



Riley Hospital for Children
Indiana University Health

MEDICATION INFORMATION

MEDICATIONS

Medications used during and after transplantation are very important to the success of the transplant procedure. Medications will be used either alone or in conjunction with total body irradiation (TBI) to prepare the body for the transplanted stem cells. This is called a "preparative regimen" and is often started 7 to 10 days before the transplant. The medications used are based on the type of disease and the source of the stem cells. These medications are used for immunosuppression and for cancer fighting (antineoplastic) effects. Immunosuppressive agents help suppress cells in the body so that the new stem cells being placed in the body are not attacked and killed but are allowed to survive and grow. These drugs are used together to get the maximum benefit with the least side effects (toxicity). TBI can provide both immunosuppression and cancer fighting effects.

Upon beginning the transplant process, several other medications are routinely required. Medications for nausea are frequently used either orally or intravenously (IV). These may include granisetron (Kytril®), diphenhydramine (Benadryl®), and lorazepam (Ativan®). There are some other medications that are used to prevent certain infections from occurring. Infections that can cause harm in someone whose immune system is suppressed include: viruses (such as herpes/HSV, cytomegalovirus/CMV), fungus (such as candida), bacteria (such as staphylococcus), and parasites (such as pneumocystis carinii/PCP). Therefore, we will be testing each patient and donor to see if they have been exposed to these infectious agents in the past. This will help us determine which medications will be needed. Acyclovir (Zovirax®) will be used to help prevent some viral infections. Fluconazole (Diflucan®) will be used to help prevent some fungal (yeast) infections, and trimethoprim/sulfamethoxazole (Septra® or Bactrim®) will be used to help prevent some types of pneumonia.

Antibiotics will be started when your child develops a fever. Commonly used antibiotics include vancomycin and ceftazidime. If the fever persists, other medications such as clindamycin, gentamicin, and amphotericin (a fungus medicine) may be added. The amount of some drugs (vancomycin, gentamicin) will be measured in the blood to assure that adequate doses of medicine are being given.

Another medication some patients receive is filgrastim (G-CSF), which is used to enhance the recovery of blood counts.

As the transplant date approaches, your child may develop a very sore mouth and throat from the mucositis. Pain medications are started to help his/her pain. Most often we start an infusion of a narcotic drug like morphine. This medication is increased gradually as needed to help control the pain. The pain will not

completely disappear. However, we will try to make it more tolerable for your child. As the mucositis improves, the pain medications will be gradually decreased. Swishing and spitting a medication called Peridex® is another measure that is employed to aid in cleansing the mouth and may also provide some soothing effect. Saline or sterile water can also be provided for swishing in the mouth which may help with the soreness and dryness. Flourigard® will be used daily as a swish and spit to aid in mouth care during transplant.

During the time you/your child has mouth sores and a poor appetite, she/he will likely be unable to take in enough calories/nutrition by mouth. A small, special tube called a nasogastric tube (NG) that carries food and medicine through the nose in to the stomach may be used to help them through this period. Another way to deliver this nutrition is through you/your child's central line catheter and is called hyperalimentation (TPN or CHA). Your stem cell transplant physician will discuss this with you during your transplant consult ("101" meeting).

After transplant, it is very important that your child take all medications prescribed by the transplant doctor. Since the body will be recovering from the transplant procedure, it is very important to take the medications that prevent certain infections. These medications usually include Septra®, fluconazole, and sometimes ganciclovir (a medicine to prevent infection by the CMV virus). In some cases, immunosuppressive drugs (such as cyclosporine, tacrolimus, methotrexate, and prednisone) will need to be continued after the transplant. It is very important to follow the medication schedules provided to you by your child's physician.

It is extremely important that certain medicines not be taken before or after transplant, due to their effects on platelets or interactions with other prescribed drugs. Your child should avoid aspirin, Advil®, Motrin®, or other drugs containing aspirin or ibuprofen. There are many cough and cold preparations that contain these drugs. Always check with your child's transplant physician before giving him/her ANY drug not prescribed by the transplant team. If your child is seen by other physicians, be sure to inform him/her of the transplant status and any other medications she/he is currently taking.

Occasionally, other types of medications such as drugs to lower blood pressure, hormonal therapy (birth control pills), or electrolyte supplements (like potassium and magnesium) may be prescribed. Birth control pills are commonly given to females of menstruating age to prevent bleeding when their platelet counts are low. It is not uncommon for patients to have problems with high blood pressure and electrolyte imbalances when they are taking cyclosporine and/or prednisone.

Included in this section you will find medication sheets on each drug that may be given to your child before or after transplant. If your child is allergic or has had

any adverse reactions (side effects) to any of the discussed medications, please inform the physician or nurse practitioner so that other forms of therapy may be used. If you have any further questions about your child's medications, please contact the stem cell transplant clinical pharmacist.

Medication Table of Contents

Acetaminophen and Codeine
Acyclovir
Amlodipide
Busulfan
Cyclosporine
Dapsone
Diphenhydramine (Benadryl®)
Erythropoietin (Epogen®)
Filgrastim (G-CSF)
Fluconazole
Ganciclovir
Granisetron (Kytril®)
Lisinopril
Lorazepam (Ativan®)
Magnesium
Morphine
Mycophenolate (CellCept®)
Nifedipine
Oxycodone
Pentamidine
Prednisone
Tacrolimus
Trimethoprim (Bactrim®, Septra®)

ACETAMINOPHEN AND CODEINE

(Capital and Codeine[®], Tylenol with Codeine[®])

TYPE OF MEDICATION AND HOW IT WORKS:

Acetaminophen and codeine is a combination medication used to relieve pain. It can also be used to reduce coughing.

HOW TO TAKE THIS MEDICATION:

Give only the amount prescribed by your child's doctor.

Your child should not take this medication more than 5 times in one day.

If giving your child a liquid, carefully measure each dose using an oral syringe or medicine spoon.

This medicine can be given with food to prevent stomach upset.

Do not give your child acetaminophen (Tylenol[®], Genapap[®], Panadol[®], Tempra[®]) or other over-the-counter medications that contain acetaminophen while using this medication.

WHAT TO DO IF YOU MISS A DOSE:

If you have been instructed to give this medicine to your child on a regular schedule and miss a dose, give it as soon as you remember it. However, if it is almost time for the next dose, skip the missed dose and go back to the regular dosing schedule. Do NOT give double the dose to catch up.

SIDE EFFECTS:

More common effects:

drowsiness, dizziness, constipation

Check with your doctor if any of the following side effects occur:

difficulty breathing; skin rashes, hive or itching; nausea or vomiting

SPECIAL INSTRUCTIONS:

Contact your doctor if you give your child too much medicine.

Do not give this medicine if your child is allergic to codeine.

Check the labels on all over-the-counter medicines you give your child to make sure they do not contain acetaminophen. Too much acetaminophen may be harmful.

This medicine may make your child drowsy. Watch carefully if your child is performing a task requiring alertness, such as climbing stairs.

If your child requires this medicine for a long period of time, the dose may need to be slowly decreased and not stopped quickly.

DOSAGE FORMS AVAILABLE:

- Tablets: Tylenol #1 (acetaminophen 300mg + codeine 7.5mg)
- Tylenol #2 (acetaminophen 300mg + codeine 15mg)
- Tylenol #3 (acetaminophen 300mg + codeine 30mg)
- Tylenol #4 (acetaminophen 300mg + codeine 60mg)
- Capsules: Tylenol #2 (acetaminophen 325mg + codeine 15mg)
- Tylenol #3 (acetaminophen 325 mg + codeine 30mg)
- Tylenol #4 (acetaminophen 325mg + codeine 60mg)

Suspension, alcohol free: acetaminophen 120mg + codeine 12mg per 5ml (Capital[®])

Elixir, 7% alcohol: acetaminophen 120mg + codeine 12mg per 5ml

ACYCLOVIR

(Zovirax®)

TYPE OF MEDICATION AND HOW IT WORKS:

Acyclovir is a medicine used to help prevent viruses from causing infections. These viruses include herpes simplex and varicella-zoster (chickenpox). It is also used in the treatment of these infections. Viral infections can be more severe in a person who is taking immunosuppressive medications (prednisone, cyclosporine). Acyclovir prevents the virus from reproducing, it does not eliminate it.

HOW TO TAKE THIS MEDICATION:

While in the hospital, the acyclovir will be administered by infusion into the central line catheter twice daily. It will begin when admitted to the hospital and discontinued upon discharge or 30 days after transplant.

If taking this medication at home:

Give capsules, tablets or liquid as directed by your child's doctor. Capsules may be opened and sprinkled on applesauce. If using liquid, shake well before use and use a specially marked measuring spoon to give the exact dose of the suspension.

WHAT TO DO IF YOU MISS A DOSE:

If your child misses a dose of this medicine, give it as soon as you remember. However, if it is almost time for your child's next dose, skip the missed dose and go back to the regular dosing schedule. Do NOT give double the dose to catch up.

SIDE EFFECTS:

More common effects:

diarrhea, nausea, vomiting, dizziness, headache and joint pain
rash, increased kidney function laboratory values

Check with your doctor if any of the following side effects occur:

If you have diarrhea, nausea, or vomiting which is severe or lasts longer than a day and prevents you from eating or taking in fluids.

If you develop a rash.

SPECIAL INSTRUCTIONS:

Make sure you drink plenty of fluids to stay well hydrated while taking this medication.

DOSAGE FORMS AVAILABLE:

Injectable: 500mg, 1000mg
Capsules: 200mg
Tablets: 400mg, 800mg
Suspension: 200mg/5ml (banana flavor)

AMLODIPINE

(Norvasc[®])

TYPE OF MEDICATION AND HOW IT WORKS:

Amlodipine is a medication used to lower blood pressure.

HOW TO TAKE THIS MEDICATION:

Give amlodipine on a regular schedule as prescribed by your child's doctor.

Do not stop giving your child amlodipine unless told to do so by your child's doctor.

Give this medicine at the same time every day.

WHAT TO DO IF YOU MISS A DOSE:

If your child misses a dose of this medication, give it as soon as you remember it. However, if it is almost time for your child's next dose, skip the missed dose and go back to the regular dosing schedule. Do NOT give double the dose to catch up. If two or more doses are missed, contact your child's doctor.

