



Heart Transplantation

A Handbook for Families

ST. LOUIS CHILDREN'S HOSPITAL

WELCOME

The heart transplant team at St. Louis Children’s Hospital would like to welcome you to our hospital and transplant program. As you know, patients are considered for heart transplantation when either medical therapy or surgery cannot significantly improve their heart disease and consequently, there is a high probability of death. Heart transplantation is not a cure, but rather a treatment. We strive to increase the quality of life for your child. It is our greatest hope that by having a transplant your child will have the opportunity to achieve life goals that are important to them.

This booklet has been written as a resource for you. It contains basic information regarding transplantation that is important for you and your child to understand. Please remember that each child who is transplanted is an individual who comes with their own complex medical history and will respond to transplantation in their own unique way. The transplant team is committed to providing the best possible care based on your child’s individual needs.

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 St. Louis Children’s Hospital, St. Louis, MO 63110

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ST. LOUIS CHILDREN'S HOSPITAL

GENERAL INFORMATION

During your child's stay in our transplant unit, the heart staff will be your main contacts for the overall care and treatment of your child. Your child's primary Cardiology physician will work closely with the heart staff and remain involved in the medical care of your child. You may need to call a staff member during the transplant process. Following are some important numbers:

IMPORTANT NAMES AND NUMBERS	
St. Louis Children's Hospital (SLCH)	314.454.6000
SLCH Toll Free Number	877.578.4449
PRIMARY NAMES AND NUMBERS	
Heart Transplant Medical Director	314.454.6095
Pediatric Nurse Practitioner	314.454.4279 314.454.2253 314-454-2221
Transplant Coordinators	314.454.4281
Transplant Program Assistant	314-454-2214
Transplant Financial Coordinators	314.454.2091 314.454.6191
TO MAKE AN APPOINTMENT	
Heart Clinic Office	314-454-2214
ADDITIONAL HELPFUL NUMBERS	
Ambulatory Procedure Center	314.454.2514
Chaplain	314.454.6211
Child Life Services	314.454.6178
Family Resource Center	314.454.2350
Information Desk	314.454.2615
Infusion Center	314.454.6065
Outpatient Lab	314.454.4130
Outpatient Pharmacy	314.454.6123
Patient Accounts	314.286.2384
Psychologist	314.454.6069
School Liaison	314.454.2173

ADDITIONAL HELPFUL NUMBERS	
Social Worker	314.454.6101

LODGING

Transplantation is a long and often complex process. Your child will be in the hospital for one to two weeks. If you live further than two hours away we may ask that you stay in St. Louis for four to seven days post-transplant for closer monitoring. Please plan on establishing a place to stay, whether with relatives, friends, local hotel, or if available, Ronald McDonald House post-transplant.

Ronald McDonald Houses: St. Louis currently has two Ronald McDonald Houses with four long-term apartments that serve as lodging for families. First-time guests must work with the social worker to arrange for this lodging. Return guests may work directly with the local Ronald McDonald House.

Haven House: Located in West County, Haven House offers many of the same amenities as the Ronald McDonald House. These accommodations also require the social worker to arrange for this lodging for first time guests.

Your social worker can provide more detailed information about reserving a place in one of these houses. She will also suggest other lodging options. Please be aware that there is often a waiting list for families, so it may be helpful to plan ahead and anticipate lodging needs.

PARKING

Parking is available in the visitor’s garage across from the entrance to the hospital on Children’s Place. Only parents and grandparents may have their parking tickets validated at the information desk.

FOOD SERVICES

- **Edison Center Atrium Café**, the hospital’s cafeteria, located on the lower level. The cafeteria opens at 6 a.m. and closes at 2 a.m. You may

order guest trays (call 42752) that will be delivered with patient trays. Vending machines are also available on the lower level near the cafeteria.

- **Barnes-Jewish Hospital** (BJH), North & South each have a cafeteria. BJH, North & South are both connected to our hospital via an enclosed walkway. Our hospital operator can provide the appropriate phone numbers to enable you to check hours of operation and selection.
- **Special food needs or requests** can be accommodated. If you have any dietary restrictions, please inform your child’s nurse, dietician, or social worker. Please also tell them of any significant family dates such as birthdays or anniversaries, so we may try to assist you in celebrating them.

THE CENTRAL WEST END

Our hospital is within walking distance of a popular area of St. Louis called the *Central West End*. Within several blocks are many dining choices, including ice cream shops, sandwich shops and full-service restaurants. There are also art galleries, antique shops, novelty shops, a movie theatre and a bookstore.

OTHER SERVICES IN OR NEAR THE HOSPITAL

For information about available services in this hospital, please refer to the *St. Louis Children’s Hospital Family & Patient Guide*, that you will receive when your child is admitted to the hospital. You will find information about our Family Resource Center, banking, postal services, the hospital chapel, the Laundromat and other available services.

UNDERSTANDING HEART TRANSPLANTATION

HISTORY

Heart transplantation has been performed since 1967. St. Louis Children's Hospital has performed heart transplants in pediatric patients since 1986. By the mid-1990s heart transplantation had become the standard of care for end stage heart disease. Children are referred to SLCH from across the Midwest. The heart transplant program is known for accepting medically challenging patients that would be turned away at other centers. As of 2013, 400 heart transplants have been performed at St. Louis Children's Hospital.

CADAVERIC TRANSPLANT

Where Do Donor Organs Come From?

Organ donors are individuals in whom all brain function has ceased due to severe brain injury, (also known as "brain death") and consent has been obtained for organ donation from family members. The evaluation of potential organ donors includes their medical history, blood tests, and studies looking at function of the specific organs (e.g. heart, lungs, kidneys, liver, pancreas). These tests are done by protocol at the site where the donor is located. In most cases, the tests are performed twice, with several hours in between to ensure an accurate result.

Brain death should not be confused with coma or vegetative state. A patient in a coma is medically and legally alive and may breathe on their own when the ventilator is removed. A patient in vegetative state retains motor reflexes, and has a natural sleep wake cycle, but is not aware of any activity.

SURVIVAL STATISTICS

St. Louis Children's Hospital Heart Transplant statistics are comparable to the national statistics. Survival statistics regarding all transplant centers in the United States can be found at the following website: United Network for Organ Sharing (UNOS) (unos.org). Please see the statistical information sheet given to you that provides survival statistics from the Scientific Registry of Transplant Recipients (SRTR) (srtr.org).

FINANCIAL

Who pays for an organ transplant?

Many insurance companies now offer at least partial coverage for transplant costs although the terms and extent of coverage vary widely. The transplant team includes staff that is able to assist with exploring your transplant medical coverage. Additionally, they can assist with exploring your options for fund-raising or other financial assistance programs. These individuals will meet with you and your family during the transplant evaluation to help you understand the financial aspects of transplantation. There are instances when we experience long delays with authorization from out-of-state Medicaid agencies to bring a child in for evaluation. We make every effort to work with those agencies on behalf of the patient; however there may be instances when it is not possible.

Your insurance coverage or financial situation may change over time. It is extremely important to notify the financial coordinator or social worker of these changes so they can help you better understand your insurance benefits.

MEDICARE APPROVED TRANSPLANT CENTER

St. Louis Children's Hospital is a Medicare approved transplant center. If your transplant is not provided in a Medicare approved transplant center, it could affect your ability to have immunosuppressive drugs paid for under Medicare Part B. Notification of Medicare Outcome Requirements not being met by Center Specific outcome requirements need to be met by transplant centers and the transplant program is required to notify you if those requirements are not met. Currently, St. Louis Children's Hospital meets all requirements for transplant centers.

TRANSPLANT TEAM MEMBERS

Transplant Surgeon The transplant surgeon is a surgeon who has had additional specialized education and training in transplant surgery and medical management of transplant recipients. The transplant surgeon will provide information to you and your child about how the transplant is performed and the potential benefits and risks of transplant surgery. Additionally, the transplant surgeon participates in the immediate post-operative management of the transplant recipient, including performing any necessary re-operations.

Transplant Medical Staff We have a specialized team of physicians dedicated to caring for children undergoing heart transplantation. The medical director coordinates the overall functioning and policy making of the heart transplant program, including pre and post-operative care. You and your child will meet with the medical director during the evaluation process. Other Transplant Medical Staff members may be caring for your child during their transplant hospitalization. These attending physicians have had extensive training in cardiology and supervise fellows and house staff physicians. A fellow is a pediatrician who is specializing in cardiology and is very important for your child's care during the nights and on weekends.

Pediatric Nurse Practitioners and Physician Assistants are clinicians who have an advanced level of education and experience. They are licensed nationally and are board-certified by the state of Missouri. Pediatric Nurse Practitioners and Physician Assistants work under the direction and supervision of your heart doctor.

Some of the responsibilities of the nurse practitioner:

- Take care of children in the clinic or the hospital
- Perform physical exams
- Write immunosuppression orders/write prescriptions
- Diagnose minor illnesses in children and prescribe treatment
- Perform procedures such as suture/staple removals and drainage tube removals
- Monitor the side effects of immunosuppression medications and provide necessary treatment

- Admit your child to the hospital if needed
- Educate children and families about their disease
- Do extensive discharge planning with local physicians, hospitals, and home health agencies
- Contact your local doctor and communicate the plan of care
- Coordinate your child's care among all services involved (transplant surgery, other specialists)
- Work closely with other team members (transplant coordinators, social work, psychology, child life, dietitians, pharmacy, etc.)
- Refer your child to another specialist if needed (dermatology, allergist, etc.)
- Ensure a smooth transition between inpatient and outpatient care

Transplant Nurse Coordinators are nurses with experience in caring for transplant patients. They will teach you about your child's disease, transplantation and how to care for your child after transplantation. Your transplant coordinator will be your main contact with the transplant team. They work under the direction and supervision of the doctors.

Some of the responsibilities of the transplant nurse coordinator:

- Educate children and families about their disease
- Coordinate the transplant evaluation including scheduling tests and consultations with members of the transplant team (surgeons, medical doctors, social work etc.)
- Add your child onto the national transplant waiting list
- Make necessary arrangements at time of transplant including contacting you about an organ being available, arranging for operating room time, contacting the hospital staff and transplant team members about your child's admission, etc.
- Educate children and their families about post-transplant care including medications, signs and symptoms of rejection and infection, follow-up visits, etc.

- Conduct extensive discharge planning with local physicians, hospitals, and home health agencies
- Work closely with all other team members (surgeons, medical doctors, nurse practitioner, social work, etc.)
- Perform telephone triage of any illnesses your child may experience and refer to the appropriate team member (medical doctor, nurse practitioner, local physician)
- Participate in your child's outpatient clinic visits (review medications, provide ongoing education, coordinate visits/referrals to other services)

Child Life Specialists help children and adolescents cope with the stress of the medical setting and treatment by providing developmentally appropriate social, emotional and educational support and activities. Services include:

- Providing materials and guidance for play and adapting activities according to a child's strengths and limitations
- Preparing children for hospitalization, surgery, and medical procedures through hands-on activities and providing support during procedures
- Emotional support to children, siblings, and parents
- Advocating for an age-appropriate and child-focused environment and treatment experience

Psychologists Staff from the St. Louis Children's Hospital Department of Psychology specialize in the psychological issues associated with chronic illnesses and disease. They work directly with children and families and provide consultation to the medical team. A psychologist sees new patients during the transplant evaluation. After this initial evaluation, follow-up services during hospitalization and/or on an outpatient basis may include:

- Emotional support and counseling
- Individual therapy with patients, siblings, and/or parents
- Family counseling
- Behavioral techniques to manage pain, anxiety, reactions to treatment side effects

- Interventions to assist with illness management
- Medication compliance

Social Workers St. Louis Children's Hospital Social Workers are members of a diverse team who serve as a liaison between families and medical staff. During the transplant evaluation, a psychosocial assessment is completed by the social worker with the patients and their families to help the medical team begin to understand your family and any social concerns there may be. Social workers also assist you and your child with stress as well as the emotional and practical problems associated with your child's illness. Assistance is also available to connect you with community resources that may be helpful to your family. Other services they can help with are:

- Advice about resources potentially available to families, including financial assistance and lodging alternatives for families from out-of-town
- Assistance with acquiring those resources
- Family support

Chaplain St. Louis Children's Hospital is committed to meeting the spiritual needs of all our patients. We have two full time chaplains on staff. Please notify your transplant team if you wish to meet with the chaplain before or during your transplant hospitalization. We can provide a religious practitioner of your choice, i.e. Roman Catholic Priest, Rabbi, Mormon Elder, etc. upon request. Other services they provide:

- 24 hour on-call service. Call 314.360.1871
- Prayer service in St. Louis Children's Hospital Chapel every Tuesday (1st floor next to Gift Shop)

Registered Dietitians are members of the team who provide recommendations to support adequate and appropriate growth both pre- and post-transplant. Registered dietitians work with physicians, nurse practitioners, nurses and other team members, as well as patients and their families to ensure adequate caloric intake and to promote balanced and varied diets. Services include:

- Meeting with patients and families during hospital admissions

- Clinic visits as requested by staff, patients or families
- Help in obtaining formulas or specific nutrition products for outpatients
- Assistance with any food allergies, intolerance, preferences, or special needs related to diet while inpatient.

Pharmacist The transplant pharmacist is an important member of your transplant team. A pharmacist is a health care professional who consults with and sometimes advises the licensed practitioner concerning drugs. Services include:

- Assisting the physician in medication selection and dosing.
- Monitoring and managing side effects
- Monitoring for adherence concerns; offering tools and alternatives as appropriate
- Educating patients and families on medications

ADHERENCE/COMPLIANCE

Adherence, formerly known as compliance, is defined as how a patient follows through with medical advice given to them by their medical team. The transplant team considers adherence very seriously because we believe it will affect your child's outcome after transplant. Transplant patients are required to follow a complex self-care regimen before and after transplant. Patients are expected to participate in and cooperate with medical recommendations throughout the transplant experience. Families are expected to support and monitor their child's self-care program as directed by the medical team. Different types of self-care and self-monitoring are required depending on your child's transplant. The transplant team will outline adherence guidelines they would like your child to follow.

POTENTIAL MEDICAL AND PSYCHOSOCIAL RISKS

Heart Transplantation can have potential medical risks and psychosocial risks. Medical risks include a) wound infection, b) pneumonia, c) blood clot formation, d) organ rejection, failure, or re-transplant, e) lifetime

immunosuppressant therapy, f) arrhythmias (slowing or fastening of the heart rate or heart rate skipping beats), g) cardiovascular collapse (heart attack), h) multi-organ failure, and i) death. Psychosocial risks include depression, post traumatic stress disorder (PTSD), generalized anxiety, anxiety regarding dependence on others, and feelings of guilt.

REFERRAL PROCESS

When a child is referred to the transplant team for evaluation, the local cardiologist contacts our medical director or one of the heart transplant coordinators. The referring doctor will then send all related medical records including insurance information. Once the records are received and reviewed, we then contact the family to discuss an evaluation.

Before we contact you, we have our financial coordinators contact the insurance company and make sure the visit would be covered at St. Louis Children's Hospital for a transplant evaluation. Often gathering the medical records and getting answers from the insurance company can take days to weeks. If your child is gravely ill, the process is expedited. If we are having difficulty getting information, we may ask for your help. Once dates are chosen for the evaluation our social worker will contact you and help you arrange travel and lodging.

WHAT YOU CAN EXPECT FROM US

- We will treat you in a respectful manner
- We will make every effort to be on time for appointments with you
- We will return your calls within 24 hours
- We will be honest, up front and keep you informed to the best of our abilities
- We will not discuss your child with other families
- We will treat your child and family as individuals and tailor a plan of care to address your needs

WHAT WE EXPECT FROM YOU

- We expect you to be on time for your appointments, biopsies, lab draws
- We expect you to take your medications on time and as prescribed
- We expect you to get testing done when it is requested
- We expect you to call us with questions, and leave a message if we are not immediately available
- We expect at least 24 hours notice to refill prescriptions and 24 hour notification of cancelled appointment or tests
- We expect you to keep us updated on phone/address/insurance information
- We expect you to have a working phone with an answering machine
- We expect you to discuss questions/concerns about your child with the transplant team and not other families
- We expect you to respect the privacy of other families

THE TRANSPLANT EVALUATION

The first step for your child is called the evaluation. Your child's medical history will be reviewed and a physical exam will be performed. Information will be provided regarding the potential risks and benefits of transplantation as well as long-term outcomes will be discussed. Tests will be done to decide how severe your child's heart disease is. Most transplant evaluations take three to five days.

Upon completion of the evaluation, the heart transplant team will meet to decide whether the child is a suitable candidate for heart transplantation. The transplant team will let you know the result of the meeting. If the child is approved, prior to the procedure, the surgeon will discuss the operation and risks and you will be asked to sign a consent form for the operation. At all times, the child's health and safety will be the primary focus. Depending on the physical condition of your child, the evaluation can be done on an outpatient basis. During the evaluation, your child will be seen by many doctors and members of the transplant team. The following are tests done during an evaluation:

- **Blood tests** – determines how well your child's liver and kidneys work, your child's blood type, and if your child has had prior exposure to certain viruses.
- **Tissue typing** and HLA antibody levels.
- **Electrocardiogram (EKG)** – records your child's heart rate and rhythm.
- **Echocardiogram (ECHO)** – uses sound waves to look at the size of your child's heart and how the heart muscle and valves are working.
- **Cardiac catheterization** – is invasive and requires that your child be sedated while a small catheter is inserted into the vein and artery in the groin and is passed to the heart. Pictures and measurements of pressures are recorded in all chambers of the heart as well as blood vessels in the lungs. After the procedure, your child must lie flat for 6 hours.
- **Heart biopsy** – may be part of the catheterization. A small piece of tissue is taken from the heart muscle itself. The tissue is examined by a pathologist in an attempt to determine the cause of your child's heart disease.
- **Glomerular filtration rate (GFR)** – a test to see how well your child's kidneys filter waste.
- **Chest x-ray** – will determine the size of your child's heart and lungs as well as how well your child's lungs inflate and if there is any fluid or infection in their lungs.
- **CT Scan of the Chest** – A special computerized X-ray of the chest, which gives a more detailed three dimensional picture of the lung tissue, lining of the chest wall, heart chambers and blood vessels.
- **Ultrasound of Blood Vessels** – a test to look for blood clots or blockages in you child's blood vessels.
- **Pulmonary Function Test (PFT)** – used to evaluate your child's lungs and airways. Different breathing techniques are used, breathing deeply and rapidly, blowing out rapidly after deep breaths in.
- **Exercise test or 6 minute Walk Test** – to evaluate exercise tolerance.
- **Neuropsychology and/or Developmental Testing** – (not applicable for infants and toddlers) developmental testing completed by the psychology staff to determine if your child is at his/her age appropriate development level. For children and teenagers, school performance and emotional and social development are evaluated.
- **Visits** with the transplant surgeon, heart doctor (cardiologist), transplant nurse practitioner, transplant coordinator, psychologist, social worker child life specialists, dietician, and pharmacist.
- **Visits** with the lung, neurology (brain), kidney, and liver doctors, depending on your child's medical condition.

