  
  Phone: 1-614-946-7544  
  Website: http://patchesoflight.org  
  Provides financial aid