SIDE EFFECTS:

More common side effects:

dizziness, lightheadedness (have your child get up slowly from lying down), headache, weakness, flushing (feeling of warmth), nausea, rash, edema

Check with your doctor if any of the following side effects occur:

prolonged dizziness; vomiting; swelling of face, lips, tongue or difficulty in breathing occurs; swelling of hands or feet

SPECIAL INSTRUCTIONS:

DOSAGE FORMS AVAILABLE:

Tablets: 2.5mg, 5mg, 10mg

Suspension: 1mg/ml (prepared at Riley)

BUSULFAN

(Myleran®)

TYPE OF MEDICATION AND HOW IT WORKS:

Busulfan is a medicine that helps to slow or stop the growth of cancer cells in your body. It is most frequently used in combination with another drug (cyclophosphamide) in preparing your body for a stem cell transplant.

HOW TO TAKE THIS MEDICATION:

This drug is only available in tablets (however, Riley pharmacy can prepare a liquid). This drug will need to be given every 6 hours (9AM, 3PM, 9PM, 3AM) for a total of 16 doses. Another medicine (Benadryl®) to try to prevent any nausea or vomiting is usually given before each dose. If the tablets are vomited, the number of tablets seen will be given again.

WHAT TO DO IF YOU MISS A DOSE:

If your child misses a dose of this medicine or the dose times get off schedule, the stem cell transplant physician-on-call must be notified immediately. NEVER give more tablets than prescribed.

SIDE EFFECTS:

More common effects:

Nausea, vomiting, decreased blood cell counts, skin darkening, dry skin and mouth

Check with your doctor if any of the following side effects occur:

Breathing discomforts, persistent cough, fever, nausea and vomiting so that you are not able to take your medicine

SPECIAL INSTRUCTIONS:

It is very important that this medicine be administered every 6 hours. If there is any deviation from this schedule, please notify the stem cell physician-on-call immediately. Each dose will consist of a number of tablets. Gelatin capsules (size 0) can be provided so that 6-8 tablets will fit in each capsule and make swallowing the drug much easier. If vomiting occurs, you must count the number of tablets vomited and call the transplant physician on call.

DOSAGE FORMS AVAILABLE:

Tablets: 2 mg

Suspension: 2 mg per 1 ml (specially prepared by Riley Pharmacy)

CYCLOSPORINE

(Neoral[®], Sandimmune[®])

TYPE OF MEDICATION AND HOW IT WORKS:

Cyclosporine is an immunosuppressive agent that helps suppress cells in the body so that the new stem cells being placed in the body are not attacked and killed but are allowed to survive and grow. Therefore, it is used to help prevent graft-versus-host disease (GVHD). While taking this medication, your child will be more susceptible to infections.

HOW TO TAKE THIS MEDICATION:

One or two days before the stem cells are transplanted; cyclosporine will begin being infused into the central line catheter every 8 or 12 hours. Once your child is able to tolerate oral medications, it will be given by mouth. Your child will continue to take this medication for approximately 6 months.

If taking this medication at home:

Give gelatin capsules or liquid as directed by your child's doctor.

The capsules are individually packaged in a foil container and will have a strong odor when opening the package. It is recommended that you allow the capsules to "air out" for several minutes before trying to give them. Only swallow capsules whole. Do not crush or mix with food. These capsules are only good for 7 days outside the special foil container. If using liquid, use the special syringe with markings for measuring the liquid in order to give the exact dose ordered. To make the liquid taste better try mixing it with milk, chocolate milk, or orange juice (preferably at room temperature). Use a glass container (cyclosporine will stick to plastics and Styrofoam). Stir well and drink at once. Refill the glass with the same beverage and drink this to make sure the whole dose was taken. The special syringe should be wiped with a clean towel after use and stored in the container provided.

WHAT TO DO IF YOU MISS A DOSE:

It is very important that your child not miss any doses of this medicine. If you forget a dose of this medicine and it is less than 4 hours late, give it as soon as you remember. However, if it is more than 4 hours late or almost time for your child's next dose, call your physician. Do NOT give double the dose to catch up. If your child misses more than one dose or if you have any questions concerning missed doses, please contact your child's doctor.

SIDE EFFECTS:

More common effects:

- nausea, vomiting, diarrhea, loss of appetite, or headache
- increase hair growth (especially on the face)
- tender or enlarged gums
- high blood pressure (especially if also taking prednisone)
- low magnesium levels in the blood
- kidney damage

Check with your doctor if any of the following side effects occur:

- Tingling of the hands or feet, tremors, blood in urine, yellowed eyes or skin

SPECIAL INSTRUCTIONS:

Do not store this medicine (liquid or capsules) in the refrigerator or in damp areas like the bathroom medicine cabinet.

Do not keep liquid cyclosporine for more than two months after opening the container.

Do not stop giving your child this medicine without being instructed to do so by your child's physician.

It is important to monitor how much cyclosporine is in your child's body. We will be testing your child's blood for drug levels. It is important that we measure levels just before a dose. Therefore, we will have you bring your child's dose of medicine with him/her to clinic and take it after his/her blood is drawn. If you do forget and give a dose, please let us know so we will not be alarmed when a high level is obtained.

If your child is seen by other physicians, it is very important for you to tell them your child is taking this medicine because there are many drugs that can interact with cyclosporine. Some drugs make the levels go too low which could lead to graft-versus-host disease. There are currently two different brand names for cyclosporine (Neoral[®] and Sandimmune[®]), it is extremely important for your child to not change between brands unless instructed to do so by your child's physician.

DOSAGE FORMS AVAILABLE:

Injectable

Capsules: 25mg, 100mg

Liquid: 100mg per 1ml

DAPSONE

(Avlosulfon[®])

TYPE OF MEDICATION AND HOW IT WORKS:

Dapsone is a medicine used to help prevent pneumonia (*Pneumocystis carinii*) in immunosuppressed patients that are allergic to sulfa medications.

HOW TO TAKE THIS MEDICATION:

While in the hospital, dapsone will be administered orally twice daily until 48 hours before the transplant. It will be restarted approximately 30 days after the transplant.

If taking this medication at home:

Give this medicine on a regular schedule as prescribed by your child's doctor.

Do not stop giving your child dapsone unless told to do so by your child's doctor.

If giving your child liquid dapsone, shake the bottle well and carefully measure with an oral syringe or medicine spoon.

WHAT TO DO IF YOU MISS A DOSE:

If your child misses a dose of this medication, give it as soon as you remember. However, if it is almost time for the next dose, skip the missed dose and go back to your regular dosing schedule.

Do NOT give double the dose to catch up.

SIDE EFFECT:

More common effects:

mild nausea or vomiting, loss of appetite, difficulty sleeping, excitability

Check with your doctor if any of the following side effects occur:

prolonged or severe nausea, vomiting, or stomach pain; blue coloring of skin, fingernails, or lips; ringing in ears; severe headache; difficulty seeing; yellowing of eyes or skin; skin rash

SPECIAL INSTRUCTIONS:

Dapsone may make your child's skin more sensitive to the sun. Dress your child in protective clothing and apply sunscreen with an SPF of 30 or greater.

Do not give your child this medicine if he/she is known to have a glucose-6-phosphate dehydrogenase (G-6-PD) deficiency.

DOSAGE FORMS AVAILABLE:

Tablets: 25mg, 100mg

DIPHENHYDRAMINE

(Benadryl[®])

TYPE OF MEDICATION AND HOW IT WORKS:

Diphenhydramine is a medication that can be used for multiple purposes. In the transplant setting, it is used most frequently to treat nausea and vomiting. It is also used to treat allergic reactions, alleviate side effects of blood product infusions or medication infusion reactions, or to help induce sleep.

HOW TO TAKE THIS MEDICATION:

While in the hospital, this medication is frequently given by injection. It is frequently used around the clock to help treat nausea or allergic reactions.

If taking this medication at home:

Give this medication only as prescribed by your child's doctor.

Give only the amount prescribed by your child's doctor.

If giving your child a liquid, carefully measure each dose using an oral syringe or medicine spoon.

WHAT TO DO IF YOU MISS A DOSE:

If your child misses a dose of this medication, give it as soon as you remember it. However, if it is almost time for the next dose, skip the missed dose and go back to your regular dosing schedule. Do NOT give double the dose to catch up. If two or more doses are missed, contact your child's doctor.

SIDE EFFECTS:

More common effects:

sedation; dizziness; paradoxical excitement (some children experience hyperactivity or excitability instead of calming or drowsy effects); fatigue; dry mouth

Check with your doctor if any of the following side effects occur:

agitation; nightmares; confusion or changes in behavior; skin rash or itching; difficulty breathing

SPECIAL INSTRUCTIONS:

May cause drowsiness and impair ability to perform hazardous activities which require mental alertness or physical coordination.

DOSAGE FORMS AVAILABLE:

Injectable: 50mg/ml (1ml)

Tablets: 12.5mg, 25mg, 50mg

Capsules: 25mg, 50mg

Elixir or syrup: 12.5mg/5ml

ERYTHROPOIETIN

(Epogen[®], Procrit[®])

TYPE OF MEDICATION AND HOW IT WORKS:

Erythropoietin is a medicine that stimulates production of new red blood cells to prevent or treat anemia.

HOW TO TAKE THIS MEDICATION:

Give this medicine on a regular schedule as prescribed by your child's doctor.

Follow the instructions you were given on how to give your child erythropoietin. Always wash your hands and clean the site for injection before preparing a dose. Use a new disposable syringe each time. Do not shake the bottle. Draw the medicine into the syringe and inject it subcutaneously (under the skin) as you were instructed. Dispose of the needle and syringe in a puncture-resistant container.

(Note: this medication may be prescribed to be given IV instead of subcutaneously)

WHAT TO DO IF YOU MISS A DOSE:

If your child misses a dose of this medication, give it as soon as you remember it. However, if it is almost time for the next dose, skip the missed dose and go back to your regular dosing schedule. Do NOT give double the dose to catch up. If two or more doses are missed, contact your child's doctor.