ALTERNATIVE TREATMENTS

Alternative treatment therapies may be available for your child's medical condition. Please discuss your child's condition and any possible alternative therapies with your health care team.

Your child’s ability to get health and life insurance in the future may be affected by finding out about these health problems.

LISTING INFORMATION

After all of the evaluation testing and physician consultations are complete, the medical director and the transplant team will review the information. A few children during the evaluation process are found to not need a transplant at that time. Some children can have new medications started to help their heart function; others may be able to have a heart surgery instead of a transplant. However, the vast majority of children are found to need a transplant. Once decided, the plan will be communicated to the family in a prompt manner.

Once determined that your child is a suitable candidate for heart transplant they will be placed on the UNOS (United Network Organ Sharing) transplant waiting list. We list for heart transplant by placing your child’s name, blood type, social security number, appropriate size range of the donor and status (how sick your child is) in the UNOS database. The status system for listing is a patient 17 years old or younger:

Status 1A A child meets at least one of the following conditions:

- needs continuous help breathing with a ventilator and is admitted to the listing hospital
- has a balloon pump and is admitted to the listing hospital
- has blood flow to the body or lungs that is dependent on a stent or prostaglandin infusion and is admitted to the listing hospital
- was born with a significant heart disease and requires certain IV medications, known as inotropes, at high dose or more than one inotrope and is admitted to the listing hospital.

Assistance of a mechanical device such as ECMO or a ventricular assist device (VAD). (may or may not be admitted to the hospital)

Status 1B -needs iv medications, known as inotropes, but does not meet status 1A criteria.

-is less than one year old and has a diagnosis of hypertrophic or restrictive cardiomyopathy.

Status 2 A child is listed for a heart transplant but does not meet the criteria for status 1A or 1B.

Please note that the status criteria for patients 18 years old and older is different than the status for pediatric patients. Your transplant coordinator will explain these criteria, as needed.

A child is inactive on the transplant list (they are too sick or too well to currently accept an organ). There is no way to predict when the transplant will occur. The amount of time you wait varies greatly. The length of time you wait depends on donor availability, blood type, body size and the status of your child. Several criteria are used to match a donor to your child. First, they must have a compatible blood type. The chart below describes which blood types are compatible with one another:

Recipient Blood Type	Compatible Blood Type of Donor
Type O	Type O
Type A	Type A, O
Type B	Type B, O
Type AB	Type AB, A, B, O

However, in babies it is possible to successfully transplant a heart from a donor with an incompatible blood group. This is called an “ABO-incompatible” transplant and has been done successfully in many hospitals around the world. If this is an option for your child, the team will discuss it with your during your child’s transplant evaluation.

Next, the donor size must be within the acceptable weight range. The lower limit is usually 75-80 percent of your child’s weight and the upper limit is 1.5-2 times your child’s body weight. For example, if a child weighs 50 pounds the donor could weigh from 40 pounds to 75 pounds. Other medical information about the donor, as well as location of the donor, also comes into play when the medical director and the surgeons make the decision to accept a donor for your child.

While waiting on the transplant list, life will remain very much as it has been prior to the evaluation. If your child is well enough to be at home, they should continue to do as much as they feel up to. This would include going to school as much as possible. While waiting for a donor, you will continue to make periodic visits to the St. Louis Children's Hospital cardiology clinic in order for the medical team to assess your child's condition. For families that live out of town, you will continue to see the local cardiologist on a routine basis and see the transplant team at St. Louis Children's Hospital at least every three months.

It is vital for the transplant team to be kept informed of your child's health status while on the waiting list. Please notify the transplant coordinator of all changes in health. Serious infections must be treated promptly before your child is transplanted. It is common for children with heart disease to get sicker over time. If your child is showing signs of worsening heart function – decreased energy level, increased water retention, more difficulty breathing, or even frequent nausea, vomiting or loss of appetite – the transplant team and your local cardiologist need to be notified. Also, notify us on any hospital admissions they may have. It may warrant upgrading your status in the UNOS system.

We will need all current phone numbers to ensure that the transplant team can reach you at any time. It is your responsibility to have a working phone number and voicemail at all times. Any changes in phone numbers or address or insurance must be relayed as soon as possible to the transplant coordinators.

WAITING FOR TRANSPLANT

The normal waiting time on the transplant list may be from several weeks to months. The following is some general information while your child is waiting for their transplant to occur:

- While on the transplant waiting list, your child will continue to see their cardiologist as usual for regularly scheduled visits. Your child's transplant coordinator will see you at these visits as well to update the rest of the transplant team on your child's health status.
- Should your child develop a fever, infection or contagious illness (i.e. chickenpox, influenza, etc.) while on the waiting list, contact your cardiologist

regarding treatment. Also contact your transplant coordinator, as your child's transplant may be temporarily postponed until your child has recovered.

- Notify your transplant coordinator if you and/or child are going out of town (i.e. family vacation, camp, etc.). We will not be able to accept a heart while you are out of town.
- Call your transplant coordinator if your family or your child has any questions or concerns about proceeding with transplantation.

PREPARING FOR THE CALL

There is no way to know when a new heart will become available; however, there are things you can do to help prepare your child and family:

- Make a list of things you and your child will need at the hospital: comfortable clothes, toiletries, your child's favorite stuffed animal or toys, book/magazines to read, etc.
- If you have other children, arrange childcare for them ahead of time.
- Have cash available for gas money, cab fare, etc., so you will be able to leave at a moment's notice.

FLIGHT INFORMATION

If you and your child live more than four hours from the hospital, flight arrangements need to be made in advance to fly your child here at a moment's notice when a heart becomes available. Your insurance company determines the flight company used. Our transplant financial coordinators will check your insurance benefits regarding the flight. In the event your child is hospitalized at another center when a heart becomes available, the St. Louis Children's Hospital Transport Team will make arrangements to bring your child to our hospital.

THE ACTUAL TRANSPLANT

One of the transplant coordinators will be taking the call when the donor offer is accepted for your child. The information the coordinator receives is from the Mid-America Transplant Coordinator. Once the information is given to our transplant physicians and they agree the donor is acceptable we call Mid-America Transplant and accept.

Once this process has taken place, the job of coordination begins. We will call you and let you know we have accepted an organ for your child. It is important that at this time, you stop giving any food or drink to your child. Also, if your child is on Coumadin or any "blood thinner", hold this medicine. Your child will be admitted to the hospital. At this point the surgeon has a clear picture of all of the risks associated with this particular organ versus the risk of waiting for the next available donor. You always have the option to decline an organ. At this time we will communicate to you through your child's nurse, the actual operating room time (OR time). Generally speaking, your child is in surgery AT LEAST two hours before the "new" organ arrives at the hospital. The coordinators are constantly updated on any changes that may affect the quality of the organ and communicates this with the transplant surgeon(s) and team members. The "timing" for the transplant may also change and as a result we may change the time your child goes to the OR or the time the organ will arrive at SLCH.

While these changes usually work out, sometimes the transplant must be aborted for decreased quality of the donor organ. This "dry-run" can be very emotional and disappointing. If this does happen, please keep in mind that we would much rather this happen than transplant an organ that is not optimal for your child. The entire process from the time we call you until your child actually goes to the operating room can take hours; we will keep you aware of any major changes. Once your child is in the operating room, the operating room nurses will be communicating with you. Please remember that many transplants occur at night, and with staffing more limited in the middle of the night, the OR nurses will do their best to keep you updated.

Certain conditions in the donor may affect the success of the heart transplant, such as the donor's history and the condition of the organ when it is received

in the operating room for the transplant operation. Additionally, there is a potential risk of contracting HIV, hepatitis, and/or other infectious diseases if these infections cannot be detected in the donor.

During the transplant operation, your child will receive general anesthesia, which means medications will be given to put him/her to sleep, block pain, and paralyze parts of his/her body. A machine (ventilator) to help with breathing will also be used. The anesthesiologist will talk about the risks of anesthesia. The transplant surgeon will make an incision through the breastbone. Through this incision, the diseased heart will be removed, and the donated heart will be placed into the chest. Your child will be in the operating room approximately 6-10 hours.

Your child may need blood or blood product transfusions during. There is a separate form for consent for transfusions you will be asked to before the operation.

During the operation, a broviac catheter and/or a large IV tube will be placed in the neck or chest and several IV tubes will be placed in the arms and/or legs to administer fluids and medications during and after the operation. Drains will be put into your child's body to allow fluids to be removed and to help healing. A urinary tube will be in place for a few days after the transplant. Special mechanical boots or sleeves around the legs may be used to keep blood flowing through the legs to help prevent blood clots.

Your child will probably feel more tired than usual for one to two months after surgery. There will be a healing period of approximately four weeks during which your child should not attend school or work or lift more than ten pounds. He/she also should not lift more than 20 to 25 pounds, participate in gym class, or exercise excessively until three months after surgery or until the doctor allows it.

DONOR RISK CRITERIA

Our transplant team is here to provide the best care possible to all our patients. Careful screening of organ donors is always done before we call any patient or family with an organ offer.

The chance of an infection from a donor organ is very low, but not zero. Examples of possible infections are undetected Human Immunodeficiency Virus (HIV), Hepatitis B Virus (HBV), and Hepatitis C Virus (HCV) infection. If one of these infections is found, there are treatments that can help. Our team will let you know the chance of an infection at the time of organ offer. We will be there to answer questions.

Testing is done before and after transplant to screen for HIV, Hepatitis B, and Hepatitis C. Any positive results will be told to patients and families. If you decide not to accept an organ from a donor that has a possible infection, this will not affect your care with the transplant program, and it will not change your position on the waiting list.

YOUR STAY IN THE HEART CENTER

Your child will go to the Cardiac Intensive Care Unit (CICU) in the Heart Center immediately following surgery. The intensive care team will require an hour or more to stabilize your child before you will be allowed to visit. Your child will be on a respirator (also known as a ventilator, or breathing machine) and will have many monitoring lines and drainage tubes present. While on the respirator your child will have a tube in his throat (called an endotracheal tube) and will not be able to speak. Your child will have two large tubes in their chest (called chest tubes) to allow drainage of fluid and to help re-expand their lungs. There will be a tube in the nose that goes to the stomach (called a nasogastric or NG tube). This tube helps to keep air from accumulating in the stomach and helps to drain stomach acid. This tube is usually removed when the breathing tube comes out. Vital signs, such as blood pressure and heart rate will be monitored closely. Lab tests will be drawn frequently from an arterial line (A-line). This special line (a type of IV that is actually placed in an artery rather than a vein) is placed during the surgery. The A-line not only allows for blood draws, but also helps to monitor blood pressure. The ICU team will keep your child as comfortable as possible. As your child recovers, the tubes and monitoring lines will be removed. Again each child is unique and the length of time your child is in the Heart Center will depend on many factors.

Please check with your nurse regarding the visitation policy. We realize that there will be many concerned and relieved family members and friends, however

your child is vulnerable to infection and we strongly discourage visiting by all but immediate family (parents, guardians or appropriate siblings) at this time. All visitors should not have any signs or symptoms of illness. Good handwashing by all visitors is strongly advised to protect your child.

The Heart Center Team can only give patient information over the phone to parents. It is suggested that you designate a friend or family member as a contact person to receive updates from you. Your transplant team will work together with the Heart Center team of doctors and nurses to provide your child with the best possible care.

The nurses will assist the Transplant Coordinators in educating your family about life after transplant. The coordinator will also assist your family after transplant with your questions or concerns, and provide for you effective communication between the family and members of the Transplant Team.

During your stay in the Heart Center the nurses will educate you and your child about transplant medications, blood draws and blood pressure measurements.

It is important to become comfortable with the medications, and any equipment needed for home care. Your Transplant Coordinator can also serve as a resource person during this educational process.

All visitors are screened for illness when entering the Heart Center. However, germs are everywhere and good hand washing by all visitors is strongly advised to protect your child. The Heart Center has restricted visitation guidelines. Please check with your nurse regarding the visitation policy. The family resource center has Ipads for your use. We try to give all families a private room, however, on occasions during busy times in the Heart Center, your child may share a room.

POST – TRANSPLANT

After the transplant, both child and parents must begin learning how to care for the new heart. You will learn about medicines, rejection, lifestyle issues, how to care for the surgical incision and what to do if you suspect infection and how to prevent it.

Once your child has stabilized after their transplant surgery, the transplant nurse coordinators will provide you with written instructions about how to care for your child after transplant. It will include the following information:

- Signs and symptoms of rejection
- Signs and symptoms of infection
- Information about medications your child will be taking post-transplant
- Reasons to call the transplant nurse coordinator or transplant physician
- General health information about immunizations, dental health, skin care, etc.

The transplant nurse coordinator will arrange times to meet with you and your child (if appropriate) to review all of these instructions. If there are other family members (i.e. grandparents, stepparents) who will be taking care of your child, you may want to have them included in the teaching sessions, especially if they will be administering medications to your child.

The staff nurses will also be working with you throughout your child's hospitalization to teach you any special skills you may need to take care of your child. Some of these skills include:

- How to take a blood pressure
- How to administer tube feedings (nasogastric or gastrostomy)
- How to administer TPN (Total Parenteral Nutrition)
- Wound care and dressing changes

If needed, arrangements will be made with Home Health Agency for any equipment or additional home nursing care that your child may need.

FOLLOW-UP CARE

Typically the first heart biopsy is performed one to two weeks after transplant. Some patients may be discharged prior to the first biopsy. You will be required to stay locally for a minimum of two weeks (including time in the hospital). If there is no rejection, or other acute issues, you will be allowed to go back home.

Some patients are able to receive all of their follow up care near their home, including biopsies, medicine regulation and any acute care needed. However, the majority of patients will receive their heart transplant care in St. Louis. You will not be required to stay in the area for a great length of time, but frequent visits at first are expected (see **Biopsies** below).

It is also encouraged that any child old enough to participate should start a formal cardiac rehabilitation program. The program will include 12 weeks of monitored exercise where the child can "learn" to exercise and improve physical endurance much faster. Usually this can be done close to home.

BIOPSIES

The procedure is performed in the cardiac catheterization lab. The procedure involves placing a peripheral IV and sedating your child. The physician then places an IV in a large vein in the neck or groin in which he can place a bioptome (biopsy forceps). The forceps are passed through the vein and into the upper chamber of the heart (right atrium) through the valve and into the lower chamber (right ventricle). The bioptome has tiny pinchers on the end to take pieces of the myocardial tissue from the right ventricle. Six little pieces are sent to the pathology lab where a pathologist looks at the heart tissue under a microscope. If the biopsy pieces are received by 11 a.m. on the day of the biopsy, we can usually tell you the results by 5 p.m. that same day. Once the biopsy is performed, an EKG, echo and chest x-ray will be done. Once your child is awake and able to eat and drink, and we have all the lab results, the physician will talk to you about any changes and you may be discharged.

CENTRAL LINE PLACEMENT

At the time of your child's transplant, a central line (Broviac or Hickman) catheter will be placed. The central line is usually inserted into a large vein under the collarbone. This catheter will be used for giving all intravenous fluids, medications, blood, and nutrition (in the event your child is unable to eat) during your child's hospitalization(s). It helps avoid the discomfort of multiple needle sticks during hospitalization. Occasionally, however, blood must still be taken directly from a vein or by finger-stick. If your child already has a central line, a decision will be made about the ability of this line to meet the needs of the transplant process. In addition to the central line,

your child may have additional IV tubes placed in the arms and/or legs to administer fluids and medications during and after the operation.

The central line will require some special care. Before you go home, a nurse will make sure you know how to care for your child's catheter. The care will include flushing the line with heparin to keep it from clotting and a dressing change over the catheter site. The **St. Louis Children's Hospital Central Line Home Care Booklet** will be provided to you during your child's hospitalization. This booklet gives detailed, step-by-step instructions on how to care for your child's central line.

Biopsies are usually scheduled as follows:

- 1-2 weeks post transplant
- 4-6 weeks post transplant
- 12 weeks post transplant
- 6 month post-transplant
- One year anniversary at which time a cardiac cath will be performed in addition to a biopsy in the cath lab and coronary angiography.
- Typically a child will only need a cardiac cath with biopsy and coronary angiography ever other year.
- If your child is at increased risk for organ rejection, biopsies may be done more frequently. The transplant team will discuss the schedule of biopsies with you.

- If the biopsy indicates significant rejection, there will be more frequent biopsies to make sure it is resolving.

Patients who participate in competitive sports at the select or high school level will have cardiac cath with biopsy and coronary angiography on a yearly basis.

RETURN CLINIC VISITS

Early after transplantation patients require frequent follow up with heart biopsies and clinic visits. A typical follow up schedule for the first year after transplant is as follows:

Clinic visit with blood work, chest x-ray, EKG, and echocardiogram at weeks 1,2,3,4,6,8,10,12, months 4,5,6,9, and 12.

Clinic visits and heart biopsies will be done more frequently if your child has antibodies to their donor heart, known as a positive crossmatch. Patients that are further out from transplantation are seen for a full clinic visit every 6 months. This includes an echocardiogram, EKG, chest x-ray, blood work and a visit with the Cardiologist.

Blood work is done every three months to monitor drug levels, cell counts and kidney function. A cardiac catheterization with coronary angiogram is done at the first year anniversary after the heart transplant and then every two years thereafter.