SIDE EFFECTS:

More common effects:

Pain at injection site; diarrhea; fever; chills; nausea; vomiting

Check with your doctor if any of the following side effects occur:

difficulty breathing; severe headache; muscle aches or pains; weakness; swelling of feet or ankles

SPECIAL INSTRUCTIONS:

Frequent blood tests are needed to determine the correct dose.

Store erythropoietin in the refrigerator. Do not freeze.

Do not shake vial.

DOSAGE FORMS AVAILABLE:

Injectable: 2,000 units (1ml); 3,000 units (1ml); 4,000 units (1ml); 10,000 units (1ml);
20,000 units (1ml)

FILGRASTIM

(G-CSF, Neupogen[®])

TYPE OF MEDICATION AND HOW IT WORKS:

Filgrastim is a medicine that will be used in some patients to try to stimulate certain blood cells to enter the circulation faster after being given chemotherapy. This is thought to decrease the time that you are without certain blood cells used to fight infections. It is also sometimes used in combination with other medicines (like ganciclovir and Septra[®]) that can cause blood counts to decrease.

HOW TO TAKE THIS MEDICATION:

This medicine will be infused through your child's central line catheter. Occasionally, it may be administered as a subcutaneous injection.

WHAT TO DO IF YOU MISS A DOSE:

If your child misses a dose of this medicine, give it as soon as you remember. However, if it is almost time for the next dose, skip the missed dose and go back to your regular dosing schedule. Do NOT give double the dose to catch up.

SIDE EFFECTS:

More common effects:

Lower back and hip pain

Check with your doctor if any of the following side effects occur: difficulty breathing, rash, severe low back pain not relieved by acetaminophen (Tylenol[®]).

SPECIAL INSTRUCTIONS:

Once filgrastim is discontinued, you can expect the ANC or neutrophil count to decrease by 50% within one to two days.

DOSAGE FORMS AVAILABLE:

Injectable 300mcg/ml and 480mcg/1.6ml

FLUCONAZOLE

(Diflucan[®])

TYPE OF MEDICATION AND HOW IT WORKS:

Fluconazole is a medicine used to help prevent or treat fungal infections (like candida).

HOW TO TAKE THIS MEDICATION:

While in the hospital, the fluconazole will be administered orally or by infusion into the central line catheter once a day. It will begin when admitted to the hospital and be discontinued approximately 60 days after transplant. If your child is taking cyclosporine and prednisone, he/she may have to continue to take this medicine longer.

If taking this medication at home:

Give tablets or liquid once a day as directed by your child's physician. If using liquid, shake well before use and use a specially marked measuring spoon to give the exact dose of the suspension.

This suspension must be refrigerated and expires in two weeks.

WHAT TO DO IF YOU MISS A DOSE:

If your child misses a dose of this medicine, give it as soon as you remember. However, if it is almost time for the next dose, skip the missed dose and go back to your regular dosing schedule. Do NOT give double the dose to catch up.

SIDE EFFECTS:

More common effect:

Diarrhea, nausea, vomiting, headaches, increased levels of liver function values

Check with your doctor if any of the following side effects occur:

If your child has diarrhea, nausea, or vomiting which is severe or lasts longer than a day and prevents him/her from eating or taking in fluids.

If your child develops a rash.

DOSAGE FORMS AVAILABLE:

Injectable

Suspension: 10mg per 1ml and 40mg per 1ml

Tablets: 50mg, 100mg, 150mg, 200mg

GANCICLOVIR

(Cytovene®)

TYPE OF MEDICATION AND HOW IT WORKS:

Ganciclovir is a medicine used to help prevent a virus (CMV – cytomegalovirus) from causing infections or to treat the CMV virus. This CMV virus can be more severe in a person who is taking immunosuppressive medications (prednisone, cyclosporine). It is believed that ganciclovir interferes with the virus so that it stops its activity.

HOW TO TAKE THIS MEDICATION:

Ganciclovir will be administered by infusion into the central line catheter once daily Monday through Fridays starting approximately 30 days after your child's stem cell transplantation if the virus is detected. It will be infused over one hour each day. If your child is being treated for an infection, the dose will initially be increased to every 12 hours, seven days a week.

WHAT TO DO IF YOU MISS A DOSE:

If your child misses a dose of this medicine, give it as soon as you remember. However, if it is almost time for the next dose, skip the missed dose and go back to your regular dosing schedule. Do NOT give double the dose to catch up.

SIDE EFFECTS:

More common effects:

- nausea, vomiting, diarrhea
- decreased blood counts (ANC)
- decreased kidney function

Check with your child's doctor if any of the following side effects occur:

- Rash, problems with infusion

SPECIAL INSTRUCTIONS:

Make sure your child drinks plenty of fluids to stay well hydrated while taking this medication. Blood counts will be closely monitored while your child is receiving this medicine. If his/her counts (ANC) decrease, he/she may be started on another medication called G-CSF (filgrastim) that will increase your child's counts.

Use gloves when handling this medicine to avoid direct contact with the skin. If contact with the skin does occur, wash thoroughly with soap and water. If contact is made with eyes, rinse the eyes thoroughly with plain water.

DOSAGE AVAILABLE:

Injectable

Capsules: 250mg (NOT recommended for use in transplant patients)

GRANISETRON

(Kytril®)

TYPE OF MEDICATION AND HOW IT WORKS:

Granisetron is a medication that prevents nausea and vomiting associated with cancer fighting drugs and total body irradiation (TBI). It has not been proven to help with nausea and vomiting caused by other drugs or circumstances, except immediately after surgery.

HOW TO TAKE THIS MEDICATION:

If used during TBI, granisetron tablets (or liquid) will be prescribed to be taken once or twice daily. If unable to tolerate medication by mouth, it will be administered by infusion into the central line catheter during the days of chemotherapy and continued for 24 hours after the last dose.

WHAT TO DO IF YOU MISS A DOSE:

If your child misses a dose of this medicine, give it as soon as you remember. However, if it is almost time for the next dose, skip the missed dose and go back to your regular dosing schedule. Do NOT give double the dose to catch up.

SIDE EFFECTS:

More common effects:

headache, constipation, diarrhea

DOSAGE FORMS AVAILABLE:

Injectable: 1mg per 1ml

Tablets: 1mg

Suspension: 200mcg per ml (specially prepared by Riley Pharmacy)

Note: Ondansetron (Zofran®) is a very similar medication that may be substituted for granisetron.

LISINOPRIL

(Prinivil[®], Zestril[®])

TYPE OF MEDICATION AND HOW IT WORKS:

Lisinopril is a medication used to lower blood pressure.

HOW TO TAKE THIS MEDICATION:

Give lisinopril on a regular schedule as prescribed by your child's doctor.

Do not stop giving your child lisinopril unless told to do so by your child's doctor.

Give this medicine at the same time every day.

WHAT TO DO IF YOU MISS A DOSE:

If your child misses a dose of this medicine, give it as soon as you remember. However, if it is almost time for the next dose, skip the missed dose and go back to your regular dosing schedule. Do NOT give double the dose to catch up. If two or more doses are missed, contact your child's doctor.

SIDE EFFECTS:

More common effects:

dizziness, lightheadedness (have your child get up slowly from lying down), headache, weakness, flushing (feeling of warmth), nausea, rash, edema

Check with your doctor if any of the following side effects occur:

prolonged dizziness; vomiting; swelling of face, lips, tongue or difficulty in breathing occurs; swelling of hands or feet

SPECIAL INSTRUCTIONS:

DOSAGE FORMS AVAILABLE:

Tablets: 2.5mg, 5mg, 10mg, 20mg, 40mg

Syrup: 2mg/ml (special formulation at Riley)

LORAZEPAM

(Ativan[®])

TYPE OF MEDICATION AND HOW IT WORKS:

Lorazepam is a medication that can be used for many purposes. In the transplant setting it is used for treating nausea and vomiting, reducing anxiety, and preventing or treating seizures.

HOW TO TAKE THIS MEDICATION:

While in the hospital, this medication is usually given by IV injection. If your child is receiving this medication frequently for a long period of time, the dose may need to be decreased slowly before stopping.

If taking this medication at home:

Give this medicine according to the schedule prescribed by your child's doctor.

Give only the amount prescribed.

Do not stop giving this medicine unless told to do so by your child's doctor. The dose may need to be decreased slowly before stopping.

If your child receives lorazepam on a regular schedule, give it at the same time every day.

WHAT TO DO IF YOU MISS A DOSE:

If your child misses a dose of this medicine, give it as soon as you remember. However, if it is almost time for the next dose, skip the missed dose and go back to your regular dosing schedule. Do NOT give double the dose to catch up. If two or more doses are missed, contact your child's doctor.

SIDE EFFECTS:

More common effects:

drowsiness; headache; dizziness; lack of coordination; diarrhea

Check with your doctor if any of the following side effects occur:

agitation; nightmares; confusion or changes in behavior; skin rash or itching; difficulty breathing

SPECIAL INSTRUCTIONS:

Oral solution and injectable dosage forms should be refrigerated. (Note: injectable form is stable at room temperature for 8 weeks)

May cause drowsiness and impair ability to perform hazardous activities which require mental alertness or physical coordination.

DOSAGE FORMS AVAILABLE:

Injectable: 2mg/ml (1ml, 10ml); 4mg/ml (1ml, 10ml)

Tablets: 0.5mg, 1mg, 2mg

Solution, oral concentrate: 2mg/ml (30ml)

MAGNESIUM

(Mag-Ox[®]; Phillips[®] Milk of Magnesia; Slow-Mag[®])

TYPE OF MEDICATION AND HOW IT WORKS:

Magnesium supplements are frequently required after transplant in patients receiving cyclosporine or tacrolimus therapy.

HOW TO TAKE THIS MEDICATION:

Give magnesium medication on a regular schedule as prescribed by your child's doctor.

Do not stop giving your child magnesium unless told to do so by your child's doctor.

Give this medicine at the same time every day.

WHAT TO DO IF YOU MISS A DOSE:

If your child misses a dose of this medicine, give it as soon as you remember. However, if it is almost time for the next dose, skip the missed dose and go back to your regular dosing schedule. Do NOT give double the dose to catch up. If two or more doses are missed, contact your child's doctor.

SIDE EFFECTS:

More common effects:

diarrhea; abdominal cramps

Check with your doctor if any of the following side effects occur: rash, difficulty breathing

SPECIAL INSTRUCTIONS:

DOSAGE FORMS AVAILABLE:

Injectable: (sulfate)- 500mg/ml (4mEq/ml)

Tablets: (oxide) 400mg; (lactate) 7mEq/tablet (84mg elemental Mg)

Suspension: 500mg/ml

MORPHINE

(MS Contin[®], MS-IR[®], Oramorph SR[®], Roxanol[®], Roxanol SR[®])

TYPE OF MEDICATION AND HOW IT WORKS:

Morphine is a medication used to relieve moderate or severe pain.

HOW TO TAKE THIS MEDICATION:

While in the hospital, this medication is given by IV injection. It is frequently used as a continuous infusion of medication into the central line and the dose is increased as needed to control pain. Extra bolus doses can be given as needed to help with pain control. This medication may be administered by a method called “PCA” (patient controlled administration), where extra doses can be controlled by your child.

If taking this medication at home:

Give this medicine on a regular schedule as prescribed by your child’s doctor.

If you have been giving your child morphine on a regular schedule, do not stop giving it unless told to do so by your child’s doctor. The dose may need to be lowered slowly before stopping.

If giving your child liquid morphine, carefully measure each dose with an oral syringe or medicine spoon.

If giving your child controlled-release (long-acting) morphine tablets, do not crush them or allow your child to chew them.

Morphine can be given with food or milk to prevent stomach upset.

WHAT TO DO IF YOU MISS A DOSE:

If instructed to give your child morphine on a regular schedule and you miss a dose, give it as soon as you remember it. However, if it is almost time for the next dose, skip the missed dose and go back to the regular dosing schedule. Do NOT give double the dose to catch up. If two or more doses are missed, contact your child’s doctor.

SIDE EFFECTS:

More common effects:

nausea; vomiting; constipation (to avoid constipation, increase fluids and fiber in your child’s diet, or use a stool softener medicine); drowsiness; dizziness; difficulty urinating

Check with your doctor if any of the following side effects occur:

difficulty breathing; increased pain; diarrhea; shakiness and sweating; rash; excessive drowsiness

SPECIAL INSTRUCTIONS:

Contact your child’s doctor if you give your child too much medicine.

Do not give this medicine if your child is allergic to morphine.

This medicine may make your child drowsy. Watch carefully if your child is performing a task requiring alertness, such as climbing stairs.

Do not give this medication at the same time with other medications that may cause drowsiness (example: lorazepam, diphenhydramine) without discussing this with your child’s doctor.

If your child requires this medicine for a long period of time, the dose may need to be slowly decreased and not stopped quickly.

Be sure to know the if form of morphine being used is immediate release (provides relief quickly and only lasts for a couple of hours) or sustained release (provides relief for longer period of time – frequently either 8 or 12 hours). Frequently, sustained release products are given on a scheduled basis with immediate release products being used for “break through” pain (pain not

controlled by the sustained released (long acting) product).

DOSAGE FORMS AVAILABLE:

Injectable: multiple sizes available

Tablets: Controlled or Sustained Release: 15mg, 30mg, 60mg, 100mg

Immediate release: 15mg, 30mg

Soluble: 10mg

Solution: 10mg/5ml, 20mg/5ml, or 20mg/ml (check concentration)

MYCOPHENOLATE

(CellCept[®])

TYPE OF MEDICATION AND HOW IT WORKS:

Mycophenolate is an immunosuppressive agent that helps suppress cells in the body so that the new stem cells being placed in the body are not attacked and killed but are allowed to survive and grow. Therefore, it is used to help prevent graft-versus-host disease (GVHD). While taking this medication, your child will be more susceptible to infections.

HOW TO TAKE THIS MEDICATION:

Give this medicine on a regular schedule as prescribed by your child's doctor.

Give your child his/her mycophenolate dose at the same time each day. Time of administration is extremely important with this medicine.

Do not stop giving your child mycophenolate unless told to do so by your child's doctor.

If giving your child a liquid, shake the bottle well and carefully measure each dose with an oral syringe or medicine spoon.

Mycophenolate should be given on an empty stomach, 1 hour before or 2 hours after a meal.

WHAT TO DO IF YOU MISS A DOSE:

It is very important that your child not miss any doses of this medication. If you forget to give your child a dose of mycophenolate and it is less than 4 hours late, give it as soon as you remember. However, if it is more than 4 hours late or almost time for your child's next dose, call the transplant physician-on-call. Do NOT give double the dose to catch up. If your child misses more than one dose or you have any questions concerning missed doses, please contact your child's physician.

SIDE EFFECTS:

More common effects:

tremor; weakness; headache; nausea; vomiting; diarrhea

Check with your doctor if any of the following side effects occur:

fever; chills; yellowing of the eyes or skin; tingling or numbness of hands or feet; tremor; skin rash; itching; difficulty breathing; difficulty urinating or decreased urination

SPECIAL INSTRUCTIONS:

Do not have your child immunized (vaccinated) until you have checked with your child's transplant doctor. Also contact the transplant doctor before other members of the family receive immunizations.

DOSAGE FORMS AVAILABLE:

Injectable: 500mg

Tablets: 500mg

Capsules: 250mg

Suspension: 50mg/ml

NIFEDIPINE

(Procardia[®], Adalat[®])

TYPE OF MEDICATION AND HOW IT WORKS:

Nifedipine lowers blood pressure.

HOW TO TAKE MEDICATION:

Give nifedipine as directed by your child's physician. Capsules and tablets should be swallowed whole. If doses less than 10mg are prescribed, special instructions will be given for using a needle and syringe to withdraw the liquid contents of the capsules for use by mouth.

WHAT TO DO IF YOU MISS A DOSE:

If your child misses a dose of this medicine, give it as soon as you remember. However, if it is almost time for the next dose, skip the missed dose and go back to your regular dosing schedule. Do NOT give double the dose to catch up.

SIDE EFFECTS:

More common effects:

headache, dizziness, lightheadedness, flushing

Check with your doctor if any of the following side effects occur:

prolonged dizziness, irregular heartbeat, shortness of breath, swelling of hands or feet

SPECIAL INSTRUCTIONS:

If your child has been given a short acting capsule it must be taken three or four times a day or if he/she is prescribed a long acting tablet it only needs to be taken once or twice daily. Do NOT crush or break long acting tablets. It is very common to have an empty tablet appear in stools. Avoid getting up from a lying or sitting position too quickly because dizziness, lightheadedness or fainting may occur.

DOSAGE FORMS AVAILABLE:

Capsules: 10mg and 20mg

Tablets (long acting): 30mg, 60mg, 90mg (usually contains notation of XL or CC after strength)

OXYCODONE

(Roxicodone[®], OxyIR[®], OxyContin[®])

TYPE OF MEDICATION AND HOW IT WORKS:

Oxycodone is a medication used to relieve moderate or severe pain.

HOW TO TAKE THIS MEDICATION:

Give this medicine on a regular schedule as prescribed by your child's doctor.

If you have been giving your child oxycodone on a regular schedule, do not stop giving it unless told to do so by your child's doctor. The dose may need to be lowered slowly before stopping.

If giving your child liquid oxycodone, carefully measure each dose with an oral syringe or medicine spoon.

If giving your child controlled-release (long acting) oxycodone tablets, do not crush them or allow your child to chew them.

Oxycodone can be given with food or milk to prevent stomach upset.

WHAT TO DO IF YOU MISS A DOSE:

If instructed to give your child oxycodone on a regular schedule and you miss a dose, give it as soon as you remember it. However, if it is almost time for the next dose, skip the missed dose and go back to the regular dosing schedule. Do NOT give double the dose to catch up. If two or more doses are missed, contact your child's doctor.

SIDE EFFECTS:

More common effects:

nausea; vomiting; constipation (to avoid constipation, increase fluids and fiber in your child's diet, or use a stool softener medicine); drowsiness; dizziness; difficulty urinating

Check with your doctor if any of the following side effects occur:

difficulty breathing; increased pain; diarrhea; shakiness and sweating; rash; excessive drowsiness

SPECIAL INSTRUCTIONS:

Contact your doctor if you give your child too much medicine.

Do not give this medicine if your child is allergic to oxycodone.

This medicine may make your child drowsy. Watch carefully if your child is performing a task requiring alertness, such as climbing stairs.

Do not give this medication at the same time with other medications that may cause drowsiness (example: lorazepam, diphenhydramine) without discussing this with your doctor.

If your child requires this medicine for a long period of time, the dose may need to be slowly decreased and not stopped quickly.

Be sure to know if the form of oxycodone being used is immediate release (provides relief quickly and only lasts for a couple of hours) or is sustained release (provides relief for longer period of time- frequently either 8 or 12 hours). Frequently, sustained release products are given on a scheduled basis with immediate release products being used for "break through" pain (pain not controlled by the sustained release (long acting) product).

There are several products that contain oxycodone in combination with acetaminophen (Tylenol[®]). Care must be taken to make sure the safe dose of acetaminophen is not exceeded if these products are being utilized (examples: Percocet[®], Roxicet[®], Tylox[®])

DOSAGE FORMS AVAILABLE:

Tablets: Controlled or Sustained Release: 10mg, 20mg, 40mg, 80mg, 160mg
Immediate Release: 5mg, 15mg, 30mg
Liquid, concentrate: 20mg/ml

PENTAMIDINE

(Pentam)

TYPE OF MEDICATION AND HOW IT WORKS:

Pentamidine is a medicine used to help prevent pneumonia (*Pneumocystis carinii*) in immunosuppressed patients that are allergic to sulfa medications.

HOW TO TAKE THIS MEDICATION:

Pentamidine will be given by IV injection while in the hospital or in the outpatient clinic. If a patient is unable to tolerate the IV injection, the medication may be administered by respiratory therapy as a breathing treatment. Several doses will be administered 48 hours or more before the transplant and then will restart at approximately 30 days after the transplant. An IV dose will be administered every 3 weeks to provide protection against PCP pneumonia.