If your child participates in competitive athletics such as select sports teams or high school sports, he or she will have a cardiac catheterization with coronary angiograms and a heart biopsy on a yearly basis.

A cardiac catheterization shows precise assessment of the function of the heart. To perform the procedure, a small area of skin over a vessel (usually the right femoral artery in the groin area) is numbed with a local anesthetic and a catheter (long narrow plastic tube) is advanced through a small skin puncture, with fluoroscopic assistance, through the body to the base of the heart. The catheter tip is inserted into the origins of the right and left coronary arteries (one at a time) and dye is injected. As the dye flows down the arteries and opacifies them, movies (angiograms) are made and, when developed, demonstrate any areas of narrowing in the walls of these vessels. The catheter is also advanced through the aortic valve into the main pumping chamber, or left ventricle, where an injection of dye allows filming of the contours of this chamber as it beats. Both coronary and cardiac angiographic studies are compared every other year to detect any changes that may have occurred.

GENERAL INFORMATION

BACK TO SCHOOL

We encourage our patients to get back to a normal life as soon as possible, including attending school. You will need to check with your child's transplant coordinator as to when it will be best for your child to return to school. The following information should be given to their teacher and school nurse:

- Medications: may need a note from your child's physician if your child must take medication while at school.
- Importance of reporting exposure to contagious illness (especially chickenpox) to which your child has been exposed.
- What to do if your child becomes ill at school, including how to reach your child's transplant nurse coordinator.
- Frequency of blood drawing and transplant clinic visits so they are aware of days when your child will be late or absent from school.

EXERCISE

Daily exercise is strongly recommended post-transplant. Your child may participate as soon as they feel up to it. The only restriction is in the first six to eight weeks while the breastbone is healing after the surgery. During that time, no driving, lifting weights greater than five pounds (varies with smaller children), no lifting arms higher than shoulders, or any other activity that puts stress on the chest. After eight weeks, your child may participate in any physical activity in which they are interested. We recommend that the older children start a formal rehab program. These programs are 12 weeks long and consist of monitored, gradual exercise. This often builds not only endurance, but confidence too. Exercise helps to maintain weight, reduce loss of calcium from bones, and improve the proportion of muscle to fat body stores. In addition, exercise may lower blood pressure and help reduce stress.

DIET

Diet recommendations will depend on your child's disease process and nutritional status. Prednisone may increase your child's appetite and thus your child's weight. We will follow weight gain and weight loss in clinic. A dietician will be available for recommendations and concerns. Older children will benefit from drinking plenty of water or non-caffeine type drinks to keep their kidney function at an optimum. Remember, several of the medications your child will be taking post-transplant are hard on the kidneys. Dehydration can be harmful to the kidneys; drinking plenty of fluids will be beneficial.

SKIN CARE

Skin problems (usually minor) are very common in transplant patients. Patients who take immunosuppressant medication are at an increased risk for skin and lip cancers. There are things you can do to help decrease your child's risk.

- Your child needs to apply lip balm and sunscreen lotion with a SPF (sun protection factor) of at least 30 **every day, rain or shine**. Apply the lotion to all exposed areas, especially the face, ears, neck and hands. Remember that sunscreen lotions wash off. Reapply the lotion as needed, especially after swimming.
- Avoid midday (10 a.m. to 3 p.m.) sun when ultraviolet rays are the strongest.
- Wear a hat and long sleeves when outdoors.

Oily Skin or Acne: Your child, especially in pubertal or post pubertal stages, may develop acne on the face, chest, shoulders, or back. Acne post-transplant is mostly due to the medication Prednisone. Primary measures used to control the acne are aimed at removing the excess oil and preventing formation of "white heads" or "black heads". Wash the areas of acne three times a day, scrubbing gently with a soapy washcloth to remove the oil, dead skin and bacteria. Neutrogena soap works well, but any drying soap is fine. Rinse soap off the skin completely to leave pores open and clean. Use a clean wash cloth each time. Shampoo hair and scalp frequently and keep the hair away from areas of acne. Benzoyl peroxide cream or lotion (5-10 percent), can be purchased over the counter and is helpful in drying the acne. When acne is present, it is best not to use cosmetics, but

if you must, use them sparingly. If the skin becomes dry, consider reducing the frequency of washing and application of medication. Remember that drying the skin is the objective of the treatment. Do not apply skin lotions to treat dry skin. If acne persists, we will refer you to a dermatologist. Please check with your transplant nurse or doctor.

Dry Skin: Use a mild soap like Dove for bathing and apply body lotion after bathing if your child has problems with dry skin without acne. Keri Lotion, Curel, and Moisturel are good over the counter lotions.

Skin Lesions: Warts may be particularly difficult to treat after transplant since they are caused by a viral infection. Moles that are changing, raised skin lesions, or sores that do not heal, should be brought to the attention of the transplant nurse or doctor. We will refer you to a dermatologist for these problems.

Cuts and Scratches: Prednisone can cause the skin to become thin, making it tear, scratch, or bruise easily. Keep the skin clean so such areas do not become infected. Keep minor cuts and scratches clean and dry by washing with soap and water. Cleanse with hydrogen peroxide if desired. For large cuts, animal bites, or cuts that appear infected (redness, swelling, pus, tenderness), contact the transplant nurse. Antibiotic therapy may be indicated.

HAIR CARE

Prednisone and Cyclosporin will affect the condition of your child's hair. Older children may want to avoid tints, dyes, bleaches, and permanent wave solutions because they may make your child's hair break. We recommend that your child wait until their Prednisone dose is less than 20mg/day before they have a permanent wave or other hair treatment.

DENTAL

Dental visits are recommended every six months. Wait until six months after transplant to schedule the first visit. Your child will require prophylactic antibiotic therapy before any dental cleaning or work. The mouth is a warm, moist area where bacteria exist in high numbers. Bacteria may enter the blood stream during dental work, therefore we recommend following the American Heart Association Guidelines for Dental Prophylaxis.

Good mouth care, including brushing teeth, tongue, palate, and flossing should be done regularly to prevent yeast infections in the mouth and painful swollen gums. Overgrowth of gum tissue on the teeth (called gingival hyperplasia) is a side effect of Cyclosporin and seems to be exacerbated by poor oral hygiene. Oral surgery to cut the gums back off the teeth may be necessary in some cases.

EYES

We recommend yearly eye exams by a pediatric ophthalmologist because your child is susceptible to cataracts and glaucoma from long term use of Prednisone.

GYNECOLOGY

Adolescent girls should have a yearly gynecological examination including Pap Smears.

VACCINATIONS

Your child may *not* have live virus vaccines. This includes MMR, Varivax (chicken pox vaccine) or Oral Polio. We recommend annual flu shots in the fall for our patients. All family members are encouraged to also receive an annual flu shot.

SMOKE

Your child must stay away from all forms of tobacco smoke. Smoke causes inflammation within the lungs whether first-hand or second-hand, making it easier to develop a lung infection. Your child should stay away from smoked filled areas as much as possible. If family members smoke they should smoke outside of the home and the family car.

MEDIC ALERT JEWELRY

We advise all transplant recipients to wear a medical identification bracelet or necklace. Information about Medic-Alert jewelry can be obtained by calling 800.ID.ALERT, or ask your transplant nurse for an application.

We suggest the following information:

- List the type of transplant your child received, "Immunosuppressed", and any allergies. Include

St. Louis Children's Hospital, 314.454.6000

and your local primary physician in the emergency contact section.

PETS

If you have a pet, it is important that it visits the veterinarian on a regular basis. Your child should wash his hands after touching or playing with your pet. The child should never change kitty litter because of the potential infectious agent toxoplasmosis. We recommend against birds as pets because of the potential airborne infectious agents in their stool. Some reptiles carry salmonella in their stool, therefore if your child handles such animals they need to wash their hands thoroughly afterwards.

TRAVEL

When packing for your vacation, make sure you have an adequate supply of your child's medications, including some extra, in the event you experience delays in your travel plans. If you are flying, carry the medications, in their original bottle, with you on the plane. Make sure you carry your child's insurance card and the phone numbers in the event your child becomes ill.

If you and your child are traveling outside of the U.S., you will need a letter from your child's transplant physician verifying all of your child's medications to show with their passport as they go through customs. Use caution in what your child eats and drinks. For instance, only water and ice from adequately chlorinated sources can be considered truly safe. If you are unsure, it's best to have your child drink only bottled or canned water and soft drinks. Select food with care to avoid illness. Avoid unpasteurized milk and milk products and eat only what can be peeled or has been cooked and is still hot. If your child needs medical care while abroad, contact your travel agent, American Embassy or Consulate for names of physicians or hospitals.

TRANSITIONING TO AN ADULT CENTER

Once your child reaches eighteen to 21 years of age, we feel that they are best served in an adult transplant unit. We generally transfer them to the Barnes-Jewish Hospital Transplant Team, however, if you wish, your child could be followed by an adult transplant center near their home or college. We can help you identify a reputable transplant center if you wish. When your child is ready to transfer we will schedule a final appointment with us at St. Louis Children's Hospital. We will have you sign a release of medical information form so we can forward your child's medical records to the new transplant center. Once the adult center has received a copy of your child's records, we will have you make your first appointment. We will continue to follow your child until they have been seen at the adult center so that there is no interruption in your child's care.

As your child moves toward adulthood it is our responsibility as health care providers and your responsibility as parents to prepare them for transition into the adult medical system. We have outlined critical milestones for patients to achieve prior to transfer to adult care and will work with you and your child to meet these important goals. We realize this time of transition to independence is a complex process and will take several years. Starting at approximately age 14, we will ask that your child be seen alone for a portion of their clinic visit to help them develop skills in communicating with medical providers. We will then invite the parent back into the clinic room to review the plan of care. We realize maturity and developmental readiness is a better indicator of capabilities versus chronological age so we will work with each family individually.

CRITICAL MILESTONES:

- Understanding of and ability to describe original cause of organ failure and need for transplant.
- Awareness of long and short-term implications of the transplant condition on their overall health and other aspects of their life:
 - Infection prevention
 - Routine surveillance
 - Academic and vocational goals
- Comprehension of the impact of their illness on their sexuality and reproductive health
 - Impact of pregnancy on their own well being
 - Effect of medication on fertility and potential
 - Teratogenicity (congenital abnormalities)
 - Role of genetic counseling
 - Risk of STD
- Demonstration of a sense of responsibility of their own healthcare
 - Knowledge of medications: indications, doses
 - Call for own prescription refills
 - Prepare own medication boxes
 - Independently communicate their own healthcare needs to their providers
 - Know when and how to seek urgent medical attention
- Ability to make, keep, and follow through with their own health care appointments.
- Understanding of their medical insurance coverage and eligibility requirements.
 - Verbalize importance of adherence to medical regimen
- Capacity to provide most self care independently
- An expressed readiness to move into adult world

IMMUNIZATION INFORMATION

Vaccines are developed to prevent certain illnesses and contain either live or killed organisms. Because your child's body has been purposefully immunosuppressed to prevent rejection, your child is at risk for infection. The introduction of live organisms through immunizations/ vaccines would result in developing the disease that the vaccine was designed to prevent. Following a transplant, **NO LIVE VACCINES** should be given.

It is important that we receive a list of vaccines that you or your child has had during the evaluation and listing process. The Immunization Action Coalition provides an updated handout on the internet detailing vaccines your child should have received and which ones MAY be due. This website is updated yearly or as new regulations occur. The website address for the Immunization Action Coalition is **immunize.org**. There is no copyright approval necessary; you may print directly from the website for updated schedules. This should be used as a guideline only. Your child's immunization schedule may differ.

DO NOT GET THESE VACCINES POST-TRANSPLANT:

Mumps, Measles, Rubella (MMR)

Polio (oral) or OPV

Varicella (Chickenpox)

Yellow Fever

Intranasal Influenza Vaccine (FluMist)

Typhoid (oral)

BCG

Rotavirus

YOU MAY GET THESE VACCINES POST-TRANSPLANT:

Tetanus

Diphtheria, Pertussis, Tetanus (DPT)

Polio (injectable) or IPV

Hemophilus influenza B (HIB)

Hepatitis B (Hep B-series of three)

Flu vaccine

Hepatitis A (Hep A-series of two)

Typhoid (injectable)

Pneumonia vaccine – Pneumovax or Prevnar

HPV

Meningococcal

While not a vaccine, your child may receive the:

Mantoux Tuberculin skin test

Synagis

Keep in mind that if immunizations are given too soon after transplant (a month or so) the vaccinations may not take effect as they would later when your child's immunosuppressive medicines are not as high.

DIET AND NUTRITION

Optimizing normal growth for your child is important both before and after transplantation. Many things impact your child's growth: the severity of your child's illness prior to transplant, nutritional status, genetic potential, other medical conditions/diagnoses, and the medications they may take after transplant. Prior to transplant, and at each clinic visit after transplant, your child's height and weight will be measured to ensure your child is growing as well as possible. A Registered Dietitian Nutritionist (RDN) will be working with your child prior to transplantation as well as after transplant to help with nutritional concerns that may affect their health, and with ways to optimize their health through nutrition and healthy lifestyle. Please see Appendix A for general tips and guidelines to choosing healthy foods and planning healthy meals for your child.

If your child is not gaining weight appropriately, special formulas, nutritional supplements and nutrition additives may be added to your child's daily diet. In some cases, it may be necessary to give extra supplemental nutrition to your child via a feeding tube into their stomach or intestines. At times supplemental nutrition may be given intravenously using Total Parenteral Nutrition (TPN), though this is rare.

After your child receives a transplant, weight gain can be an important part of the healing process. Often children are behind on nutrition or underweight due to illness prior to transplant and may be encouraged to gain weight. After transplant, some patients will experience "catch-up" growth and may achieve an improved height and weight pattern compared to how they were growing prior to transplant. In many cases this catch up growth does not occur until 6 months or more after transplant.

It is important to know that some (but not all) patients gain excessive weight after transplant. Your child's medications themselves do not cause weight gain. There are certain medications, such as steroids, that may cause an increased appetite. Just feeling better after transplant in combination with foods tasting better may also increase their appetite. Because of this increased appetite a child may be tempted to eat

more calories than they need, which causes weight gain. When a child is on high doses of steroids it may be difficult to avoid some weight gain due to increased appetite. It will help to encourage low calorie foods, such as fruits and vegetables, when it seems like your child may want to snack all the time. It is important to avoid sugary beverages, and foods with low nutrition and high calories, as this may cause excess weight gain given an already increased appetite. When steroids are weaned to lower doses or discontinued, healthy well balanced meals, planned snacks and healthy activity levels can help maintain a healthy weight for life.

It is usually beneficial for the whole family to adopt a healthier lifestyle with family meals and planned snack times. It can be important to encourage activity after transplant, if your child can be physically active, to help your child maintain a healthy body weight. It can be helpful for families to do moderate exercise together, making it part of your lifestyle.

Drinking appropriate amounts of fluid is an important part of your medical care after transplant. It is important that these fluids in general do not contain calories. We ask that you limit sugary drinks such as sodas, fruit drinks (Kool-Aid, Capri Sun) and even fruit juices to no more than 4 ounces (120 ml) per day to avoid excess calories. Water and milk are most encouraged and should be the majority of the fluids your child will drink. Other sugar free, calorie-free beverages may be appropriate as well, and you can discuss these options with your transplant dietitian.

BONE HEALTH AFTER TRANSPLANT

A number of factors can affect bone health both before and after transplant. Vitamin D and Calcium are important nutrients for bone health.

For a number of reasons your child may not have adequate Vitamin D levels in their body. This may be due to medical causes, less sunlight exposure or sunscreen use. Very few foods contain vitamin D naturally. Some foods that do contain Vitamin D are fatty fish (tuna, mackerel and salmon), egg yolks and

mushrooms. Vitamin D is also fortified in some foods such as cow's milk, soy milk, cereals and orange juice. Because it can be difficult to get adequate Vitamin D from foods alone, additional Vitamin D dietary supplements may be needed.

A diet low in calcium can contribute to decreased bone density. Steroids can cause bones to lose calcium particularly if dietary calcium is inadequate. People who are physically inactive also have a higher risk for decreased bone density than people who are more active.

Dairy products are the main sources of calcium in our diet and should be included if possible to help keep bones strong. Choosing at least 3 servings of milk and dairy products a day will help you get more calcium in your diet. If your child does not eat or tolerate dairy products talk to your child's dietitian about other ways to get adequate calcium. Weight bearing physical activity can help build bone mass, so regular exercise can be very helpful. Transplant patients may need supplementation of Calcium and Vitamin D if they can't meet their needs for these nutrients with their diet alone.

DANGEROUS FOOD INTERACTIONS WITH TRANSPLANT MEDICATIONS

The fruits and juices listed below may cause an interaction with your immunosuppression levels, and this is further described in the medication section. These fruits should be avoided. The potential food and medication interactions still occur if you separate the time of medication administration and the fruit consumption, therefore it is important to always avoid grapefruit and the other fruits listed below that can interact with your immunosuppressive agents.

- Grapefruit, grapefruit juice or any foods containing grapefruit needs to be completely avoided due to interaction with immunosuppressive levels. Some citrus-flavored drinks have a grapefruit extract in the "citrus blend" that is listed on the ingredient list. Although most of these drinks would have "grapefruit" in their name, there are several beverage products that don't have the word "grapefruit" in the product name, but have been verified to contain grapefruit in their citrus blend. These are: Sun Drop, Diet Sun Drop, Fresca, Diet Fresca, Squirt, Diet Squirt, Ruby Red Squirt, and Citrus Blast and they should be avoided with

immunosuppression medications. If you drink a beverage that contains a citrus blend and are not sure if it may contain grapefruit, please talk to your dietitian before using.