SIDE EFFECTS:

More common effects:

decreased blood pressure; rash; decreased blood sugar; metallic taste; coughing; nausea

Check with your doctor if any of the following side effects occur:

difficulty breathing; rash

SPECIAL INSTRUCTIONS:

DOSAGE FORMS AVAILABLE:

Injectable: 300mg

PREDNISONE, PREDNISOLONE, METHYLPREDNISOLONE

(Deltasone[®], Prelone[®], Solu-Medrol[®])

TYPE OF MEDICATION AND HOW IT WORKS:

Prednisone, prednisolone, and methylprednisolone are called corticosteroids. They are similar to a natural hormone produced by your body. They can be used for many different reasons. Some examples include: relief of inflammation (swelling, heat, redness, and pain); treatment of certain forms of arthritis and skin, blood, kidney, eye, thyroid, and intestinal disorders; treatment of certain types of cancer; severe allergies; and asthma. In relationship to stem cell transplant, your child will receive it to try to prevent graft-versus-host disease (GVHD), to destroy cancer cells, or to try to help alleviate side effects of some drugs.

HOW TO TAKE THIS MEDICATION:

While in the hospital, this drug may be infused into the central line catheter once or twice daily.

If taking this medication at home:

Give the tablets or liquid as directed by your child's physician. It is recommended that this medicine be taken with food or milk to try to alleviate stomach upset. If using liquid, use a specially marked measuring spoon or syringe to give the exact dose ordered

WHAT TO DO IF YOU MISS A DOSE:

If your child misses a dose of this medicine, give it as soon as you remember. However, if you only give one dose a day and it is almost time for the next dose, skip the missed dose and go back to your regular dosing schedule. If you usually give more than one dose a day, give the missed dose as soon as you remember it; then give any remaining doses for that day at evenly spaced intervals. If you remember a missed dose when it is time for you to give another, you may give both doses at one time.

SIDE EFFECTS:

More common effects:

nausea, vomiting, stomach irritation, anxiety, behavior changes, unusual mood swings, thinned skin, increased sweating, weight gain, increased appetite, swollen feet and ankles, "moonface", increased blood pressure, brittle bones

Check with your doctor if any of the following side effects occur:

unusual weight gain, swelling of the lower extremities, muscle weakness, black tarry stools, prolonged sore throat, fever, cold or infections.

SPECIAL INSTRUCTIONS:

Inform any physician or dentist your child sees that he/she is taking prednisone.

Your child's physician may suggest a low-sodium, low-salt diet to help your body with fluid retention.

Do NOT abruptly stop giving this medicine. A "taper" schedule (decreasing dose) will be provided to instruct you on how to gradually discontinue therapy.

If prednisone is being used together with cyclosporine, there is an increased chance that your child will develop high blood pressure. This may require that blood pressure medicines be used until the doses of one or both drugs are decreased and your child's blood pressure returns to normal.

DOSAGE FORMS AVAILABLE:

Injectable

Solution: prednisone = 5mg per 1ml; prednisolone = 15mg per 5ml

Tablets: prednisone = 1mg, 2.5mg, 5mg, 10mg, 20mg, 50mg

methylprednisolone = 4mg, 16mg, 32mg

TACROLIMUS

(Prograf[®], FK506)

TYPE OF MEDICATION AND HOW IT WORKS:

Tacrolimus is an immunosuppressive agent that helps suppress cells in the body so that the new stem cells being placed in the body are not attacked and killed but are allowed to survive and grow. Therefore, it is used to help prevent graft-versus-host disease (GVHD). While taking this medication, your child will be more susceptible to infections.

HOW TO TAKE THIS MEDICATION:

Give this medicine on a regular schedule as prescribed by your child's doctor.

Give your child his/her tacrolimus dose at the same time each day. Time of administration is extremely important with this medicine.

Do not stop giving your child tacrolimus unless told to do so by your child's doctor.

If giving your child a liquid, shake the bottle well and carefully measure each dose with an oral syringe or medicine spoon.

Tacrolimus should be given on an empty stomach, 1 hour before or 2 hours after a meal.

WHAT TO DO IF YOU MISS A DOSE:

It is very important that your child not miss any doses of this medication. If you forget to give your child a dose of tacrolimus and it is less than 4 hours late, give it as soon as you remember. However, if it is more than 4 hours late or almost time for your child's next dose, call the transplant physician-on-call. Do NOT give double the dose to catch up. If your child misses more than one dose or if you have any questions concerning missed doses, please contact your child's physician.

SIDE EFFECTS:

More common effects: tremor; weakness; headache; nausea; vomiting; diarrhea

Check with your child's doctor if any of the following side effects occur:

fever; chills; yellowing of eyes or skin; tingling or numbness of hands or feet; tremor; skin rash; itching; difficulty breathing; difficulty urinating or decreased urination

SPECIAL INSTRUCTIONS:

Your child will need to have blood samples taken to adjust the dose and make sure that tacrolimus is not causing serious side effects.

Do not give your child any other medicines, including over-the-counter medicines, until you have checked with your child's doctor or pharmacist.

Do not have your child immunized (vaccinated) until you have checked with your child's transplant doctor. Also contact the transplant doctor before other members of the family receive immunizations.

DOSAGE FORMS AVAILABLE:

Injectable: 5mg/ml (1ml)

Capsules: 1mg, 5mg

Suspension: 0.5mg/ml

TRIMETHOPRIM/SULFAMETHOXAZOLE **(Bactrim[®], Septra[®], Co-Trimoxazole, Trim/Sulfa)**

TYPE OF MEDICATION AND HOW IT WORKS:

Bactrim[®] or Septra[®] is a medicine used to help prevent pneumonia (*Pneumocystis carinii*) in immunosuppressed patients. It is also used in the treatment of a variety of infections such as urinary tract infections, ear infections, etc.

HOW TO TAKE THIS MEDICATION:

While in the hospital, Bactrim[®] will be administered orally twice daily until 48 hours before the transplant. It will be restarted approximately 30 days after the transplant IF the blood counts are high enough. After transplant the medication will be administered twice a day on Mondays, Tuesdays and Wednesdays only.

If taking this medication at home:

Give tablets or liquid as directed by your child's doctor. If using liquid, shake well before use and use a specially marked measuring spoon to give the exact dose of the suspension.

WHAT TO DO IF YOU MISS A DOSE:

If your child misses a dose of this medicine, give it as soon as you remember. However, if it is almost time for your child's next dose, skip the missed dose and go back to your regular dosing schedule. Do NOT give double the dose to catch up.

SIDE EFFECTS:

More common effects: nausea, vomiting, diarrhea, loss of appetite, rash

Check with your doctor if any of the following side effects occur:

If your child experiences difficulty breathing, wheezing, itching, hives, difficulty swallowing, pale skin, yellowing of skin or eyes-CONTACT YOUR DOCTOR IMMEDIATELY.

If your child has diarrhea, nausea, or vomiting which is severe or lasts longer than a day and prevents him/her from eating or taking fluids.

If you develop a rash.

SPECIAL INSTRUCTIONS:

Make sure your child drinks an increased amount of fluids to stay well hydrated while taking this medication. He/she should drink a full glass of water with each dose.

Apply sunblock with an SPF of 30 or greater and dress in protective clothing (hat and sunglasses) if you are going to be outside, even for a short period of time.

DOSAGE FORMS AVAILABLE:

Injectable

Suspension: Sulfamethoxazole 200mg and trimethoprim 40mg per 5ml

Tablets: Sulfamethoxazole 400mg and trimethoprim 80mg.

Tablet, double strength: Sulfamethoxazole 800mg and trimethoprim 160mg.

MEDICATION LIST

PATIENT NAME:_____

Dates														
Medication	Directions	Times												

PATIENT

MEDICATION LIST

[illegible]

PREDNISONE TAPER SCHEDULE

Patient: _____

Date:_____

[illegible]

INFORMED CONSENT

The informed consent process is a very important one which starts at the time of your initial consult/meeting with the Stem Cell Transplant physician to discuss the possibility of transplant for you/your child. After you have had the initial transplant conference with a Stem Cell Transplant physician, pre transplant work-up testing has been completed and you/your child have been determined to be medically able to proceed to transplant, your coordinator will contact you to schedule a consent conference meeting.

During the consent conference, your doctor will review with you the treatment plan for you/your child and describe the potential risks and benefits of following this plan. Alternative methods of therapy should also be described to you/your child. We know it is not uncommon for families to have a difficult time absorbing all of this information, which is why this consent conference typically happens separately from the initial consult (sometimes called the “101 meeting”). Feel free to ask your doctor to repeat or further explain anything that you don’t understand. Whenever possible your coordinator will provide a copy of the consents to you before the meeting so you will have a chance to read through them prior to the meeting and think about any questions you might have. She will also provide a copy of the Caregiver Agreement, which will also be signed at the consent conference. Please be aware that signing an informed consent does not bind you/your child to a specific therapy. It does mean you (if age 18 or older) or the child’s parent/legal guardian(s) have understood the information provided about the upcoming therapy.

If your child is 10 years of age or older, he or she will have the opportunity to participate in the consent conference and sign an assent form. By signing this form, your child is stating that he/she understands and agrees to undergo the therapy but is not a legal consent.

DISCHARGE PLANNING

PREPARING FOR DISCHARGE

Discharge planning and teaching begins before you/your child is admitted to the hospital! We will encourage you to remain very involved in your child's care throughout his/her hospitalization, and this will be especially important in this phase. Transition from the hospital to the Ronald McDonald House/local housing or home can be an exciting but stressful time. The goal of discharge planning is to ensure that you are ready to care for your child at home. Some of the important aspects of discharge planning are discussed below.

If you live outside of the Indianapolis area, we may recommend that you/your child stay at the Ronald McDonald House or other local housing for a period of time. Our social work team will arrange for an apartment type suite for you/your child in a somewhat protected environment. It is important to note that an adult will be required to remain with the patient at all times. The time you will need to stay in Indianapolis before returning home will be dependent upon your child's health needs. The out-patient physician and nurse practitioner/physician's assistant will discuss the timing of discharge from the local Indianapolis housing to home.

Reasons why you/you and your child may need to stay locally before heading home may include the following:

- You/your child will need to come to clinic 2-3 times a week for the first few weeks after being discharged from the hospital. Driving long distances multiple times a week can make this difficult. Staying locally makes it an easier process.
- You may need additional time to learn a particular aspect of care for you/your child before going home.
- Your home is not prepared for you/your child to return home after transplant.