- Some studies suggest that the following fruits may also cause fluctuations in some immune-suppressive drug levels: papaya, pomegranate and star fruit use with caution and talk to your transplant team if you eat these foods.
- Seville Oranges also known as "Bitter Oranges" should be avoided due to interaction with immunosuppressive levels. Typical oranges in grocery stores, that are sold to be eaten as fruit, as well as tangerines, clementine oranges and mandarins are ok to eat. Seville oranges (bitter oranges) would rarely be sold as a fruit to eat alone because they are so sour. They are used often times to make orange marmalade, so orange marmalade should be avoided. The extract of Seville or Bitter orange (and Seville/Bitter orange peel) also has been marketed as dietary supplement purported to act as a weight-loss aid and appetite suppressant.
- Pomelo is a thick skinned fruit which is similar botanically to grapefruit. It will also need to be avoided. It is a fruit that is native to South and Southeast Asia and the peel is sometimes used to make marmalade, can be candied, and is sometimes dipped in chocolate.

VITAMIN/MINERAL AND OTHER DIETARY SUPPLEMENTS

It is recommended that before your child would start taking any vitamin and mineral supplements that you discuss this with your transplant team and dietitian. Some vitamin and minerals in large doses can potentially interact with medications your child is taking.

Also, do not take any herbal supplements or homeopathic remedies unless you check with your transplant team first. These may mix with your transplant medications in a way that can make them less effective. This may harm your transplanted organ. Another concern is that herbal and botanical preparations include a variety of products derived directly from plants. They may be sold as tablets, capsules, liquid extracts, teas, powders, and topical preparations. There are no manufacturing regulations for the cleanliness or purity of these products. Therefore, there is a danger the products may be contaminated with fungus, bacteria, parasites, or other chemicals, which can cause significant illness to a person with an impaired immune system.

WATER SAFETY FOR TRANSPLANT PATIENTS

Cities and Municipalities usually have tap water that is regulated by The Environmental Protection Agency (EPA). Bottled water is regulated by The Food and Drug Administration (FDA). Both the EPA and the FDA have similar standards to ensure the safety of drinking water. City Tap Water is generally considered safe for transplant patients. City tap water is known generally to be just as safe as bottled water. Well water is not regulated by the EPA and can have potential contaminants.

Tips regarding water safety:

- Close attention should be paid to directions given during local governmental recommendations for 'boil water' advisories for any waterborne pathogen. If your city or municipality has FREQUENT boil orders, you may want to talk to your dietitian regarding safety of your home tap water.
- Well water from private wells should be avoided because of the risk of Cryptosporidium, Giardia and bacterial Coliform contamination. Even if your well has been screened, it is difficult to know whether contamination could have occurred between screenings.
- Transplant recipients should not drink water directly from lakes or rivers because of the risk of cryptosporidiosis, giardiasis and bacterial pathogens.

If bottled water is your main source of drinking water due to a well source, you could be missing the benefits of fluoride. Fluoride is a naturally occurring mineral that helps prevent tooth decay. Water fluoridation is a community health measure that is recognized for its role in preventing tooth decay. If you have to drink mostly bottled water, keep in mind the fluoride content of bottled water varies greatly and the vast majority of bottled waters do not contain optimal levels of fluoride and some contain no fluoride. When water is treated with distillation or reverse osmosis before it is bottled, the fluoride is removed. Currently the U.S. Food and Drug Administration (USDA) does not require that bottled water companies indicate fluoride content on bottled water labels unless fluoride has been added to the water. To determine the fluoride content of your bottled water you will need to contact the company who bottles the water to ask the fluoride level. Amounts of fluoride are the same whether they are reported in parts per million or milligrams per liter. One ppm is equal to 1 mg/L. To help prevent tooth decay water should contain 0.7 to 1.2 ppm of fluoride. As you determine if the level of fluoride in your bottled water is adequate for your child keep in mind these things...

- How much bottled water do you or your child consume each day?
- Is bottled water also used for meal preparation?
- Is another source of drinking water used during the day, for example an optimally fluoridated water supply at day care, school or work?

Fluoride supplements require a prescription and need to be used with caution. A 2010 American Dental Association (ADA) guideline recommends fluoride supplements be prescribed only to children determined to be at high risk for the development of caries whose water source is suboptimal. Never add a fluoride supplement to your child's regimen without discussing it with your transplant doctor or transplant team, as it is possible to get too much fluoride and fluoride supplements need to be used with caution.

FOOD SAFETY AND TRANSPLANTATION

Food safety is a very important part of your child's transplant care because of immunosuppression after transplant that can make them more susceptible to food borne illness. Food borne illness can be more severe in immunosuppressed children.

INFANT FORMULA SAFETY

Ready to use infant formula is sterile as packaged. It also is very expensive in relation to other products. Liquid Concentrate infant formula is also sterile as packaged, keep in mind water added needs to be from a safe source or this could be a potential risk for contamination. When using liquid concentrate, the can opener needs to be cleaned every time before opening a can to ensure cross-contamination doesn't occur from previous uses.

Please note that powdered infant formula is not sterile. It may contain bacteria (Cronobacter or Salmonella) that can cause serious illness in infants that are immunosuppressed. If your child is taking powdered infant formula please see Appendix B regarding proper preparation of powdered infant formula to reduce the risk of serious illness from these potential contaminants.

BREAST MILK: HANDLING AND STORAGE

If you are using pumped Breast Milk for your child it is important to handle it safely to avoid potential bacterial contamination.

How do I store fresh breast milk at home safely?

- Breast Milk can remain at room temperature for 4 hours.
- Breast Milk can be kept in the refrigerator for 5 to 7 days at 39°F.
- Breast Milk can be kept in a refrigerator's freezer up to 6 months.
- Breast Milk can be kept in a deep freezer up to 12 months if kept at -4°F.

Tips for thawing and warming Breast Milk:

- Thaw in a refrigerator. Do not thaw breast milk at room temperature. It may take up to 12 hours for 2 ounces of frozen milk to thaw in the refrigerator.
- Lukewarm water should be used for thawing and warming breast milk because it is about the same temperature as the human body, 98.6°F.
- When thawing breast milk in lukewarm water, the water level should not be higher than the top of the bottle or syringe to prevent contamination.
- Do not use hot water to thaw or use a microwave to thaw. The elevated temperatures destroy antibodies in the milk.
- Partially thawed milk (less than 50% thawed) that will not be used within 24 hours may be refrozen.
- Fully thawed milk must be used within 24 hours and cannot be refrozen.
- Any remaining fully thawed milk needs to be discarded after 24 hours.

TRANSPLANT MEDICATIONS

OVERVIEW

This next section includes an overview of your child's medications, plus specific information about the medicines he or she will likely be taking. Please read this section carefully and ask any questions you may have. Following is a list of dosage forms and abbreviations that you may see. This is for informational purposes only and need not be memorized.

Your child's medications are prescribed in grams, milligrams or micrograms:

- One gram (g) = 1000 milligrams (mg)
- One milligram (mg) = 1000 micrograms (mcg)
- One teaspoon (tsp) = 5 milliliter (mL)
- One tablespoon (tbsp) = 15 milliliter (mL)

Your child's medications are administered according to a preset schedule:

- Daily (one a day)
- BID (twice a day)
- TID (three times a day)
- QID (four times a day)

Your child may take his/her medications via different routes:

- PO (by mouth)
- NG (by nasogastric tube)
- SL (sublingually — under the tongue)
- IV (intravenously)
- Inhaled

MEDICATIONS

Immunosuppressive therapy is necessary to prevent or decrease the body's ability to reject the new organ. The goal of therapy is to induce the body's tolerance of the new organ while leaving the immune system intact to provide protection against infection. A combination of drugs is utilized to most effectively meet this goal. The type, dosage, and frequency of these medications are prescribed on an individual basis. Each person's medications are prescribed according to his or her blood levels, body size, absorption, and tolerance of the drug.

These are powerful medications that have side effects. Therefore, they must be taken **EXACTLY** as prescribed to maintain the delicate balance in your child's body. Taking too little of the drugs may allow the immune system to destroy the new organ. However, too much of these drugs may alter the body's ability to fight off infections. Any alteration in medications that is not prescribed by your doctor may lead to serious consequences! If you are concerned about any medication side effects please contact your transplant nurse coordinator. There are several medication "rules" which you and your child must follow:

1. Never stop taking medication unless your doctor tells you to do so.
2. Do not skip a dose of medicine. If your child misses a dose, do not double the following dose. Please call your transplant coordinator for further instructions.
3. Do not take medicine that the doctor has not prescribed. Tylenol is acceptable in moderation.
4. Do not take medications at times other than what has been written on the schedule unless you have discussed this with your child's doctor. Make a schedule and get into the habit of taking medications at the proper times.

5. If your child becomes ill and cannot take medication or if he/she is throwing up or having diarrhea, please call your transplant coordinator for further instructions. If your child throws up within 15 minutes of taking medications, please repeat dose. Do not repeat the dose more than once. If it has been greater than 15 minutes, DO NOT REPEAT DOSE.
6. Do not allow your child's medicine to run out. Refill your child's medication before the bottle is empty. It is important to not miss a dose. Allow 7 days for your pharmacy to refill prescription.
7. Please check the expiration date on all medications. Do not take expired medications.
8. Please check liquid medication concentrations when refilled at the pharmacy. Liquid medications come in many different concentrations so check carefully for proper dosage.
9. Please learn medications by brand and generic name. It is also very important that you know medication doses by concentration or strength (gram, milligram, microgram, or units) as well as form (capsule, tablets, liquid).

For children too young to take pills, we will prescribe a liquid form of the medication. All doses of the liquid medication will be measured by a syringe. The nurses will teach you how to use different size syringes and draw up the correct dose of medicine.

It is best to get in the practice of giving your child the medications directly out of the syringe so it is not spilled or wasted. We will send you home with a large supply of syringes. You may wash and reuse the syringes as long as the numbers are visible. When you need more, you can refill the prescription at the hospital or your local pharmacy.

Since children on immunosuppressant medicines are at a higher risk for infections it is important to treat each infection appropriately. Antibiotics are important medicines used to treat infections caused by bacteria. If antibiotics are used inappropriately they may cause unnecessary side effects and may not work as well in the future. This is called "antibiotic resistance." Bacteria can become "super bugs" which are not able to be killed by antibiotics. You can help to make sure your child's infection is treated appropriately:

- Ask if the infection is caused by a bacteria or virus. Viruses should not be treated with antibiotics.
- Take medications as prescribed by your doctor. Do not skip doses or stop the course early if your child is feeling better (unless your doctor tells you to do so).
- Never save antibiotics for the next time your child is sick.
- Never give your child antibiotics prescribed for someone else.

Store all medications out of the reach of young children. If accidental swallowing of any medication occurs, take the child and the medication to the nearest Emergency Center immediately.

Never stop any medication unless instructed by your child's doctor.

DRUG INTERACTIONS

Many medications (both prescription and over the counter) can interact with your child’s immunosuppression (anti-rejection) in an undesirable way. For instance, some antibiotics affect the absorption of these medicines, either causing the drug levels to become too high or too low. We have provided a brief list of medications known to interact with your child’s transplant medications. Prior to starting your child on any of these medications, you must notify the transplant team.

This is just a small list of medications known to interact with your child’s transplant medicines; there are many others that interact as well.

Do not give your child any over-the-counter medications or medications prescribed by a physician who is unfamiliar with your child’s medical history, without first consulting the transplant team.

Medications are essential to the success of your child’s transplant. Your child will be on many different medications early after his/her transplant. Two or three of these will be immunosuppression (anti-rejection) medications. Without these medications, the body will reject the new organ. Each medication is prescribed for your child’s individual needs and is adjusted according to the body’s response.

COMMON MEDICATIONS THAT INTERACT WITH IMMUNOSUPPRESSION		
Medications used to treat infections (bacterial, viral, fungal, or other) including:	Over the counter medications to treat pain, cough/cold, or gastrointestinal (GI) issues:	Other medications with known drug interactions:
Biaxin (clarithromycin) Ciprofloxacin Fluconazole Itraconazole Voriconazole Rifampin	Ibuprofen (Advil, Motrin) Naproxen (Aleve) Nyquil Pepto Bismol Pseudoephedrine (Sudafed)	Dilantin (phenytoin) Phenobarbital Reglan Tegretol Herbal supplements

The medications must be taken as directed; DO NOT change or quit giving your child’s medications unless instructed by a member of the transplant team. We expect parents, and eventually the child, to understand the actions of each medication; so please be sure to ask questions to clarify any information given to you. Understanding the medications enables you to better identify the side effects when they occur.

Prior to discharge, your family will begin to administer medications to your child, with the assistance of your nurse. Before discharge from the hospital, we will teach you:

- the generic and brand names of each medication;
- what each looks like;
- the purpose and action of each drug;
- how to determine the correct dosage;
- precautions required for each one;
- how and when to take the drugs; and
- the common and uncommon side effects for each drug.

Before discharge, your transplant nurse coordinator will give you a medication schedule for your child listing the names of the drugs, dose, any special instructions, and times to administer the medications. Each time you or your child is getting ready to take their medications, you should have the medication schedule in front of you as you get the medications ready.

Each time a change is made in medication (either the dose or the frequency), you should make the change on the schedule. Medications should be given by your schedule, not according to the instructions written on the medication bottle. If you have any questions, please contact your transplant nurse coordinator.

Be sure to store all the medications in their original containers. This will be helpful in keeping up with the expiration dates and who prescribed each drug. Store all medications away from heat, direct light and moisture, each of which can cause deterioration of the drug. Always consistently administer medications at the same time of day. Each of the

routine medications needs to achieve a stable level in the blood. Monitoring of these blood levels will be done at intervals and the test results are used to make adjustments in medication dosages. Therefore, it is crucial that medications are given in a consistent manner.

Always carry your child's medication schedule with you so changes may be made if necessary. You may also wish to provide your child a copy of medications for his/her wallet. Should your child require hospital admission, please bring all your medications.

The pharmacy may change brands or liquid concentrations without your knowledge resulting in an improper dosage. Pay close attention to your label and the appearance of your medication. Ask the pharmacy or transplant team if the medication looks different than usual.

IMMUNOSUPPRESSANT MEDICATIONS

PROGRAF® (Tacrolimus)

Action:

Tacrolimus is an immunosuppressant drug that decreases the number of specific white blood cells to help prevent rejection.

Preparation:

Available in 5 mg, 1 mg, and 0.5 mg capsules. Also available as a liquid preparation compounded by a pharmacy.

Frequency:

Twice a day (bid) at 12 hour intervals.

Possible Side Effects:

- **Infection:** Because this drug suppresses the immune system, infection is one of the leading potential risks.
- **High blood sugar:** Tacrolimus may cause high blood sugar and progress to diabetes.
- **Kidney Impairment:** Kidney function is carefully monitored in patients on this drug because kidney damage can occur.
- **Tremor:** Fine shaking of the hands may occur during the first month of using this medicine. If it worsens and/or interferes with the child's daily activities, contact your child's doctor. Seizures are a rare complication seen in the first several months.
- **High Blood Pressure:** This may be a common early side effect and can be controlled with blood pressure medicine.
- **Hair Loss:** Sometimes occurs but usually not permanent. Hair will grow back.

Special Instructions:

- There are a number of medications that interact in various ways with tacrolimus either increasing or decreasing tacrolimus levels in the bloodstream. Your child should not take any other medications (over-the-counter or prescription) without checking with the transplant team first.
- Do not take tacrolimus with grapefruit or grapefruit juice.

- While taking this medicine, lab work will be obtained to monitor the drug level. It is important to have this done as scheduled so dosages can be correctly adjusted according to your child's needs.
- Capsules should not be opened or crushed.
- For liquid preparations, shake the bottle well before drawing up the dose.
- Take consistently with regards to food.

PREDNISONE OR PREDNISOLONE (Orapred®) – Steroid

Action:

Prednisone decreases the body's response to foreign cells by altering the immune system, to help prevent rejection.

Preparation:

Available in liquid preparation and various pill strengths.

Frequency:

Usually given once per day.

Possible Side Effects:

- **Infection:** Because this drug suppresses the immune system, infection is one of the leading potential risks.
- **Increased appetite and weight gain:** Transplant patients taking prednisone often have an increased appetite leading to weight gain.
- **Acne:** Most often occurs on the face but can also occur on the chest and back. Keep affected areas clean and dry. Refer to section on Acne (see page 15).
- **Increased sensitivity to the sun:** Always apply sunscreen to exposed skin when in direct sunlight. A minimum SPF (sun protection factor) of 30 is recommended.
- **Delayed growth:** Slows down growth and delays puberty.
- **Muscle weakness or cramps:** These can be decreased by walking, biking, or doing exercises that strengthen muscles.
- **High blood sugar:** Prednisone may cause high blood sugar and progress to diabetes.

- **Change in Vision:** Cataracts may occur in some patients who receive Prednisone in high doses for a long time.
- **Mood Changes:** Very “up” or very “down”. Children may cry easily, be giggly, or have increased irritability. This usually improves as the child adjusts to the medication and the dose is decreased.
- **Decreased bone density:** Thinning of the bones.
- **Insomnia:** May cause sleep disturbance.

Special Instructions:

- Never stop this medication unless instructed by your child's doctor.
- Take this medication in the morning if possible. This may help alleviate sleep disturbances.

CELLCEPT® (Mycophenolate Mofetil, MMF) or MYFORTIC® (Mycophenolic acid)

Action:

Mycophenolate is an immunosuppressant drug which decreases the number of specific white blood cells which are responsible for rejection.

Preparation:

Mycophenolate mofetil (CellCept) available in 250 mg and 500 mg capsules. Liquid preparation is also available as 200 mg/mL. Myfortic (mycophenolic acid) available in 180 mg and 360 mg delayed release tablets. Preparations are not interchangeable.

Frequency:

Twice a day (bid) at 12 hour intervals.

Possible Side Effects:

- **Infection:** Because this drug suppresses the immune system, infection is one of the leading potential risks.
- **Bone Marrow Suppression:** May decrease white blood cell counts leading to increased risk of infection and decreased platelets, causing bruising. Dosage adjustment is required if this occurs.

- **GI Distress:** Signs and symptoms include nausea/vomiting/diarrhea/cramping. Generally this resolves in time.
- **Birth defects:** Females of childbearing age on mycophenolate are at higher risk for birth defects.

Special Instructions:

- Capsules should not be opened or crushed.

IMURAN® (Azathioprine)

Action:

Imuran is an immunosuppressant drug which decreases the number of specific white blood cells which are responsible for rejection.

Preparation:

Available in 50 mg tablets. Also available as a liquid preparation compounded by a pharmacy.

Frequency:

Once per day, usually at bedtime; need to take consistently at the same time every day.

Possible Side Effects:

- **Infection:** Because this drug suppresses the immune system, infection is one of the leading potential risks.
- **Bone Marrow Suppression:** May decrease white blood cell counts leading to increased risk of infection and decreased platelets, causing bruising. Dosage adjustment is required if this occurs.
- **Hair Loss:** Sometimes occurs, but usually not permanent. Hair will grow back.

RAPAMUNE® (Sirolimus) or ZORTRESS® (Everolimus)

Action:

Sirolimus and everolimus are immunosuppressants used to prevent transplant rejection.

Preparation:

Sirolimus is available in tablet and liquid form. Everolimus is available in tablet form.

Special Instructions:

- The liquid form of sirolimus must be mixed in 2 ounces (60 ml) of water or orange juice in a plastic or glass cup. Stir the solution well and drink immediately. The cup should then be refilled with 4 ounces (120 ml) of water or orange juice, stirred, and the patient should drink this as well.
- **DO NOT** use sirolimus with apple juice, grapefruit juice or milk products. Patients who have taken sirolimus undiluted have developed mouth ulcers.

Possible Side Effects:

- Infections.
- Impaired wound healing.
- High cholesterol and high triglycerides.
- High blood pressure, edema (swelling), fever, headache, acne, upset stomach, decrease in white blood cell and platelet counts, and joint pain.
- Renal impairment.

Special Instructions:

- While taking this medicine, lab work will be obtained to monitor the drug level. It is important to have this done as scheduled so dosages can be correctly adjusted according to your child's needs.
- Take consistently with regards to food.

INFECTION PREVENTION MEDICATIONS

BACTRIM®/SEPTRA® (Sulfamethoxazole/ trimethoprim – (SMZ-TMP))

Action:

Bactrim is given to children for the treatment and/or prevention of urinary tract infections (kidney/bladder infections). In the case of transplant patients, it is given to prevent a specific type of pneumonia called pneumocystis pneumonia (PCP or PJP).

Preparation:

Bactrim is supplied in both liquid and tablet form. The strength of the liquid is: Sulfamethoxazole 200 mg and Trimethoprim 40 mg per 5 ml (1 teaspoon).

A single strength (SS) tablet contains Sulfamethoxazole 400 mg and Trimethoprim 80 mg.

A double strength (DS) tablet contains Sulfamethoxazole 800 mg and Trimethoprim 160 mg.

Possible Side Effects:

- Rash
- **Bone Marrow Suppression:** May decrease white blood cell counts leading to increased risk of infection and decreased platelets, causing bruising. Dosage adjustment is required if this occurs.
- Sun sensitivity

Special Instructions:

- Please notify your physician if your child has sulfa allergy

FLUCONAZOLE or VORICONAZOLE

Action:

An antifungal used to treat or prevent fungal/yeast infections in the body.

Preparation:

Supplied in IV, liquid, and tablet forms.

Possible Side Effects:

- Increase in liver enzymes.
- Prograf (tacrolimus) levels will run higher when on these medications. Dose adjustments and increased monitoring of tacrolimus levels may be necessary.

Special Instructions:

- Always tell your child's doctor that he/she is taking fluconazole or voriconazole.

NYSTATIN

Action:

Nystatin is an antifungal used to prevent or treat yeast infections (thrush) of the mouth and throat.

Preparation:

Supplied as liquid. Clotrimazole is available in a lozenge form.

Possible Side Effects:

- Side effects are very rare

Special Instructions:

- For infants, apply liquid nystatin directly to gums and inside cheeks.
- Older children should hold the medicine in their mouth for as long as possible (several minutes) and then swallow.
- Do not eat or drink anything for a least 20 minutes after taking nystatin.

ZOVIRAX® (Acyclovir)**Action:**

Acyclovir is an antiviral drug that fights or helps prevent viruses of the Herpes family i.e. Herpes Simplex (virus that causes "cold sores"), Varicella (chickenpox), etc.

Preparation:

Available in 200mg/5 ml liquid preparation. Available in 200mg, 400mg, and 800mg capsules/tablets. Also available as an IV preparation.

Frequency:

Variable, depending on if it's being used for prevention or for treatment.

Possible Side Effects:

- **Bone Marrow Suppression:** May decrease white blood cell counts leading to increased risk of infection and decreased platelets causing bruising. Dosage adjustments are required if this occurs.
- **Kidney Impairment:** Because this drug is cleared through the kidneys, possible damage may occur. Kidney function is carefully monitored in patients on this drug.

Special Instructions:

- Important to increase oral fluid intake while on this medicine.

VALCYTE® (Valganciclovir) or CYTOVENE® (Ganciclovir)**Action:**

Valganciclovir and **ganciclovir** are anti-viral drugs used to prevent and/or treat Cytomegalovirus (CMV).

Preparation:

Valganciclovir is available in 450mg scored tablets. Liquid preparation is also available. Ganciclovir is available in IV form.

Frequency:

Usually once or twice a day (BID). Depends on if used for prevention or treatment of infection.

Possible Side Effects:

- **GI Distress:** Signs and symptoms include nausea/vomiting/diarrhea/cramping. Generally this resolves in time.
- Headaches, Confusion
- **Bone Marrow Suppression:** May decrease white blood cell counts leading to increased risk of infection and decreased platelets, causing bruising. Dosage adjustment is required if this occurs.
- **Kidney Impairment:** Because this drug is cleared through the kidneys, possible damage may occur. Kidney function is carefully monitored in patients on this drug.

Special Instructions:

- Wash hands thoroughly after handling this medication.
- Capsules should not be opened or crushed.

ANTI-HYPERTENSION/DIURETIC**NORVASC® (Amlodipine)****Action:**

Amlodipine is given for the treatment of high blood pressure.

Preparation:

Available in 2.5 mg, 5 mg and 10 mg tablets. Liquid preparation also available.

Possible Side Effects:

- Headache, dizziness
- Swelling of hands and feet

Special Instructions:

- Always tell your child's doctor that he/she is taking Norvasc.

LASIX® (Furosemide)**Action:**

Furosemide stimulates the kidney to remove excess water from the body. There is usually an increase in urine output starting about one hour after the dose and lasting from four to eight hours.

Preparation:

Furosemide oral solution is supplied as 10 mg/ml liquid.

Furosemide is also supplied in 20 mg, 40 mg, and 80 mg tablets.

Possible Side Effects:

- Weakness or unusual tiredness
- Irritability or listlessness
- Sudden weight change
- **GI Distress:** Signs and symptoms include nausea/vomiting/diarrhea/loss of appetite. Generally this resolves in time.
- Dizziness, headaches, blurred vision
- Ringing in the ears or hearing loss
- Light-headedness upon standing
- **Signs of dehydration:** May include inability to make tears, dry mouth, decreased urine output, and sunken eyes.

Special Instructions:

- Once opened, furosemide liquid is good for 90

days.

- When furosemide stimulates the kidneys to release the excessive water in the body, an important body element, potassium, is also washed out of the body. To help replace the potassium you need to include foods from this list in your child's diet to replace the potassium.

All Baby Formulas	Orange Juice
Bananas	Peaches
Beans (pinto or kidney)	Potatoes
Citrus fruits	Prunes
Dried dates	Prune Juice
Milk	

- Contact the dietitian for further nutritional information.

ALDACTONE® (Spironolactone)**Action:**

Spironolactone stimulates the kidney to remove excess "water" from the body without losing potassium.

Preparation:

Available as 25 mg, 50 mg, and 100 mg tablets. Also available as a liquid preparation compounded by a pharmacy.

Possible Side Effects:

- Weakness, unusual tiredness
- Irritability or listlessness
- Sudden weight change
- Abdominal cramping and diarrhea
- Dizziness, headaches, mental confusion
- Irregular menstrual cycle, or swelling of breast tissue
- Deepening of the voice
- **Signs of dehydration:** May include inability to make tears, dry mouth, decreased urine output, and sunken eyes.

Special Instructions:

- Shake the bottle well before measuring.

MEDICATIONS GIVEN FOR INDUCTION OR TREATMENT OF REJECTION

THYMOGLOBULIN® (Antithymocyte Globulin – Rabbit) or ATGAM® (Antithymocyte Globulin – Equine)

Action:

Thymoglobulin and **ATGAM** are very potent immunosuppressants only used in the hospital for prevention or treatment of transplant rejection.

Preparation:

IV formulation

Possible Side Effects:

- Fever and chills
- **Bone marrow suppression:** Decrease in white blood cell count and decreased platelet count.
- Pain
- Headache
- Diarrhea
- Increased blood pressure
- Severe allergic reactions can occur in rare instances. Patients are pre-treated with acetaminophen, antihistamines, and steroids to reduce the severity of adverse reactions. Vital signs and blood work will be used to monitor for adverse effects.

SIMULECT® (Basiliximab)

Action:

Basiliximab is an intravenous medication used to prevent organ rejection.

Preparation:

IV formulation

Frequency:

Given prior to transplant, and then 96 hours post-transplant.

Possible Side Effects:

Because this drug suppresses the immune system, infection is one of the leading potential risks.

IMMUNE GLOBULIN or IVIG (Gamunex®)

Action:

Immune Globulin works on specific cells to treat antibody mediated rejection. It can also be given before and after transplant in patients with high

antibody levels to help prevent rejection.

Preparation:

Available only as an IV infusion and is usually given at the hospital, in clinic or by a home care agency.

Possible Side Effects:

- **Infusion related reactions:** chills, flushing, headache, itching, muscle pain, fever and fast heart rate.

Special Instructions:

- Acetaminophen (Tylenol®) and diphenhydramine (Benadryl®) may be given prior to the infusion.
- The nurse giving the medication will start the infusion slowly and increase the rate as tolerated.

OTHER IMPORTANT MEDICATIONS

MAGNESIUM

Action:

Magnesium is an important element used by the body to complete many enzyme reactions. It is vital for muscle function including heart function. Several immunosuppressant drugs can decrease magnesium levels.

Preparation:

Many tablet and liquid forms of magnesium are available. Please check with your physician for recommendations.

Possible Side Effects:

- **GI Distress:** Generally this resolves in time.
- Muscle weakness

PHOSPHORUS (NEUTRAPHOS® or OSMOPREP®)

Action:

Phosphorus is an important electrolyte in the body. It works together with calcium to keep bones strong and healthy. In patients who are urinating large amounts (i.e. new kidney transplant recipient), too much phosphorus is lost in the urine so it needs to be replaced.

Preparation:

Available as a capsule or individual packets.

Possible Side Effects:

- **GI Distress:** Signs and symptoms include diarrhea and nausea. Generally resolves in time.

Special Instructions:

- Neutraphos capsules and packets must be mixed with fluid. Open capsule or packet and dissolve in at least 2 ½ ounces (75 mL) of fluid of choice (i.e. water, juice, punch, etc) and drink. **DO NOT SWALLOW CAPSULES WHOLE – MUST BE DILUTED.**
- Do not take magnesium or other antacids at the same time as Neutraphos. Allow at least 2 hours between these medications.

CALCIUM**Action:**

Calcium is an important mineral used by the body. It is vital to proper bone structure and many functions of the nerve and muscle systems. For transplant patients, calcium is used to help prevent calcium loss from bone due to steroids (Prednisone).

Preparation:

Many brands of calcium are available. Please check with your physician or dietitian for recommendations.

Possible Side Effects:

- Constipation.

POTASSIUM CHLORIDE**Action:**

Potassium is sometimes given to children who are taking diuretics ("water medicine"). Potassium is a body element, which is very important for proper functioning of the heart and body cells. Although diet usually provides adequate amounts of potassium, children taking diuretics may require more.

Preparation:

Potassium comes in various liquid and tablet forms.

Possible Side Effects:

- Weakness, unusual tiredness, irritability or listlessness
- GI Distress: Signs and symptoms include nausea/vomiting/diarrhea/loss of appetite. Generally this resolves in time.
- Numbness in hands or feet

Special Instructions:

- Potassium has a bitter taste that cannot be completely hidden, but mixing it in different juices and having something to drink immediately afterward helps. It is usually better to take it at the beginning of the meal when the child is hungry. Potassium can also cause an upset stomach; giving it at mealtime helps avoid this.
- **DO NOT REPEAT ANY VOMITED DOSES. IF YOUR CHILD HAS THE "FLU" AND IS FREQUENTLY VOMITING OR HAS DIARRHEA, CONSULT YOUR CHILD'S DOCTOR.**

Many medications will affect the absorption of the immunosuppressive drugs or may interact with them in an undesirable way. Therefore, do not give your child any over-the-counter medications or medications prescribed by a physician who is unfamiliar with your child's medical history without first **consulting the transplant team.**

WHAT TO REPORT

If you have any questions about your child's care after you leave the hospital, please contact one of the transplant nurse coordinators during daytime hours (8 a.m. to 5 p.m. Monday through Friday).

Some things to call the transplant nurse coordinators about are:

1. **Unexplained fever:** temperature above 38.5°C or 100.0°F
2. **Heart-failure symptoms:** decreased exercise tolerance, fluid retention, difficulty breathing, nausea and vomiting
3. **Wound infection:** redness and/or draining from incision site
4. **Medication questions:** any question regarding dose, how to give, if started on new medication, missed dose

5. Exposure to contagious disease:

especially chicken pox

6. Cold or flu-like symptoms:

fever, diarrhea, vomiting, congestion, nasal drainage

8. Diarrhea:

loose, watery stools and/or more than six stools a day

Often you will be directed to the primary care doctor if the issue is not directly transplant related, but the transplant team is always willing to help you get the best care for your child.

If your concern cannot wait until daytime hours, please call the cardiologist on call at 314.454.6000.

READMISSION TO THE HOSPITAL

READMISSION

Readmission to the hospital may occur for several reasons:

- **Fever** – especially if your child has a Broviac (central line)
- **Infections** – such as pneumonia, CMV, UTI, etc. as your child may need antibiotics.
- **Vomiting and Diarrhea** – especially if your child is unable to keep down fluids and/or their medications
- **Observation after a procedure** – i.e. after a biopsy
- **Treatment for organ rejection**

In the event your child is to be admitted to the hospital after transplant, please bring the following with you:

- All current medications

- Medical records (including x-ray films) – if your child was initially seen at an outside physician office or hospital for this current illness or problem
- Current insurance card

In most cases, your child will be admitted on the same floor as they were on post-transplant. However, if your child has an infectious illness such as chickenpox or influenza, they may be on the general medicine or infectious disease floor to decrease exposure to other children who have been transplanted.

TRANSPLANT

COMPLICATIONS

There are many complications that are associated with transplantation. Complications may be a result of the surgical procedure itself or due to side effects from the many medications your child will be taking after transplant. There is no way to predict if your child will develop any of these problems or how severe they may be. Some complications are more severe than others; some are temporary and some are long term. Most complications are treatable however, some complications may result in permanent conditions. If complications do occur, the transplant team will take the necessary steps to treat and/or minimize the problem.

SURGICAL COMPLICATIONS

Surgical complications after heart transplant include but are not limited to graft non-function, heart failure, and post-operative bleeding/hemorrhage.

PRIMARY GRAFT NON-FUNCTION

Primary graft non-function is a very rare but life threatening complication. Malfunction of the new heart results from an intense reaction by your child's body against the new heart graft (hyperacute rejection). Should this occur, your child will have to be treated with increased doses of medications and/or additional therapies to treat this rejection. In rare instances, the new heart may not respond to treatment and will likely result in death.

HEART FAILURE

Primary graft non-function and rejection may cause your child to develop heart failure. Signs and symptoms of heart failure may be similar to those your child was experiencing prior to transplant including increased water retention, more difficulty breathing, and decreased energy level. Signs of heart failure will be closely monitored for post-operatively and if they develop, will be treated aggressively with medications.

POST-OPERATIVE BLEEDING

If your child is going to develop post-operative bleeding, this would most likely occur within the first 48 hours

following transplantation. Signs of bleeding include a rapid or ongoing drop in hemoglobin and hematocrit, increased heart rate, low blood pressure, and increased bleeding from chest tubes. If there is a large amount of bleeding, your child will need to be taken back to the operating room so the surgeon can find the cause of bleeding and stop it. Your child may require additional blood transfusions to help replace the blood that is being lost.

POST-TRANSPLANT INFECTIONS

The immunosuppressant medications that your child will be taking after transplant to prevent rejection will also interfere with your child's ability to fight off infections. Your child will not necessarily be more prone to catching colds or other illnesses but when they are ill, it may take them longer to get over the illness. Additionally, your child is more prone to "opportunistic" infections; these are infections that your child has already been exposed to either prior to transplant or from the transplant itself, that reactivate when your child's immune system is suppressed.

It's very important for you to re-establish your child with their pediatrician once they return home from the hospital. We recommend that you take your child in for a well-visit appointment within the first month after returning home. This will give your pediatrician the opportunity to see your child when they are healthy as well as review your child's transplant course with you.

BACTERIAL INFECTIONS

Bacteria can be found everywhere. We all have bacteria on our skin, in our mouth, and in our intestine. When we are healthy, this bacteria does not hurt us or make us sick. However, children who have had surgery, such as a transplant, or who are on immunosuppressant medications, can develop infections from their normal body bacteria. Bacterial infections are usually treated with oral or IV antibiotics, depending on the severity of the infection.

The following are signs that your child may have a bacterial infection:

- Fever – temperature greater than 101°F or 38.5°C
- Sore throat – may be a strep throat infection
- Redness around your child's incision and/or pus draining from incision, drainage tubes, or central line site
- Pain or burning with urination – may be a urinary tract (bladder) infection
- Difficulty breathing or shortness of breath.

If your child develops any of these symptoms, you need to call your child's transplant nurse coordinator or transplant physician on call for further instructions. For minor illnesses such as earache, we will most likely have you take your child to their pediatrician for exam and treatment. However, before starting your child on any new medications, contact your transplant nurse coordinator to make sure these medications are compatible with your transplant medications. If your child has been transplanted for less than three months, has a central line (broviac), and develops any of the above symptoms, we may ask you to come to the transplant clinic for further evaluation. You should bring extra clothes, as your child may need to be admitted to the hospital for evaluation and treatment.