ORAL HYGIENE

As a result of total body irradiation (TBI) and chemotherapy, the glands that make saliva are not able to effectively wash bacteria from the mouth. This increases the patient's risk of developing infections and/or cavities. Fluoride treatments as well as special hygienic measures are used to prevent oral and dental infections.

Mouth Care:

If your child's WBC is greater than 1500 and the platelet count is greater than 50,000, use a soft nylon toothbrush to clean the teeth; otherwise use toothettes to gently swab the teeth, tongue and gums. Mouth care should be done at least twice a day; three times a day is ideal. If your child is resistant to this care, please remember that the most important time to care for the mouth is at bedtime, so that food and other debris is not in the mouth overnight. For children over 12 years of age, with a WBC greater than 1500 and a platelet count greater than 50,000, use dental floss only when instructed by your physicians.

A product called Peridex is used for mouth care twice daily. If mouth care is done more frequently please use sterile water or saline.

Fluoride Treatments:

Use a fluoride supplement (ie: ACT, Fluoridgard) as prescribed every day to prevent tooth decay. This should only be used once daily, at bedtime.

Mouthwash:

Do not use commercial mouthwash or hydrogen peroxide, as these products dry out mucous membranes. You may cleanse the mouth with saline rinses (1/2 teaspoon salt plus 1/2 teaspoon baking soda in 8 oz of water).

Use of Mycelex or Nystatin:

These medications will be prescribed for your child if there is a positive yeast culture from the nose, mouth or throat. If there is not a positive culture, these medications may not be needed. Using Fluconazole will reduce the incidence of fungal infections because it fights growth of yeast in the GI tract. Your doctor will tell you when to stop using Fluconazole. In general, you will continue on Fluconazole until day 60 if you received an autologous transplant or until your child is off immune suppression if an allogeneic transplant.

Dental Checkups:

Because all transplant patients are at risk of developing infections, they should avoid having extensive dental work (such as tooth extractions, fillings, and orthodontia) done by a local dentist without first consulting us. The dentist at the transplant center will be consulted for any extensive dental work. It is important for the patient to have regular dental follow-up appointments; however, please

consult the transplant physician prior to seeing the dentist. Routine dental visits should start 1 year after discharge and twice yearly thereafter.

Your child will need prophylactic (preventive) antibiotics for dental procedures as long as he/she has a central or PICC line, or is on immune suppressing medications.

PERSONAL HYGIENE

As a patient on the SCT unit, your child should be accustomed to having a daily bath. This practice should be continued when you go home. The skin is the body's first line of defense against infections, so keeping it clean and healthy is essential.

Bathe daily

Use regular tap water and an antibacterial soap (i.e., Dial or Zest). For sensitive or severely dry skin, use Dove or other mild hypoallergenic soap. Alpha-Keri in the bath water is fine. Be sure to protect your central line dressing by carefully covering it during bath time, and change it immediately if it becomes damp.

Lotions

Apply daily after the bath. Avoid use of heavily scented or colored (dyed) lotions. Brands labeled "hypoallergenic" are best (i.e., Eucerin, Lubriderm, or Keri-lotion). Sunscreen (SPF 30) should always be applied whenever spending time outdoors—even in the winter-time. Always wear a hat and spend only short periods of time in direct sunlight during “off” hours (before 10:00 a.m. or after 2:00 p.m.).

Deodorant

May be used. Roll-ons or stick are preferred over sprays. The patient should use their own personal supply.

Cosmetics

May be used if labeled hypoallergenic and tested for skin sensitivity before applying to large areas of skin. Products can be tested by placing a small amount on the inside area of the arm and observing the skin for any redness or itching within 24 hours of application. Use only new unopened products and do not share your supply with other family members. Be sure to remove all cosmetics every night.

Avoid use of astringents and commercial mouthwashes. Both cause severe drying of the skin and mucosal surfaces. Talcum powders should not be used as they can harbor fungus.

Clothing

All clothing, including socks and underwear, should be changed daily and laundered between uses. Avoid laundering patient's clothing with other heavily soiled items, or with items stained with chemicals or soilage from animals.

Towels

Should be used only by the patient and allowed to dry thoroughly between uses. Launder at least 2 times a week.

NUTRITION

Good nutrition is very important for your child's continued recovery. Please refer to the following nutritional guidelines prepared by the dietitians of Riley Hospital. Autologous transplant patients should follow these for several months after transplant. Allogeneic patients should follow them until they are off all immunosuppressive therapy, including cyclosporine, prednisone and methylprednisolone. The transplant team will determine when these guidelines are no longer necessary.

Nutritional support:

Many children do not wish to eat for weeks or even months after a transplant, even when presented with their favorite foods. Your child may experience a change in taste of many foods due to the chemotherapy and/or radiation the child received. Children's food preferences are much more pronounced than adults, which is complicated by the restrictions imposed in the diet after transplant. Some suggestions to get your child to eat include:

- make sure your child has company at mealtime to make this time more enjoyable
- encourage small, frequent meals (5-7 per day)
- make the meal more pleasing by serving brightly colored foods, using brightly colored utensils, straws, etc.
- serve food chilled, taste abnormalities are less noticeable in cold foods
- allow your child to have some control in the food he or she eats -- allow your child to choose foods from a select menu
- use spices or sauces to enhance the taste of the food being served.

Because nutritional status is a major factor in the recovery after transplant, it is imperative that the child receive the required daily nutrients and calories she/he needs. Often, children are sent home on hyperalimentation, a special mix of nutrients and fats given through the central line catheter. This may be needed for the first one to two weeks after the child is discharged from the hospital. If needed, a home health nurse may come to your home to assist you.

Calorie counts:

You may be asked to keep a record of everything your child eats and drinks each day when you first go home. This is so your doctor and other health care providers can track how much your child is taking in nutritionally. This is especially important if your child is receiving hyperalimentation, so that adjustments can be made to best suit your child's needs. You will also find a blank page in this section so that you may write down any questions you have concerning your child's diet and bring them with you to clinic visits.

Drinking water:

Generally speaking, water from your faucet is considered safe if your water is from a city water supplier serving highly populated areas. However, if you drink tap water (water from your faucet), be sure to watch for any media reports in your area regarding water contamination concerns. During these times, you will need to boil water (usually for 15-20 minutes) before consuming.

Bottled water may also be consumed as long as it is processed in one of the following three ways: 1) reverse osmosis, 2) distilled, 3) filtered through a filter with an absolute pore size of 1 micron or smaller (NSF Standard 53). Most bottled waters will list their processing information on each bottle. LOOK for this information before drinking. If it is not on the bottle, it probably has not been done! You can usually also find this information on the company's website.

Well water is NOT considered safe for consumption by immunosuppressed people who are at risk for infection. Common home water filtration devices do not remove bacteria and viruses, so this is still NOT considered safe. Whenever you have concerns about the quality of your water at home, water can be made safe by bringing tap water to a rolling boil for 15-20 minutes before consuming.

SAFE FOOD HANDLING GUIDELINES FOR RILEY CHILDREN'S CENTER FOR BLOOD DISEASES AND CANCER

We follow the “safe food handling general diet” guidelines and no longer have a specific “neutropenic diet” or “low bacteria diet”. These safe food handling general diet guidelines are as follows:

Foods to avoid at home and in restaurants:

- Raw and undercooked meats and fish (like sushi)
- Cold smoked fish (salted/brined and then smoked at low temperature, like lox)
- Aged cheeses such as brie, Roquefort, bleu
- Raw or unpasteurized dairy products and unpasteurized fruit and vegetable juices
- Raw and undercooked eggs
- Refrigerated salad dressings and sauces that contain raw/undercooked eggs (like Caesar dressing)
- Raw miso products or tofu
- Raw seeds, nuts and grains
- Unpacked items that sit out in open bins
- Herbal and non-traditional supplements
- Reference: Trefilio S. et al, Biol Blood Marrow Transplant 18:1385-1390, 2012.

Restaurant food guidelines:

- AVOID buffets, salad bars, and places where food can sit out for a long time, even if chilled (like deli counters and sandwich shops) – if food sits out, bacteria can grow.
- Go to restaurants that are busy. The food is less likely to sit out waiting to be ordered or eaten.
- Ask that food be made to order for you/your child. This way it will not sit around and have the chance to grow germs. If the restaurant is too busy to make your food to order, come back later or eat somewhere else.
- Ask that foods be fully cooked. Send it back if it looks undercooked.
- Use your common sense. If the restaurant and staff do not look clean, don't eat there.
- Carry-out food should be either eaten or refrigerated within one hour of purchase.
- *Stem cell transplant patients may have carry-out food that follows the above rules, but should not go to restaurants while in isolation from crowds after transplant. Talk to your doctor or nurse practitioner about isolation rules and ask when it will be safe for you to go to restaurants again.*

Safe food handling guidelines:

- **WASH YOUR HANDS before, during and after preparing food and before eating.**
- Use separate utensils and plates for cooked and uncooked foods.
- Keep hot foods hot (above 140 °F) and cold foods cold (below 40 °F). If food is left out at room temperature for more than an hour, throw it away. This includes milk, juice and soda.
- Put leftovers in the refrigerator right away. Heat leftovers completely before eating. Throw away leftovers after 24 hours.
- Pour foods out of packages instead of sticking your hand in the package. Store packaged foods in zip-lock plastic bags.
- Do not use food from cans or jars that are dented, cracked or have swollen lids. Wipe can lids off with a soapy cloth then rinse with warm water before opening.
- At home, wash dish towels, dish cloths and sponges often. They carry germs.
- Watch the news. Don't eat any “trouble” foods based on Centers for Disease Control (CDC) reports and news releases..

For more safe food handling tips, visit www.fightbac.org

FOOD SAFETY GUIDELINES

Personal Hygiene:

Wash hands with soap and warm, running water before and after any food preparation. Wash hands before eating, and after using the toilet, smoking, diapering, sneezing, touching pets, or handling garbage.

Proper hand washing requires at least 20 seconds of working the soap into the hands, including the fingernail area and in between fingers. Rinse with warm running water. Use paper towels for drying hands.

Equipment:

All food preparation equipment must start out clean and stay clean throughout the preparation process.