VIRAL INFECTIONS

Viruses most often cause illnesses such as the common cold, stomach flu, and influenza. In most cases, these illnesses are caught from other people in the community who are currently sick. There is no "cure" for these types of viral illnesses – it just takes time for the virus to go away. There are things you and your child can do however, to help prevent them from getting these infections:

- Practice good hand washing! Most cold germs are passed from your hands to the mucous membranes in your nose and eyes.
- Avoid friends and relatives you know to be ill. If an immediate family member is ill, use common sense: have them use separate drinking glasses, cover their mouth when coughing and sneezing, etc.
- Instruct your child to not share drinking glasses or eating utensils with others, at home and at school.

Should your child develop any of the following symptoms, please contact your child's transplant nurse coordinator or physician on call:

- Fever – temperature greater than 101°F or 38.5°C
- Vomiting and diarrhea – especially if your child is unable to keep fluids and medication down or is having persistent diarrhea (watery and/or more than six stools per day) for more than two days
- Cold symptoms such as cough, earache, sore throat, or runny nose
- Low grade fever, muscle aches, excessive fatigue

There are a few other viruses of which transplant patients need to be aware. The viruses described below can come from different sources:

- For a first time infection, the virus could have been transmitted from the donor organ or from a blood transfusion.
- Reactivation of a person's own virus – in other words, the patient had been exposed to the virus prior to transplant and the virus "reactivated" when the patient was immunosuppressed with medication.

Blood tests are performed on your child and the organ donor prior to transplant to see if they have been exposed to these viruses. Exposure to these viruses does not exclude either the patient or the donor from transplant; it merely helps the transplant team to plan for surveillance of developing infection and treatment after transplant.

CYTOMEGALOVIRUS (CMV)

CMV is a type of virus in the **Herpes Virus Family**. It causes flu-like symptoms such as fever (usually spike a fever at the same time every day), muscle ache, and fatigue. CMV can also affect different organs in the body as well. For instance, the virus can settle in the retina of the eye, cause pneumonia, or cause hepatitis (inflammation of the liver). A medicine called Ganciclovir is used to try to prevent an active CMV infection immediately after transplant; this same medicine is also used to treat patients who develop active CMV. Unfortunately, it does not get rid of the virus completely; it merely returns it to an inactive state. Some transplant recipients have multiple CMV infections.

EPSTEIN-BARR VIRUS (EBV)

EBV is also a member of the **Herpes Virus Family**. It is the same virus that causes mononucleosis ("mono"). It is transmitted the same as the CMV virus – either reactivation of the virus or transmission from the donor organ. Signs and symptoms of an EBV infection include low grade fever, extreme fatigue, sore throat, and swollen lymph glands in the neck. Treatment of EBV infections consists of supportive care and often a reduction in your child's immunosuppressant medications. Reducing your child's anti-rejection medicines will allow your child's natural defenses to combat the EBV infection. In some cases, the EBV virus continues to grow or proliferate within your child's lymph system causing swollen lymph nodes throughout your child's body. This condition is called **Post-Transplant Lymphoproliferative Disease (PTLD)**. PTLD can be pre-cancerous but it can also develop into a lymphoma, which is a type of cancer. In some cases, chemotherapy is given to treat this condition.

HERPES SIMPLEX VIRUS (HSV)

There are 2 types of HSV – Type I and Type II. **HSV Type I** is more commonly known as the virus that causes fever blisters or cold sores on the lips and in the mouth. **HSV Type II** is more commonly known as the virus that causes genital herpes and is spread through sexual intercourse. In both cases, the virus initially causes a tingling sensation followed by redness then small blisters. The fluid in the blisters is very contagious, and if broken open, can spread to other areas. HSV can be treated with a medication called Acyclovir. Should your child develop cold sores, please contact your transplant nurse coordinator.

VARICELLA ZOSTER (VZV, CHICKENPOX, SHINGLES)

Chickenpox is a very common childhood illness that most children tolerate well. For children who get chickenpox after they've received a transplant however, it can be very serious, even fatal. During your child's transplant evaluation, if it's determined that your child has not had chickenpox, we will ask you to have your child be vaccinated with the Varivax, which is the vaccine that prevents chickenpox. If your child is too young to receive the vaccine and/or is transplanted prior to receiving the vaccine, you must notify the transplant office in the event your child is exposed

to chickenpox so he/she can receive VZIG (Varicella Zoster Immune Globulin). VZIG, if given within 72 hours of exposure, can sometimes either prevent or lessen the severity of chickenpox. If your child should develop active chickenpox, contact your transplant nurse coordinator immediately so treatment with Acyclovir can begin. In some cases, your child may need to be admitted to the hospital.

In some people who have had chickenpox, the virus stays in the body and settles along nerves. When patients are stressed or immunosuppressed with medications, the virus can "wake up" and cause what's known as shingles. When shingles occurs, the patient will develop pain, itching, or tingling followed by the development of small blisters. It usually is found on the chest, back, or hip but can occur on the face, arm or leg. It is usually only present on one side of the body. The fluid in blisters is contagious to people who have not had chickenpox. Treatment for shingles is the same for chickenpox; Acyclovir until the lesions crust over. Your child may also need pain medicine until the shingles resolve.

FUNGAL INFECTIONS

The most common type of fungal infection that affects transplant recipients is **candida albicans**, which is a type of yeast. Most often this presents as **oral thrush**. Thrush is thick, white patches that are present on the tongue and inside cheeks. It can also be present in the throat and esophagus. Oral thrush is most often treated with a medication called Nystatin; in severe cases, it may be treated with another medication called Diflucan. Girls can also get **vaginal yeast (candida)** infections. This presents as white or yellow vaginal discharge as well as they may complain of itching and burning in the genital area. In most cases, vaginal yeast infections are treated with Diflucan.

There are many other types of fungus and molds that are in the environment that can be dangerous to transplant recipients if inhaled. These types of fungus and molds are most often found in construction areas (in the dust), compost piles and in bird droppings. If you are remodeling your home, check with your transplant nurse coordinator to determine if your child needs to stay elsewhere while the construction is being done. If your child has a pet bird, they should not clean out the birdcage.

OTHER COMPLICATIONS

ACUTE REJECTION

Acute Rejection is the most common complication in the post-transplant period. It occurs when the immune system of the recipient recognizes, becomes sensitized against, and tries to destroy the transplanted organ. Different types of rejection are possible, including acute cellular rejection (caused by the white blood cells in your body) and antibody-mediated rejection (caused by proteins called antibodies that recognize “foreign” things in your body). **All** patients who have received transplants have some degree of rejection, however, the severity of the rejection is individualized. The chance of your child developing rejection will likely decrease over time, however, it can occur many years after transplant, especially if your child quits taking their medications. Signs and symptoms of acute rejection vary: your child may feel ill or feel perfectly fine. Rejection can be determined through biopsy and sometime echo, or physical symptoms. Acute rejection is usually always treatable by adjusting your child's current immunosuppressant medications or by adding additional medications and treatments.

Rejection of the transplanted heart is classified as mild, moderate, or severe. It is characterized by swelling of the tiny cardiac (heart) cells with destruction, and finally, if left untreated, cellular death. Often such changes are subtle and limited. Many people do not experience any symptoms or feel any different during a rejection episode. Ideally, we like to detect the process of rejection before any damage occurs. Therefore, periodically, a biopsy is performed, as it is the most accurate and reliable method currently available to diagnose rejection in the transplanted heart.

TRANSPLANT CARDIAC ALLOGRAFT VASCULOPATHY (CAV)

CAV occurs when the coronary arteries (small blood vessels that carry blood) thicken and narrow, making it harder for blood to get to the heart. This causes parts of the heart muscle to die when they do not get enough oxygen.

This problem can happen at any time after transplant, the exact cause is unknown. It is typically a long term complication and continues to be the major reason people eventually die or need another heart transplant.

CAV is often difficult to diagnose. Adult patients with blocked coronary arteries have chest pain, but this often does not happen to patients after transplant because the heart does not have any nerve signals.

Coronary angiography is performed at one year after transplant and then every other year thereafter to assess for CAV.

In some cases, nothing can be done to stop CAV from developing. A number of things thought to be helpful include: regular exercise, following a healthy diet, taking medication regularly and not missing any doses, maintaining a normal body weight, not smoking.

At the moment, there is no cure for CAV. A number of medications may be started to try and slow down the narrowing in the coronary arteries and prevent blot clots from forming in the small coronary arteries. In some cases, your child may have surgery to open up the blocked arteries. In very severe cases, your child may need another heart transplant.

SEIZURES

A frequent and often worrisome side effect of some immunosuppressants is **tremor**. Tremors are an uncontrollable trembling or shaking of the limbs that is sometimes accompanied by numbness.

Seizures, however, are a less common but more serious side effect of Cyclosporine and Prograf. Seizures may be tonic/clonic in nature (jerking of arms or legs or whole body) or focal in nature (staring, eye deviation, or unable to speak). These medicines can lower the “seizure threshold” in the brain and then allow the seizures to happen. These seizures are not usually life threatening, however, if they occur outside of the hospital, call 911 for emergency medical assistance. If seizures occur, your child would have to be admitted to the hospital for medical treatment including observation and anti-seizure medications, if needed. Often the anti-seizure medicines can be stopped after several months.

HYPERTENSION

Hypertension, also known as high blood pressure, can be very common after solid organ transplant. Most often this is due to the amount of IV fluids needed during and after surgery but may also be due to medications that are needed after transplant. Sometimes your child's blood pressure will return to normal before discharge. If not, there are many

different medications available to treat hypertension. It is important to remember that diet and exercise are important factors in helping to keep blood pressure in good control.

RENAL INSUFFICIENCY

A common post-transplant complication is renal insufficiency, or decreased function of the kidneys. Decreased kidney function is a known side effect of the anti-rejection medicines Cyclosporine and Prograf. Chronic antibiotic therapy (especially aminoglycosides) and post-operative complications such as bleeding and hypotension (blood pressure that is too low) can also contribute to decreased kidney function. Signs and symptoms of renal insufficiency include hypertension and elevated kidney function tests (i.e. elevated creatinine and BUN). Most transplant recipients have some degree of renal insufficiency, especially in the first few months post-transplant when their anti-rejection drug levels are at their highest. In many cases, once these drug levels decrease, the kidney function improves. Some patients, however, have more significant and progressive renal insufficiency requiring ongoing monitoring by a kidney doctor (nephrologist). In rare cases, these patients may have such severe renal insufficiency that they will need dialysis. There isn't any way to determine how much renal insufficiency your child will experience after transplant; your transplant team will continually monitor your child's kidney function post-transplant for evidence of decreasing kidney function.

PTLD – POST-TRANSPLANT LYMPHOPROLIFERATIVE DISEASE (PTLD)

Heart transplant recipients are at risk of developing **Post-transplant Lymphoproliferative Disease (PTLD)**. PTLD is a form of cancer that occurs most often in children who have never been exposed to the Epstein-Barr Virus (EBV) prior to transplantation, but who are exposed after transplant. The exposure can be from the heart of a donor who was EBV positive or from exposure to EBV in the general environment. EBV is the virus that causes mononucleosis. Children who have compromised immune systems due to powerful anti-rejection drugs are vulnerable to EBV infection complications. An individual who has had EBV in the past will always “test positive” for the virus. This is because once the initial infection with the virus is over, the virus lies dormant

in their system. EBV can still be detected in the blood of a person who had the infection, even if it was many years ago. PTLD tends to develop in children who are newly infected with EBV some time after transplant, although a child who has had EBV in the past may develop PTLD. The EBV may reactivate because the child is immunosuppressed. The Epstein-Barr virus causes “B cells” to proliferate, or grow. B cells are normally occurring cells found in the body but they can become “hyperactive” in response to an EBV infection and cause tumor growth.

PTLD most commonly occurs in the first two to three months following transplantation but may occur many years after transplant. Some patients do not have symptoms at all and the tumor is found during routine physical examination. Other patients have flu-type symptoms. Some patients complain of symptoms related to the organ impairment at the site that the tumor is found. The prognosis of the disease depends on the amount and location of tumor formation and the disease's response to treatment. In a small number of cases PTLD may be fatal. There are a number of treatment options for PTLD. Decreasing the dose of immunosuppression drugs may cause the tumor to shrink or disappear. The risk of organ rejection increases when immunosuppression doses are decreased. The transplant team will follow you closely for signs of rejection. Decreasing the dose of immunosuppression drugs may not be effective in the treatment of PTLD. Surgery, chemotherapy and/or radiation therapy may be necessary to treat PTLD. The Heart transplant team will ask for help with the management of PTLD from medical doctors who specialize in cancer treatment (Oncologists).

OBESITY

A large number of patients gain weight during the first 6 – 12 months after transplant. Your medications do not cause the weight gain. Medications such as Prednisone cause an increased appetite so you are tempted to eat more calories than needed. It is important to begin an exercise program after transplant, with permission from your child's transplant team. We encourage exercise and have never “lost” an organ due to activity. Your transplant team is comprised of a dietitian who is available to guide you with a healthy eating and exercise plan.

DIABETES (Diabetes Mellitus)

A condition characterized by high blood sugar resulting from the body's inability to use sugar (glucose) efficiently. In Type 1 diabetes, the pancreas is not able to make enough insulin; in Type 2 diabetes, the body is resistant to the effects of available insulin. Diabetes is one of the leading causes of kidney disease.

DIABETES POST-TRANSPLANT

Post-transplant Diabetes Mellitus (PTDM) is seen in approximately 5 to 40 percent of post-transplant patients. The leading cause is medication. Steroids increase glucose levels and cause the body to resist insulin. Cyclosporin and Tacrolimus inhibit the release of insulin and add to the effect of the steroids by causing elevated blood sugar. Certain factors predispose patients to developing PTDM: increase in age, family history of diabetes, and African Americans are at higher risk.

The treatment of PTDM may depend on the severity of the hyperglycemia. A change in diet, decrease in steroids, and or insulin may be used to treat elevated blood sugar.

HAIR

Excess hair growth on both the face and body in the transplant population is an unfortunate side effect of some of the anti-rejection medications. This can pose emotional problems in the pediatric and female patients. Both Cyclosporine and Prednisone can cause increased hair growth. Children that are on higher doses of Cyclosporine and prednisone will see more changes than children on low doses of those medicines. The increased growth will be seen about two to four weeks after beginning the medicines. Patients that have not seen the increase in hair growth by 3 months after the transplant are less likely to have this side effect at all.

Most children remove hair with depilatory cream, shaving or waxing. Every method has drawbacks. Shaving or clipper cutting seems to be more preferred method for older children and boys. With waxing, the results last longer, however, it is often more expensive and painful than the other options.

Our dermatology department recommends **Nair Gentler Formula Cream Hair Remover with Baby**

Oil, For Face Too. We have a special protocol to remove the hair. Be sure to test a skin area according to the directions on the bottle. This cream can cause irritation to the eyes and mucous membranes, so apply it carefully.

Instructions for Hair Removal:

- Apply Nair to the affected area. Leave on for 5 minutes **ONLY**.
- Remove with a wet wash cloth, rub with the hair and press firmly.
- Wash skin with soap and water after removing hair. Dry the area and then apply Hydrocortisone ointment 0.5 percent to the area.
- You only need to apply the Hydrocortisone once after removing the hair.
- It is very important to only leave Nair on the skin for 5 minutes, or severe burn may develop.

If the hair growth becomes psychologically debilitating, talk to your transplant team as there may be other medication options for your child.

GROWTH AND DEVELOPMENT

GROWTH

Optimizing normal growth for your child is important both pre- and post-transplant. Many things impact your child's normal growth: the severity of your child's illness prior to transplant, nutritional status, and the medications they take after transplant, especially steroids. Prior to transplant, and at each clinic visit thereafter, your child's height and weight will be measured to ensure your child is growing as normally as possible. If your child is not gaining weight appropriately, dietary supplements such as special formulas or nutrition additives, may be added to your child's daily diet. In some cases, it may be necessary to give extra nutrition to your child through a nasogastric or gastrostomy tube or intravenously using Total Parenteral Nutrition (TPN). After transplant, some patients will experience "catch-up" growth and can actually get to a more normal height and weight pattern. In many cases, this catch-up growth does not occur until they are more than 6 months out of transplant and/or are on a lower dose of steroids. If you have concerns about your child's growth, please

talk to your transplant nurse coordinator or physician.

DEVELOPMENT

Delay in meeting developmental milestones such as sitting independently, walking, talking, etc. is common in infants and children who have chronic illness.

Older children may have regression of behaviors as a way to cope with their illness. Prior to transplant, your child will undergo testing (neuropsychological testing) to determine if they are at the appropriate developmental stage for their age. Referrals may be made to programs such as Parents As Teachers, to help with your child's development. After transplant, most children catch up quickly and continue to meet their milestones appropriately. If there are continued concerns about your child's development, testing may be repeated.

COMMUNICATIONS AND MEDIA RELATIONS

Following your child's transplant, we will provide you with a packet from Mid-America Transplant called The Gift of Life. This packet includes the brochure, Writing to the Donor Families. The decision to write to the donor family is a very personal one; we urge you to write a letter when you feel the time is right for you.

MEDIA RELATIONS

The overall purpose of media relations is to increase and manage the public awareness of St. Louis Children's Hospital (SLCH) and its role in the community. This requires a delicate balance between the needs of reporters, patients, parents, physicians, and SLCH employees while maintaining a high level of privacy and adherence to our mission to *"Do what's right for kids"*.

In addition to protecting the health and general welfare of its patients, a hospital's responsibilities include protecting the patient's legal rights as well. That includes the legal right to privacy concerning medical information. To ensure patient privacy and confidentiality, we require a media relation staff escort anytime the media come into SLCH or interview a patient. We also require a signed consent form from each patient and/or parent.

When working with transplant patients and their families, the most common theme is the need for organ donations and creating awareness of the need for organ donations. When a child is listed for a transplant at St. Louis Children's Hospital, there are several reasons why the family might want to contact the media relations department:

- If the family is working with COTA or another fundraising group, and would like to contact the local media in their hometown, or the media in St. Louis.
- If the family has already had some media attention in their hometown, and their local media would like to interview the patient at St. Louis Children's Hospital.
- If a reporter calls the family and would like to set up an interview with their transplant physician.
- If a reporter would like to know the patient's current condition.

If you would like further information, please contact the Media Relations Department at 314.286.0416 or 314.286.0304.

RESEARCH AND PATHWAYS TO THE FUTURE

St. Louis Children's Hospital and Washington University School of Medicine are committed to making transplant outcomes better. We can only do so with your help. You/your child will join a team that also includes your physicians and scientists here at Washington University and around the world. As a member of that team, you/your child will be asked to participate in both clinical and basic research studies. As with all research studies, participation is entirely voluntary and will not impact your ability to receive care.

Each research project you/your child is asked to participate in will have been reviewed and approved by an institutional review board (IRB). At Washington University, this board is called the Human Studies Committee (HSC). The function of the HSC is to review and monitor research to ensure protection of any person thinking about participating in research studies. Before enrolling in any study, you/your child will be asked to review and sign a consent form that outlines the potential benefits of the study as well as the potential risks to you/your child. Minor children will be asked for their consent as well.

AUTOPSIES

When a transplant recipient dies, sometimes there are questions that remain unanswered for family members and physicians. The goal of an autopsy is to understand the reasons that lead to death. For these reasons, we seek permission to perform an autopsy on all transplant patients who die. An autopsy is a special type of surgical operation performed by an autopsy assistant and a pathologist (a specially-trained physician). It may be performed on the whole body or on specific body parts. It is performed with respect and compassion as well as in accordance to religious beliefs. When completed, it allows for any type of funeral ceremony, including an open casket. It generally takes 8 to 12 weeks for the complete autopsy report to become available. When it is available, the results will be discussed with you by your child's physician.

GLOSSARY

A

ABO compatibility There are four blood types: O, A, B, and AB. Type O is the universal donor and type AB is the universal recipient. Type O can receive only type O blood, Type A can receive type A or O. Type B can receive type B or O. Type AB can receive A, B, AB or O.

Acquired Not caused by hereditary or developmental factors but by a reaction to environmental influences outside of the organism.

Acute Beginning abruptly.

Acute Rejection Attempt of body to destroy transplanted organ usually within the first year after transplant.

Adverse Reaction An unintended response from a drug.

Allocation System of ensuring that organs/tissues are distributed fairly to patients in need of transplant.

Allograft A graft between 2 individuals who are of the same species but have genetic differences, i.e. Human – Human.

Anaphylaxis A severe allergic reaction that can be fatal.

Anastomosis A surgical joining of two ducts, blood vessels, or bowel segments to allow flow from one to the other.

Anesthesia The absence of normal sensation, especially sensitivity to pain. Topical, local, regional, or general.

Antibody A substance that is produced by the immune system in response to specific antigens, helps the body fight infection and foreign substances.

Antigen Substances that trigger an immune response.

Antihypertensives Substance or procedure that lowers high blood pressure.

Antiviral Destructive to viruses.

Arterial Line A catheter inserted into an artery which allows for continuous direct blood pressure readings as well as access to the blood supply for monitoring labs.

Arteriogram An x-ray of the arteries taken with the aid of a dye.

Ascites An abnormal accumulation of fluid in the abdomen.

ATN — Acute Tubular Necrosis Reversible kidney damage resulting in delayed kidney function.

B

B-Cell A specialized white blood cell responsible for the body's immunity. B-cells function in antibody production.

Bacteria Tiny organisms (germs) that cause infection.

Bile A greenish-yellow fluid produced by the liver which is needed to help your body use fats and vitamins.

Biopsy The removal and examination of tissue to determine how well the organ is working or if it is rejecting.

Bladder Part of the urinary tract that receives and stores urine from the kidneys until you urinate.

Bronchoscopy Procedure used to diagnose infection and/or rejection of the lungs.

Broviac A type of IV that is placed through a large vein in the chest that allows for delivery of medicine and drawing of blood for labwork.

BUN – Blood, Urea, and Nitrogen A waste product normally excreted by the kidneys. The BUN, along with creatinine, will represent how well the kidney functions.

C

Cadaver A donor that has recently expired for reasons that do not affect the function of an organ to be transplanted.

Candida A type of yeast.

CAPD – Continuous Ambulatory Peritoneal Dialysis A cleansing fluid that fills a person's abdomen and then is drained to filter out wastes and excess fluid from the body.

Cardiologist A doctor who specializes in treating heart disorders and diseases.

Catheter A hollow, flexible tube that can be inserted into a vessel or cavity of the body to withdraw or instill fluids.

Central Line A type of IV that goes directly to the heart through a large vein in the shoulder or neck.

Chest X-ray A picture of the lungs and upper body taken by an x-ray machine.

Cholangiogram Dye is injected into the bile ducts of the liver to show leaking or blockage within the bile duct.

Cholangitis Inflammation of the bile ducts caused by bacteria from the bowel.

Cholestasis Stoppage or suppression of bile flow.

Cholesterol A fatty substance that comes partially from foods eaten.

Chronic Developing slowly and persisting for a long period of time.

Chronic Rejection Slow failure of the transplanted organ/tissue.

Cirrhosis A disease of the liver in which normal, healthy tissue is replaced with nonfunctioning tissue and healthy cells are lost.

CMV/Cytomegalovirus A viral infection common to immunosuppressed patients

Coagulation Blood clotting.

Compatible The degree to which the body's immune system will tolerate the presence of foreign material (organ, blood) without an immune reaction.

Compliance The degree to which someone follows medical instructions and protocols.

Congenital Present at birth.

Contraindication Prohibited.

Corticosteroids Hormones secreted by the adrenal gland. Can be man-made and given for immunosuppression.

Creatinine A substance found in blood and urine monitored to determine kidney function.

Cross Match A test which mixes a potential donor's blood with the recipient's blood and after several hours is examined under a microscope to determine compatibility. If there is cell death, the result is positive which means that the recipient has cells that attack the donor's blood. If there is no cell death, the result is negative and the recipient and donor are compatible.

D

Dexascan A type of x-ray that measures the density of the bones.

Diabetes A disease in which patients have abnormally high sugar levels in their blood.

Dialysis Cleaning the body of waste by artificial means.

Diastole The bottom number of the 2 blood pressure numbers which measures blood pressure when the heart is at rest.

Discharge To release from the hospital or from care.

Discontinue or D/C To stop.

Distention Visible increase in abdomen.

Diuretic A drug given to promote the formation and excretion of urine.

Dormant An infection that is currently not active.

Drain A type of tube that may be attached to a collection device that allows an accumulation of fluid to be removed.

Dressing change To remove an old covering of a wound or incision and replace, with clean or sterile technique.

E

Echocardiogram Sound waves that are bounced off the heart to look at size and function.

Edema A build-up of too much fluid in the body tissue resulting in swelling.

EKG/Electrocardiogram A measurement of the current through the heart that tells us how the heart is working.

Electrolytes Refers to the dissolved form of a mineral in the body, sodium, potassium, magnesium, etc.

Encephalopathy When the liver can no longer clear the wastes in the blood. Wastes build up and cause lethargy and coma.

Endocrinologist A doctor who specializes in treating diseases of the endocrine system (pancreas, thyroid, etc). These physicians manage the care of patients with diabetes.

Endotracheal Tube A breathing tube that is connected to a ventilator that helps you breathe.

Epstein-Barr Virus (EBV) – Mononucleosis A type of virus that causes fever, sore throat and swollen lymph nodes.

ERCP – Endoscopic Retrograde

Cholangiopancreatography An x-ray procedure that helps evaluate the liver and the bile ducts. Dye is injected into your biliary tree and x-rays are taken. A tube with a small light attached (endoscope) will look down your throat to examine the bile ducts.

Erythropoietin A hormone that helps make new red blood cells.

Evaluation A series of tests and meetings with the members of the transplant team to make sure that each candidate is ready for transplantation.

Extubate To remove a breathing tube.

F

Fibrosis Scarring caused by healing response to injury, infection or inflammation.

Foley Catheter A tube is inserted into the bladder via the ureter which is connected to a pouch for the collection and measurement of urine.

Fulminant Hepatic Failure A rapid, sudden and severe insult to the liver which can cause liver failure.

Fungal infection An infection caused by a type of fungus. Can be life threatening in an immunosuppressed patient.

G

Gastroenterologist A physician who specializes in the treatment of disorders of the digestive tract.

Generic A drug's chemical name.

Genetic Referring to hereditary, birth.

Gingival hypertrophy Enlargement of the gums. A common side effect of Cyclosporine.

Glucose A type of sugar found in the blood.

Graft A transplanted tissue or organ (kidney, heart, bone marrow or liver).

Graft survival A transplanted organ or tissue that is accepted by the body and functions properly.

H

HCT – Hematocrit A measure of the amount of red blood cells in the blood.

Helper T-Cell A white blood cell that tells other parts of the immune system to fight infection or foreign material.

Hemodialysis A method of dialysis in which blood is cleaned of waste by circulating through a machine outside of the body.

Hemoglobin – Hgb A compound in the blood that carries oxygen to the cells.

Hemorrhage A rapid loss of blood/excessive bleeding.

Hepatic Having to do with the liver.

Hepatologist A physician who specializes in treating liver disease.

Hereditary A condition, characteristic or disease that is passed from parents to offspring.

HIDA Scan Dye is given through an IV and flows through the liver. An x-ray is taken to show the flow and possible blockages in the bile ducts that drain the liver.

Hirsutism An excessive increase in hair growth. A common side effect of Cyclosporine and steroids.

Histocompatibility The compatibility of the antigens of donor and recipient transplanted tissue.

HLA – Human Leukocyte Antigen Genetically determined series of antigens that are present on white blood cells and tissues.

Hyperacute Rejection Very rare rejection that occurs very suddenly and unexpectedly. Usually occurs within the first few hours after surgery.

Hypertension High blood pressure.

I

Immune response A defensive reaction to foreign material by the immune system.

Immunity Being able to resist a particular infectious disease.

Immunization Resistance to an infectious disease is induced by giving a vaccination.

Immunosuppression Prevention or suppression of the immune response either by drug therapy or by disease.

Intravenous (IV) Into or within a vein. Also refers to fluids or medications that are infused through a needle or catheter that is inserted into a vein.

Intubated A breathing tube inserted into the mouth or nose to the throat. The tube is connected to a breathing machine that will help them breathe until they are strong enough to breathe on their own.

Invasive A diagnostic or therapeutic technique that requires entering the body.

IVP – Intravenous Pyelogram Dye is injected into a vein. The dye concentrates in the kidneys and makes them show up on an x-ray. The doctor looks at the x-ray to see if there are two functioning kidneys with normal internal structure. Used in evaluating potential kidney donors.

J

Jackson-Pratt A small drain that is sometimes placed near an incision to drain any blood or fluid that may accumulate.

Jaundice Yellowing of the eyes and skin caused by an increased amount of bilirubin.

K

Kangaroo Pump A type of feeding pump used to deliver tube feedings.

Kidney Rids body of waste materials and maintains fluid balance through the production of urine.

L

LRD – Living Related Donor A blood relative that donates an organ.

Lymphocyte A white blood cell.

M

Mononucleosis – (EBV – Epstein-Barr Virus)

A type of virus that causes fever, sore throat and swollen lymph nodes.

MRI – Magnetic Resonance Imaging A type of x-ray that uses magnetic waves to take pictures of tissues.

Myalgia Muscle aches and pains.

Myopathy Muscle disorder that causes severe weakness.

N

Nasogastric Tube A tube inserted through the nose that drains the stomach of excess bile to prevent nausea.

Nephrologist A doctor that specializes in treating problems involving the kidney.

Neuropathy A breakdown of the peripheral nerves . Symptoms are numbness and tingling in extremities.

Neutropenic Severe decrease in the amount of white blood cells.

Noncompliance Failure of the patient to cooperate by doing what is necessary or required for his/her medical care.

Noninvasive Does not require skin to be broken or body entered.

NPO – Nothing By Mouth Term used when someone is without food/drink prior to exam/procedure.

O

Oncologist A doctor who specializes in treating patients with cancer.

OPO – Organ Procurement Organization

Link between the potential recipient and donor. Responsible for retrieval, preservation and transportation of organs for transplantation.

Opportunistic Infection Infections that in healthy persons would not pose a threat but in immunocompromised persons can be very harmful.

Organ Part of body made of tissues specialized to perform a certain function.

Osteoporosis Weakening of the bones.

OTC – Over the Counter A type of medicine or product that does not require a prescription.

P

PACU Post Anesthesia Care Unit

Papilloma Virus Viruses that cause warts on hands, face and fingers.

PCP – Pneumocystis Carinii Pneumonia

A type of pneumonia that is seen primarily in immunocompromised patients.

PELD – Pediatric End-Stage Liver Disease A scoring system for pediatric liver patients. Based on certain lab values and growth failure; assigned a number 0-40 based on need.

Percutaneous Through the skin.

Peripheral IV A small IV that is placed in the arm, hand or foot for delivery of IV fluids or medicines. Usually placed during surgery.

PFT – Pulmonary Function Test A test used to determine the ability of the lungs to exchange oxygen and carbon dioxide.

PICU Pediatric Intensive Care Unit

Platelet A small blood cell needed for blood clotting.

P.O. By mouth.

Primary Care Physician Pediatrician or doctor that follows patient for primary illness/also obtain necessary referrals for insurance from PCP office.

PRN As needed.

Prophylactic An agent or regimen used to prevent an infection or disease.

PTLD (Post-Transplant Lymphoproliferative Disorder) A type of cancer that attacks the lymphatic system of some immunocompromised patients.

Pulmonologist A doctor who specializes in treating lung disease.

R

Recurrence Reappearance or a sign or symptom of a disease after a period of remission.

Rejection An immune response against the transplanted tissue which if not successfully treated will result in graft failure.

Renal Having to do with the kidneys.

Resistance Ability of a virus to fight the effects of a treatment because the information in the virus changed. Can be caused from a person's noncompliance with certain medicines.

S

Sensitized Being immunized or able to mount an immune response against an antigen by previous exposure to that antigen.

Shingles A type of varicella zoster, characterized by a painful, blistering rash on one side of the body.

Stent A tube used to support openings and vessels during and after surgical procedures.

Stricture or Stenosis A narrowing or passage in the body.

Systolic The top number of the blood pressure, measures the maximum blood pressure as the blood is pumped out of the heart.

T

T-Cell White blood cell responsible for the body's immunity. Can destroy cells infected by viruses, graft cells and other altered cells.

T-Tube A tube placed in the bile duct to drain bile externally into a small bag.

Thrush A fungal infection in the mouth.

Tissue Typing A blood test that evaluates the closeness of tissue match between the donor's organ and the recipient's HLA antigens.

Total Parenteral Nutrition (TPN) – Parenteral (Intravenous) Nutrition A method of supplying nourishment to children unable to eat.

Transplant to transfer an organ or tissue from one person to another or from one body part to another to replace a diseased structure, restore function, or to change appearance.

U

Ultrasound Sound waves are bounced off the organs to check size and function.

UNOS – United Network for Organ Sharing Governing body that oversees organ transplantation in the U.S.

Ureter A tube that carries urine from kidney to the bladder.

URI Upper respiratory infection.

UTI Urinary tract infection.

V

Vaccine Protects a person against infection and/or disease. Made from killed or weakened forms of the disease and given to cause an immune response to create resistance to a certain disease.

Varicella Zoster Virus that causes chicken-pox and shingles.

VCUG – Voiding Cystourethrogram A bladder and kidney x-ray.

Ventilator Breathing machine.

Virus Small disease causing germs that can only multiply when inside the cell of another organism.

Vital Signs Pulse, temperature, blood pressure, respiration.

V/Q Scans Ventilation perfusion scan of the lungs. Indicates air exchange and blood flow in the lungs.

W

Waiting List A nationwide computerized network called UNOS. All transplant centers in the U.S. belong. Supervised by the federal government to ensure that patients throughout the country receive organs as soon as they become available.

WBC – White blood cell Composed of several different types that all work to fight infection.

CONVERSION TABLES

WEIGHT (MASS)

Pounds to Kilograms (1 pound = 0.4536 kilograms)

Example: To obtain pounds equivalent to 33.2 kilograms, find 33.11 and 33.57 in table, read "70" on side scale and "3" or "4" on top scale. Equivalent is between 73 and 74 pounds, closer to 73 pounds.