Use separate cutting boards for cooked foods and raw foods. Use separate cutting boards for poultry and other meats and one for vegetables and fruits. Sanitize daily by rinsing in a solution of ¼ cup bleach in 4 cups water (1 tablespoon bleach to 1 cup water for small jobs). Boards should be washed with warm water and soap between cutting different food items.

Use clean utensils each time and wash them with soap and warm water after each use. Sanitize cutting boards, knives, counter tops, blender, mixer blades, and can openers weekly as above.

Keep refrigerator clean and at the correct temperature (refrigerator: no warmer than 40°F; freezer: no more than 0°F). Clean up spills immediately; sanitize shelves and door regularly. Keep uncooked food on shelves **below** cooked /ready to eat foods whenever possible.

Towels and dish cloths can harbor bacteria. Change them daily. Throw out dirty sponges and replace weekly.

Shopping:

The first step in safe-food practice is to buy quality foods.

As you shop:

- Make sure frozen foods feel solid and refrigerated foods cold.
- Carefully read the “sell by” date (how long the grocer can keep the product for sale on the shelf) and “use by” date (how long the product is at its best eating quality).
- Make frozen and refrigerated foods your last purchase, especially during the summer months.
- Don’t buy cracked or unrefrigerated eggs.
- Take groceries home and store them promptly.

Storage:

Keep the cupboard and pantry clean, dry, dark and cool. Ideally, keep temperature between 50-70°F. High temperatures (over 100°F) are harmful to canned goods.

Rotate stock so that older items are used first (pantry, refrigerator and freezer).

When you refrigerate or freeze:

- Leave food in store wrapping unless the wrap is torn.
- Keep all foods wrapped or in sealed storage containers.
- Store foods in small portions in shallow containers for faster cooling.
- Be sure to label and date each container before freezing
- Discard foods with mold or those past the expiration dates.

Food Preparation:

Thaw meat, fish or poultry in the refrigerator and in a dish to catch drips.

Wash tops of canned goods before opening.

Do not taste the food with the same utensil used for stirring.

Cook meats until well done (gray or brown with no pink remaining).

Wash fruits and vegetables thoroughly under running water and then peel and cut or cook.

Never taste food that looks or smells strange.

When cooking or heating foods in the microwave oven, use a lid or vented plastic wrap for thorough heating; stir and rotate several times for even cooking.

Eggs:

Foods that contain raw or lightly cooked eggs should be prepared with caution. Commercial products of this type are safe, since they use pasteurized eggs, and the pasteurization kills bacteria.

Discard eggs and egg dishes left at room temperature for more than one hour.

Serve cooked eggs and egg-rich foods hot, immediately after cooking, or refrigerate them at once for serving later. Use them within 3-4 days.

Use grade AA or A eggs with clean, uncracked shells. Refrigerate them in the original carton at a temperature no higher than 40°F.

Use raw shell eggs within 5 weeks. Wash your hands after handling eggs. And be sure to clean blenders and other appliances and utensils after they come in contact with raw eggs and before they are used for anything else.

During Easter holidays use plastic eggs instead of hard-boiled eggs.

Dining Out:

Go early to avoid crowds. Ask to sit away from other parties in a high-back booth.

In fast food restaurants, request that food be prepared fresh and without the trimmings (such as raw vegetables, mayonnaise, etc.).

Use single serving condiments when possible.

Be cautious about salad bars, deli's, smorgasbords and buffets, side-walk vendors, pot luck meals, foods cooked in a crock pot, soft serve ice cream, milkshake, or yogurt machines.

Avoid foods that have been sitting under warming lights.

INFECTION

Most stem cell transplant patients have been prepared for transplant with a preparative regimen (chemotherapy and/or radiation) that causes a period of severe immune suppression. Infections during the first three months post-transplant can be caused by bacteria, fungus, or viruses and are the most common complication during this phase of recovery. Immune function gradually returns between six to 24 months post-transplant. Immune recovery can be very delayed in patients who received T-depleted marrow transplants, cord blood transplants, or patients who develop chronic graft versus host disease requiring prolonged use of immunosuppressive drugs (i.e., Prednisone®, Cyclosporine®).

Readmission to the hospital for infections following initial discharge from transplant is very common.

Herpes zoster (shingles) occurs in nearly half of all post-transplant patients and requires treatment with an IV drug called Acyclovir. Other common viruses include CMV, herpes simplex, and adenovirus. Many different bacterial infections can occur, but they are most commonly associated with the central line. Treatment of central line infections requires IV antibiotics and possible removal of the central line.

Signs and Symptoms of Infection:

- fever of 100°F (38°C) or higher
- flushed skin, sweating, or shaking chills (especially after flushing or infusing through the central line)
- redness, swelling or tenderness of the central line site
- blurred vision
- burning or frequency of urination
- rectal pain
- blisters or sores in the mouth or on the skin

You should immediately contact your medical team for any fever or other signs/symptoms of illness!

Infection Prevention:

WASH HANDS! WASH HANDS! WASH HANDS! WASH HANDS!

The Center for Disease Control (CDC) recommends that children who have had a stem cell transplant should be supervised by an adult during hand washing to ensure adequate cleaning. Hand washing should be performed using an antimicrobial soap and water. If no soap or water is available, use of hygienic hand sanitizers are acceptable.

- Follow discharge guidelines for central line care, oral and personal hygiene, diet and care of the home environment.

- Patient contact should be limited to family members living in the patient's home until day 100 post-transplant. A mask must be worn for any contact with non family members and anytime when you are out of the home.
- Avoid all contact with people who have fever, cough or flu symptoms (including ill family members.)
- Avoid children who have been recently immunized with any live virus vaccine (eg: chicken pox)
- Avoid crowded public places such as malls, theaters, school and church until approved by your transplant physician, nurse practitioner or physician assistant (return to school in 9-12 months generally for allogeneic transplants, 6-9 months generally for autologous transplants).
- Isolation and dietary restrictions will be removed according to each patient's individual progress. Feel free to ask questions regarding restrictions at your regular clinic visits.
- Patients should avoid exposure to tobacco smoke. **They should not be in an environment where anyone is smoking either cigarettes or pipes.**
- Patients should minimize direct contact with animals. If you currently have a pet, (cat or dog) they must have up to date vaccinations. Patients should wash hands thoroughly after any contact with a pet and avoid all contact with animal poop. Patients cannot sleep in the same bed (couch, chair, etc.) with their pet.
- Patients should not clean pet cages or litter boxes. Patients should have no contact with reptiles (snakes, lizards, turtles, iguanas, etc.) or exotic pets.
- For homes with cats, the following precautions should be taken:
 - Litter boxes should not be placed in kitchens, dining rooms, or other areas where food preparation and eating occur.
 - Daily litter box changes are recommended to help prevent transmission of toxoplasmosis from cat poop.
 - Transplant recipients should not have any contact with kitty litter.

HOME ENVIRONMENT

Before your child is discharged to home, you need to learn how to protect him/her from harmful germs that are present in the normal environment. Normally, a person would have an immune system that could fight these germs. However, having had a stem cell transplant, your child is at much higher risk to get sick from infectious agents that others in the family can fight.

Initial Cleaning:

Perform a thorough “spring” cleaning.

- Steam cleaning upholstery and carpets (may disregard if cleaned in last 6 months, unless there are pets in the house). Professional steam cleaning is preferred. Do not use dry powder chemicals to clean (i.e. Chem-Dry).
- Wipe down walls with soap and water solution. If you have wood walls, use Pledge or Murphy's oil soap).
- Clean all surfaces with strong household cleanser (Lysol, Pine-sol).
- Patient should avoid wood burning stoves and their care.
- Use central air if possible. Change furnace filters before your child comes home, and regularly thereafter. Windows should be kept closed to avoid bacteria/germs from blowing in from outside.
- Vent duct work should be cleaned, as financial ability allows.
- Curtains and blinds need to be washed. If you have mini-blinds, you may “dust” or wipe them down.

Daily Activities:

- Patient should avoid housework.
- Keep bedroom/sleeping area clean.
- Weekly dusting/vacuuming
- The patient should have his/her own eating utensils at any given meal. May be used by others if washed in between uses. She/he should not eat from someone else's plate or drink after someone else.
- The patient should have his/her own linens, wash them 1-2 times per week, or more often if they are dirty.
- Avoid any standing water or handling soils (plants, aquariums).
- City or bottled water (if approved by the Intl. BWA) can be used for drinking, or for making ice, Kool-aid, iced tea, etc. Well water should be avoided and may only be used for drinking if precautions are followed (see section on water). City water is generally treated with chlorination and is safe for drinking and bathing.
- Bathe/shower daily. It is okay to bathe in well water. Just be sure to protect the central line.
- No live plants or flowers, living dried plants or flowers.
- Children should not play in sand, dirt, clay, or potting soil.
- Frequently used toys should be washed in hot water (washing machine/dishwasher preferred) at least once a week. We do not recommend any sharing of toys between toddlers who may put them in their mouths.

Water retaining bath toys should not be used as they can have bacteria growing in them.

- If your child has a large number of stuffed animals in their room, ones they no longer use should be packed away and the remainder washed.

Sleeping Arrangements:

- The patient should not share a bed with anyone else.
- Use a foam pillow (NOT feather, down). The pillow must be your own.
- If your children have bunkbeds, the patient should sleep on the top bunk or put a protector on upper mattress to avoid filtering down of dust and other particles at night.

Pets:

Pets such as dogs and cats may stay in the house but need to be kept clean and have updated vaccinations. Your child should not be involved in cleaning litter boxes or equivalent. Additionally, the litter boxes should not be placed in areas of the home where the child will be spending his/her time. The pet should not sleep in the child's bed or bedroom. Other pets such as reptiles, birds, and rodents need to be removed from the house following transplant until your child's immune system has recovered. Outdoor pets are permissible providing that the child does not interact with the pet. Fish in a well-covered tank with a good filter are permissible. Your child should not feed the fish, clean or touch the tank. If your child has contact with the pet, make sure she/he washes hands thoroughly after the contact.

*Please see "Stem Cell Transplant Patient/Family Home Readiness Checklist" sheet on next page. This sheet will be given to you shortly after you/your child's admit as a "cheat sheet" or quick reference guide to make sure your home is ready to return to after transplant.