WEIGHT (MASS)										
Pounds	0	1	2	3	4	5	6	7	8	9
0	0.00	0.45	0.91	1.36	1.81	2.27	2.72	3.18	3.63	4.08
10	4.54	4.99	5.44	5.90	6.35	6.80	7.26	7.71	8.16	8.62
20	9.07	9.53	9.98	10.43	10.89	11.34	11.79	12.25	12.70	13.15
30	13.61	14.06	14.51	14.97	15.42	15.88	16.33	16.78	17.24	17.69
40	18.14	18.60	19.05	19.50	19.96	20.41	20.87	21.32	21.77	22.23
50	22.68	23.13	23.59	24.04	24.49	24.95	25.40	25.85	26.31	26.76
60	27.22	27.67	28.12	28.58	29.03	29.48	29.94	30.39	30.84	31.30
70	31.75	32.21	32.66	33.11	33.57	34.02	34.47	34.93	35.38	35.83
80	36.29	36.74	37.19	37.65	38.10	38.56	39.01	39.46	39.92	40.37
90	40.82	41.28	41.73	42.18	42.64	43.09	43.54	44.00	44.45	44.91
100	45.36	45.81	46.27	46.72	47.17	47.63	48.08	48.53	48.99	49.44
110	49.90	50.35	50.80	51.26	51.71	52.16	52.62	53.07	53.52	53.98
120	54.43	54.88	55.34	55.79	56.25	56.70	57.15	57.61	58.06	58.51
130	58.97	59.42	59.87	60.33	60.78	61.23	61.69	62.14	62.60	63.05
140	63.50	63.96	64.41	64.86	65.32	65.77	66.22	66.68	67.13	67.59
150	68.04	68.49	68.95	69.40	69.85	70.31	70.76	71.21	71.67	72.12
160	72.57	73.03	73.48	73.94	74.39	74.84	75.30	75.75	76.20	76.66
170	77.11	77.56	78.02	78.47	78.93	79.38	79.83	80.29	80.74	81.19
180	81.65	82.10	82.55	83.01	83.46	83.91	84.37	84.82	85.28	85.73
190	86.18	86.64	87.09	87.54	88.00	88.45	88.90	89.36	89.81	90.26
200	90.72	91.17	91.63	92.08	92.53	92.99	93.44	93.89	94.35	94.80

TEMPERATUREFahrenheit (°F) to Centigrade (°C): $C = (°F - 32) \times 5/9$

TEMPERATURE											
F	C	F	C	F	C	F	C	F	C	F	C
95.0	35.0	97.0	36.1	99.0	37.2	101.0	38.3	103.0	39.4	105.0	40.6
95.2	35.1	97.2	36.2	99.2	37.3	101.2	38.4	103.2	39.6	105.2	40.7
95.4	35.2	97.4	36.3	99.4	37.4	101.4	38.6	103.4	39.7	105.4	40.8
95.6	35.3	97.6	36.4	99.6	37.6	101.6	38.7	103.6	39.8	105.6	40.9
95.8	35.4	97.8	36.6	99.8	37.7	101.8	38.8	103.8	39.9	105.8	41.0
96.0	35.6	98.0	36.7	100.0	37.8	102.0	38.9	104.0	40.0	106.0	41.1
96.2	35.7	98.2	36.8	100.2	37.9	102.2	39.0	104.2	40.1	106.2	41.2
96.4	35.8	98.4	36.9	100.4	38.0	102.4	39.1	104.4	40.2	106.4	41.3
96.6	35.9	98.6	37.0	100.6	38.1	102.6	39.2	104.6	40.3	106.6	41.4
96.8	36.0	98.8	37.1	100.8	38.2	102.8	39.3	104.8	40.4	106.8	41.6

APPENDIX A:

HEALTHY TIPS



United States Department of Agriculture

10
tips
Nutrition
Education Series



MyPlate
MyWins

Based on the
Dietary
Guidelines
for Americans

Build a healthy meal

Each meal is a building block in your healthy eating style. Make sure to include all the food groups throughout the day. Make fruits, vegetables, grains, dairy, and protein foods part of your daily meals and snacks. Also, limit added sugars, saturated fat, and sodium. Use the [MyPlate Daily Checklist](#) and the tips below to meet your needs throughout the day.

1 Make half your plate veggies and fruits

Vegetables and fruits are full of nutrients that support good health. Choose fruits and red, orange, and dark-green vegetables such as tomatoes, sweet potatoes, and broccoli.



6 Get creative in the kitchen

Whether you are making a sandwich, a stir-fry, or a casserole, find ways to make them healthier. Try using less meat and cheese, which can be higher in saturated fat and sodium, and adding in more veggies that add new flavors and textures to your meals.

2 Include whole grains

Aim to make at least half your grains whole grains. Look for the words "100% whole grain" or "100% whole wheat" on the food label. Whole grains provide more nutrients, like fiber, than refined grains.



7 Take control of your food

Eat at home more often so you know exactly what you are eating. If you eat out, check and compare the nutrition information. Choose options that are lower in calories, saturated fat, and sodium.



3 Don't forget the dairy

Complete your meal with a cup of fat-free or low-fat milk. You will get the same amount of calcium and other essential nutrients as whole milk but fewer calories. Don't drink milk? Try a soy beverage (soymilk) as your drink or include low-fat yogurt in your meal or snack.



8 Try new foods

Keep it interesting by picking out new foods you've never tried before, like mango, lentils, quinoa, kale, or sardines. You may find a new favorite! Trade fun and tasty recipes with friends or find them online.

4 Add lean protein

Choose protein foods such as lean beef, pork, chicken, or turkey, and eggs, nuts, beans, or tofu. Twice a week, make seafood the protein on your plate.



9 Satisfy your sweet tooth in a healthy way

Indulge in a naturally sweet dessert dish—fruit! Serve a fresh fruit salad or a fruit parfait made with yogurt. For a hot dessert, bake apples and top with cinnamon.

5 Avoid extra fat

Using heavy gravies or sauces will add fat and calories to otherwise healthy choices. Try steamed broccoli with a sprinkling of low-fat parmesan cheese or a squeeze of lemon.

10 Everything you eat and drink matters

The right mix of foods in your meals and snacks can help you be healthier now and into the future. Turn small changes in how you eat into your MyPlate, MyWins.



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MyPlate snack tips for parents

Snacks can help children get the nutrients needed to grow. Prepare snacks that include two or more food groups. For younger children, help them get just enough to satisfy their hunger. Let older kids make their own snacks by keeping healthy foods in the kitchen. Visit ChooseMyPlate.gov to help you and your kids select a satisfying snack.

1 **Save time by slicing veggies**
Store sliced vegetables in the refrigerator and serve with hummus. Top half of a whole-wheat English muffin with spaghetti sauce, chopped vegetables, and low-fat shredded mozzarella and melt in the microwave.

6 **Keep an eye on the size**
Snacks shouldn't replace a meal, so look for ways to help your kids understand how much is enough. Store snack-size bags in the cupboard and use them to control serving sizes.

2 **Mix it up**
For older school-age kids, mix dried fruit, unsalted nuts, and popcorn in a snack-size bag for a quick trail mix. Put fat-free yogurt, 100% fruit juice, and frozen peaches in a blender to make a tasty smoothie.



7 **Fruits are quick and easy**
Fresh, frozen, dried, or canned fruits, such as applesauce, frozen grapes, or raisins, can be easy "grab-and-go" options that need little preparation. Offer whole fruit and limit the amount of 100% juice served. Choose canned fruits that are lowest in added sugars.



3 **Grab a glass of milk**
A cup of low-fat milk or fortified soy beverage is an easy way to drink a healthy snack.

8 **Consider convenience**
A single-serving container of low-fat yogurt or individually wrapped string cheese can be just enough for an afterschool snack.



4 **Go for great whole grains**
Offer whole-wheat breads, popcorn, and whole-oat cereals that are high in fiber and low in added sugars, saturated fat, and sodium. Limit refined-grain products such as snack bars, cakes, and sweetened cereals.



9 **Swap out the sugar**
Keep healthier foods handy so kids avoid cookies, pastries, or candies between meals. Add seltzer water to a ½ cup of 100% fruit juice instead of offering soda.

5 **Snack on protein foods**
Choose protein foods such as unsalted nuts and seeds, hummus or other bean dips, and hard-cooked (boiled) eggs for a healthy, easy snack. Store hard-cooked eggs in the refrigerator for up to 1 week for kids to enjoy any time.

10 **Prepare homemade goodies**
For homemade sweets, add dried fruits like apricots or raisins and reduce the amount of sugar in the recipe. Adjust recipes that include fats like butter or shortening by using unsweetened applesauce or prune puree for half the amount of fat.



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Got your dairy today?

The **Dairy Group** includes **milk, yogurt, cheese, and fortified soymilk**. They provide calcium, vitamin D, potassium, protein, and other nutrients needed for good health throughout life. Choices should be low-fat or fat-free—to cut calories and saturated fat. How much is needed? Older children, teens, and adults need 3 cups* a day, while children 4 to 8 years old need 2½ cups, and children 2 to 3 years old need 2 cups.

1 “Skim” the fat

Drink fat-free (skim) or low-fat (1%) milk. If you currently drink whole milk, gradually switch to lower fat versions. This change cuts saturated fat and calories but doesn't reduce calcium or other essential nutrients.



2 Boost potassium and vitamin D, and cut sodium

Choose fat-free or low-fat milk or yogurt more often than cheese. Milk and yogurt have more potassium and less sodium than most cheeses. Also, almost all milk and many yogurts are fortified with vitamin D.

3 Top off your meals

Use fat-free or low-fat milk on cereal and oatmeal. Top fruit salads and baked potatoes with low-fat yogurt instead of higher fat toppings such as sour cream.



4 Choose cheeses with less fat

Many cheeses are high in saturated fat. Look for “reduced-fat” or “low-fat” on the label. Try different brands or types to find the one that you like.

5 What about cream cheese?

Cream cheese, cream, and butter are not part of the dairy food group. They are high in saturated fat and have little or no calcium.

6 Switch ingredients

When recipes such as dips call for sour cream, substitute plain yogurt. Use fat-free evaporated milk instead of cream, and try low-fat or fat-free ricotta cheese as a substitute for cream cheese.



7 Limit added sugars

Flavored milks and yogurts, frozen yogurt, and puddings can contain a lot of added sugars. Get your nutrients from dairy foods with fewer or no added sugars.

8 Caffeinating?

If so, get your calcium along with your morning caffeine boost. Make or order coffee, a latte, or cappuccino with fat-free or low-fat milk.

9 Can't drink milk?

If you are lactose intolerant, try yogurt, lactose-free milk, or soymilk (soy beverage) to get your calcium. Calcium in some leafy greens is well absorbed, but eating several cups each day to meet calcium needs may be unrealistic.



10 Take care of yourself and your family

Parents who drink milk and eat dairy foods show their kids that it is important for their health. Dairy foods are important to build the growing bones of kids and teens and to maintain bone health in adulthood.

* What counts as a cup in the Dairy Group? 1 cup of milk, yogurt, or soy beverage; 1½ ounces of natural cheese; or 2 ounces of processed cheese.

**10
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be a healthy role model for children

10 tips for setting good examples



You are the most important influence on your child. You can do many things to help your children develop healthy eating habits for life. Offering a variety of foods helps children get the nutrients they need from every food group. They will also be more likely to try new foods and to like more foods. When children develop a taste for many types of foods, it's easier to plan family meals. Cook together, eat together, talk together, and make mealtime a family time!

1 show by example

Eat vegetables, fruits, and whole grains with meals or as snacks. Let your child see that you like to munch on raw vegetables.

2 go food shopping together



Grocery shopping can teach your child about food and nutrition. Discuss where vegetables, fruits, grains, dairy, and protein foods come from. Let your children make healthy choices.

3 get creative in the kitchen

Cut food into fun and easy shapes with cookie cutters. Name a food your child helps make. Serve "Janie's Salad" or "Jackie's Sweet Potatoes" for dinner. Encourage your child to invent new snacks. Make your own trail mixes from dry whole-grain, low-sugar cereal and dried fruit.

4 offer the same foods for everyone

Stop being a "short-order cook" by making different dishes to please children. It's easier to plan family meals when everyone eats the same foods.



5 reward with attention, not food

Show your love with hugs and kisses. Comfort with hugs and talks. Choose not to offer sweets as rewards. It lets your child think sweets or dessert foods are better than other foods. When meals are not eaten, kids do not need "extras"—such as candy or cookies—as replacement foods.

6 focus on each other at the table

Talk about fun and happy things at mealtime. Turn off the television. Take phone calls later. Try to make eating meals a stress-free time.



7 listen to your child

If your child says he or she is hungry, offer a small, healthy snack—even if it is not a scheduled time to eat. Offer choices. Ask "Which would you like for dinner: broccoli or cauliflower?" instead of "Do you want broccoli for dinner?"

8 limit screen time

Allow no more than 2 hours a day of screen time like TV and computer games. Get up and move during commercials to get some physical activity.

9 encourage physical activity

Make physical activity fun for the whole family. Involve your children in the planning. Walk, run, and play with your child—instead of sitting on the sidelines. Set an example by being physically active and using safety gear, like bike helmets.



10 be a good food role model

Try new foods yourself. Describe its taste, texture, and smell. Offer one new food at a time. Serve something your child likes along with the new food. Offer new foods at the beginning of a meal, when your child is very hungry. Avoid lecturing or forcing your child to eat.



United States Department of Agriculture



Find Your Healthy Eating Style & Maintain It for a Lifetime

Start with small changes to make healthier choices you can enjoy.

Follow the MyPlate building blocks below to create your own healthy eating solutions—"MyWins." Choose foods and beverages from each food group—*making sure that your choices are limited in sodium, saturated fat, and added sugars.*

Make half your plate fruits and vegetables: Focus on whole fruits

- Choose whole fruits—fresh, frozen, dried, or canned in 100% juice.
- Enjoy fruit with meals, as snacks, or as a dessert.

Make half your grains whole grains

- Look for whole grains listed first or second on the ingredients list—try oatmeal, popcorn, whole-grain bread, and brown rice.
- Limit grain desserts and snacks, such as cakes, cookies, and pastries.

Move to low-fat or fat-free milk or yogurt

- Choose fat-free milk, yogurt, and soy beverages (soy milk) to cut back on saturated fat.
- Replace sour cream, cream, and regular cheese with low-fat yogurt, milk, and cheese.

Make half your plate fruits and vegetables: Vary your veggies

- Try adding fresh, frozen, or canned vegetables to salads, sides, and main dishes.
- Choose a variety of colorful veggies prepared in healthful ways: steamed, sautéed, roasted, or raw.

Vary your protein routine

- Mix up your protein foods to include seafood, beans and peas, unsalted nuts and seeds, soy products, eggs, and lean meats and poultry.
- Try main dishes made with beans and seafood, like tuna salad or bean chili.

Drink and eat less sodium, saturated fat, and added sugars

- Use the Nutrition Facts label and ingredients list to limit items high in sodium, saturated fat, and added sugars.
- Choose vegetable oils instead of butter, and oil-based sauces and dips instead of ones with butter, cream, or cheese.
- Drink water instead of sugary drinks.



Everything you eat and drink matters. The right mix can help you be healthier now and into the future. Find your MyWins!

Visit ChooseMyPlate.gov to learn more.

Center for Nutrition Policy and Promotion
January 2016

USDA is an equal opportunity provider and employer.

APPENDIX B:

PREPARATION OF POWDERED MILK

Powder infant formula is not sterile (germ-free). It may contain bacteria that can cause serious illness in infants.

- **Cronobacter** bacteria has been found in powdered infant formula. This type of bacteria is also found in the home and in the environment. This bacteria can cause infection, bacteremia (blood infection), necrotizing enterocolitis (serious infection of the bowels), and meningitis (infection of the covering around the brain and spinal cord).
- **Salmonella** bacteria has also been found in powdered infant formula.

Infants most at risk:

- Infants younger than 2 months
- Preterm infants
- Infants born at a low birth weight (less than 2.5 kg)
- Infants who have difficulty fighting infections (immunocompromised).

Formula usually comes in 3 different types. Liquid Concentrate and Ready to Use/Feed options do not require use of boiling water as they are considered sterile as packaged before they are opened.

- Powder
- Concentrate
- Ready to Use/Feed

By making and storing powdered infant formula correctly, the risk for serious illness can be reduced.

- There are new guidelines for preparing powder formula by the World Health Organization (WHO) and the Centers for Disease Control and Prevention (CDC).
- It is now recommended to prepare powder formula using hot water (greater or equal to 158 degrees F). The hot water helps to kill bacteria like Cronobacter or Salmonella that could be in the powder formula.
- It is very important to continue:
 - Good hand washing before formula preparation
 - Sterilizing bottles and parts
 - Cleaning of surfaces where formula is prepared
 - Proper storage of formula.

THE FOLLOWING IS A STEP-BY-STEP GUIDE TO PREPARING POWDERED INFANT FORMULA.

This project was adapted from the U.S. Department of Agriculture, Food and Nutrition Services, Infant Nutrition and Feeding - A Guide for Use in the WIC and CFP Programs. The content of this publication does not necessarily reflect the view or policies of the U.S. Department of Agriculture, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.

STEP 1: Clean the surface where you are going to prepare the bottles. Wash and dry your hands.



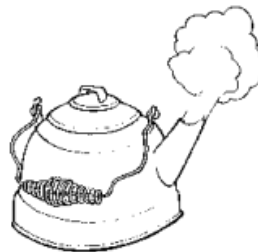
STEP 2: Wash the bottle parts with warm water and dish soap. Rinse everything well. Make sure to squeeze clean water through the nipple holes.



STEP 3 - Sterilize bottle parts: Bring water and bottle parts to a rolling boil. Boil for 5 minutes. Remove items with tongs. Allow items to air dry. Remember to keep children away from boiling water at all times.



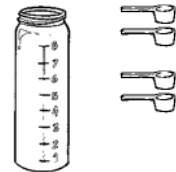
STEP 4 - Make Formula: Bring more water to a rolling boil. Boil for 2 minutes. Allow the water to cool to 158° F (70°C). This will take about 5 minutes for 8 ounces of water and 10 minutes for 16 ounces of water.



STEP 5: Remove plastic lid from the can of powder. Wash the lid with soap and clean water. Allow the lid to dry. Write the date on the outside of plastic lid.



STEP 6: Open the can and remove the scoop. Only use the scoop that comes with the formula. Always add the water before you add the powder formula (no matter how you are making the bottles).



Talk with your child's medical team about how much water to use and how many scoops of powder to add.

STEP 7: Put the nipple on the bottle. Screw the ring onto the bottle. Cover the nipple with the bottle cap. Shake the bottle until the powder is dissolved.



STEP 8: If a large amount is made, pour the formula into bottles or a covered pitcher. Place a label with the date and time.



STEP 9: Place all bottles in the refrigerator until it is time to feed. Use all bottles in the batch within 24 hours.

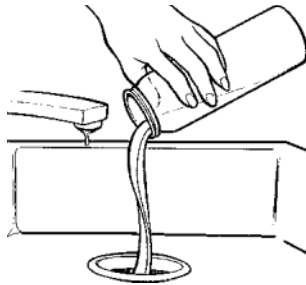
Warming the bottle:

- Hold bottles under warm water to warm
- **Do not** leave formula at room temperature to warm
- **Do not use a microwave to warm bottles**

STEP 10: If you are ready to feed right away, it is very important to cool the formula so it is not too hot to drink! Hold the bottom half of the bottle under cold running water. Make sure the water does not run over the nipple cap.

Test the temperature of the formula on the inside of your wrist before feeding your baby. The formula should feel warm or cool, but not hot.

STEP 11: Throw away any unused formula left in the bottle after feeding, or if the bottle has been left out of the refrigerator for 1 hour or more.



Storage of powder formula:

Store the container in a cool dry place. Do not store in the refrigerator. Use within 4 weeks after opening the container.



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