Stem Cell Transplant Patient/Family Home Readiness Checklist

- Steam-clean upholstery, drapery and carpets (preferably by a professional)
 - Do not use dry-powder chemicals (such as Chem-dry)
- Clean all surfaces in your home
 - Use strong household cleaner (Lysol, Pine-sol, etc.) for most (non-wood) surfaces, following the instructions for “disinfection” on the product label
 - Pay special attention to: door handles, kitchen surfaces, inside of the refrigerator, bathroom, non-wood tables, mini-blinds, TV remote control, telephone headset, and toys that cannot be washed in the laundry
 - Wipe down walls with soap and water
 - Use wood surface cleaner (Pledge, Murphy’s Oil Soap, etc.) on wood
- Burn gas logs only (no wood-burning stoves or fires)
- Change furnace/air filters immediately before discharge and regularly thereafter according to filter product instructions
 - Utilize central air (if available)
 - Keep windows closed
- Clean vent ductwork (if applicable)
- Mop the floors
- Wash all bed linens in hot water
 - Continue to wash 1-2 times per week after discharged home
- Ensure that the patient has his/her own bed with his/her own pillow (foam – not down or feather)
 - Place a mattress protector around the patient’s mattress and launder weekly.
 - Place a mattress protector around the upper mattress of the bunk bed if the patient sleeps on the bottom mattress of a bunk bed
- Wash all toys that can be laundered in hot water
- Avoid fresh plants, flowers, greenery, or live decorations (including live Christmas trees)
- Avoid sand, dirt, and clay
- Maintain pet health (vaccinations current, recent healthy check-up)
 - No new pets
 - Do not allow your child to sleep with the pet or allow the pet to lick the child on his/her face
 - Clean litter boxes daily (patient should not touch the litter box)
 - Prevent patient contact with animal feces, cages, reptiles, exotic pets, rodents, or birds
 - Practice hand hygiene after pet contact
- Prepare food according to the safe food-handling guidelines
- Arrange transportation
 - Home
 - Clinic
 - Emergency

ACTIVITIES

The following is a list of activities your child should AVOID post-transplant until your child's immune system has fully recovered:

- raking leaves
- going to orchards
- hayrides
- hunting
- dressing, skinning, or taxidermy of dead animals
- playing in the sandbox
- playing with dirt
- dirt biking or 4 wheeling
- carving pumpkins
- cutting trees
- bonfires
- mushroom hunting
- visiting construction areas
- caving
- planting crop, seeds, or plants
- harvesting crops
- public swimming pools
- lakes, ponds, oceans
- unprotected sexual activity

Fishing is allowed but your child should not handle bait or fish.

Sledding and skiing is okay, as long as platelets have recovered and your child wears a helmet.

No lake or ocean swimming.

No fires in fireplace unless gas logs.

No live Christmas trees, pumpkins, or other live holiday decorations.

Please check with the Stem Cell Transplant team regarding specific activities your child is wanting to do. The best rule of thumb is if you have to think twice about an activity... your child probably shouldn't participate.

BLEEDING

Every post-transplant patient recovers their ability to make red blood cells and platelets at a different rate. Some patients are discharged from the hospital and do not need further transfusion support, while others require transfusions. Platelets are usually the last blood cell line to recover following transplant. The platelet count recovery for an autologous transplant may be particularly delayed (even beyond day 100).

When transfusions are required following transplant, the blood products that are given must be irradiated before being given in order to prevent the patient from developing graft versus host disease. This can happen because the patient is still severely immune suppressed.

Discharge from the hospital need not be delayed for red blood cell or platelet recovery as transfusions of both can be done easily in the outpatient setting. Transfusions will be arranged for Monday through Friday in the outpatient clinic area when possible. Transfusion requirements on weekends may require a trip to the Riley Emergency Room, or to the SCT Unit.

Signs of a low platelet count (thrombocytopenia):

- bruising from light pressure, such as the belt line or elastic on socks
- petechiae, or small purple dots about the size of a freckle which can appear at pressure sites
- blood in the urine or stool (old blood in the stool can look like tar, and vomited blood can look like coffee grounds. Either symptom should be reported immediately.)
- oozing of blood from the mouth or gums
- heavy periods or spotting in females who are on medication to stop menstruation
- bleeding from any site

Precautions for low platelet counts: platelet count is $< 50,000/\text{mm}^3$:

- Use a toothette, not a conventional toothbrush.
- Avoid use of aspirin, aspirin containing products, Ibuprofen, Motrin, Advil, etc.
- Do not use rectal thermometers or give rectal suppositories.
- Report symptoms of constipation.
- Avoid strenuous activity (football, bike riding, and rollerblading as a few examples).
- Do not blow your nose forcefully.
- Tampons and vaginal douches should not be used.
- Shave with an electric razor only.
- Check with your child's physician prior to any air travel.

WHEN TO CALL THE MEDICAL TEAM

Do not hesitate to call for any signs or symptoms that concern you!

Report these symptoms immediately:

- fever of 100.5° F (38°C)
- pain, redness, or swelling of any part of the body
- diarrhea (5-7 stools per day)
- nausea and vomiting
- rash or any changes in skin appearance
- painful or dry eyes, or blurred vision
- mouth sores
- bleeding
- cough, sneezing, or nasal congestion
- chest pain or shortness of breath
- shaking chills, sweating, or flushed skin
- inability to swallow or keep down oral medications

Central line catheter changes:

- inability to flush the central line
- drainage or redness of the central line site
- pain or swelling around or near the catheter

Items that can wait until clinic is open:

- questions regarding diet or isolation should not be an emergency. Simply comply with the last standard you were given to follow until the question can be discussed in clinic, or by telephone during clinic hours.
- medication refills (unless completely empty, then call immediately with local pharmacy number in hand)
- clinic appointment changes

HOW TO CONTACT YOUR STEM CELL TRANSPLANT MEDICAL TEAM

You can reach someone from the Stem Cell Transplant Team 24 hours a day. Daytime hours Monday-Friday 8:00 a.m. until 4:30 p.m., you should contact the nurse practitioner by calling 317-312-1247. This is a pager. At the prompt, please dial the best phone number (including area code if outside of the 317 area code) to reach you and your call will be returned as soon as possible.

After 4:30 p.m. until 8:00 a.m. during the week and on weekends and holidays, you should call the physician on call at (317) 944-5000. **Ask to speak with the pediatric stem cell transplant physician on call.** The operator will then contact the stem cell transplant physician on call.

Please avoid using the inpatient nurse's desk phone number for outpatient questions or concerns.

NOTES

POST- TRANSPLANT FOLLOW-UP

ORIENTATION TO STEM CELL TRANSPLANT CLINIC

Frequency:

Clinic visits will be scheduled according to each patient's individual needs. Typically, patients will be seen twice weekly for one month, then once weekly for an additional month. How often you/your child are seen after this time period will be discussed with you by your outpatient nurse practitioner. Treatment of graft versus host disease and the use of immunosuppressive drugs (such as Cyclosporine and Prednisone) or treatment of an active infection may require that clinic visits occur more often and for a longer period of time.

Location:

The Stem Cell Transplant Outpatient Clinic is located in the Hematology/Oncology Medical Service Area (MSA) on the third floor of the Riley Outpatient Center (ROC). The ROC is easily accessed off of Michigan Avenue, and parking is available in the ROC parking garage attached to the outpatient center. Please bring your garage parking ticket in with you to your child's appointment. The clinic reception staff will stamp/validate your ticket which will give you a reduced rate to park in the garage.

When you arrive to the clinic with your child, please check in at the front desk of the Hem/Onc MSA at your scheduled time. Please be sure to bring your child's current insurance card with you to every visit. If you have any questions about your appointment, you can call the stem cell transplant scheduler at 317-948-2778. If you have a question pertaining to your child's care, please call 317-312-1247 to reach one of the outpatient nurse practitioners. If your question is regarding a pre stem cell transplant admit, please contact your transplant coordinator.

Until your child's immune function returns to normal, he/she will need to wear a green high filtration mask. This mask needs to be worn once your child exits your car until he/she is inside the clinic exam room. These masks will also help identify the transplant patients and expedite getting them into a room quickly.

If your child needs a transfusion, this will be done in the infusion room. If a transfusion is needed on the weekend, this will be pre-arranged for the Riley Emergency Room.

Clinic Personnel:

Out-patient staff nurse

Out-patient nurse practitioner/physician's assistant

Dietician

Social Worker (same person you saw on the inpatient unit)

Attending physicians (on rotating schedule)

Pharmacist

Child Life Specialist

Infectious exposures:

Should your child be exposed to an infectious illness (i.e. chicken pox), please call the transplant office or physician. Your child may require special medications and may need special isolation or clinic visit in a different area.

HELPFUL HINTS FOR CLINIC VISITS

What to Bring:

1. **This book!**
2. All **medications** your child may need for the trip to and from clinic as well as during the clinic visit. Emergency doses of your child's oral medications can be obtained, but require an extra charge and a trip to the outpatient pharmacy. Oral medications your child needs are not stocked in clinic. Remember to bring your morning dose of Cyclosporine® to clinic to give after the nurse has drawn labs for a Cyclosporine® level. Also bring any home IV antibiotics that may be due while you/your child are in clinic.
3. **Snacks** or special food or drinks that your child needs should be brought along. There is a microwave in clinic. The cafeteria and snack bar are available during daytime hours.
4. A special **mask** called the N95 mask must be worn when walking from your car to check in to clinic and back to your car. These are special high filtration masks and are usually green in color. We will send you home with a supply upon discharge from the Stem Cell Transplant Unit. Your child can remove the mask when in a private examination room in clinic. Wearing a mask anywhere you go including around the hospital is required until your child's immune function has returned to normal. Check with your clinic nurse or physician if you are unsure of the guidelines to follow for your child.
5. You may want to keep an **overnight bag** of essential items for you and your child packed and in the car for trips to Riley Hospital. This may include a change of clothes, toiletries, and an emergency supply of oral medications. This is a very good idea if you are bringing your child to clinic with a fever or other symptoms that may require an unexpected hospital admission. A '

NOTES

NOTES