

BEFORE TRANSPLANT

Transplants at University Hospital

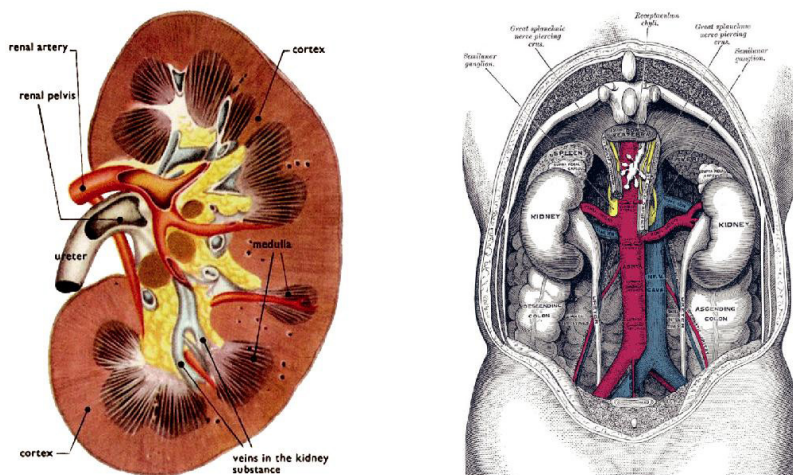
In 1964, a team of surgeons at the University of Michigan Health System (UMHS) performed the first kidney transplant operation in Michigan. Our transplant surgeons perform between 200 and 250 kidney transplants a year of which about 15 are pediatric patients. This makes the UMHS team among the most experienced in the nation. Our kidney transplant team includes transplant surgeons, urologists, nephrologists (kidney doctors), physician assistants, nurse practitioners, nurses, transplant coordinators, social workers, psychologists, dietitians, pathologists, pharmacists and other specialized support staff. These professionals can help you have the best possible kidney transplant experience. In addition to an expert transplant team, UMHS also has the most comprehensive medical facility in the state.

Kidneys

Normal Kidneys

Kidneys filter waste products and excess water from your blood. They also make hormones that control your blood pressure and red blood cell count. They keep the water, salt and acid levels in your body balanced. Most people have two kidneys that are located toward the back and under the rib cage, where they are protected. There is one on each side of the spine.

Kidneys produce urine that carries waste products out of your body. Each kidney is attached to a ureter, a tube-like structure. The urine travels through the ureter and empties into a bag-like organ called a bladder. The bladder can stretch to hold urine until it is full. It then signals your brain that you need to urinate. The urine leaves your body through a tube called the urethra. This tube exits through the penis in men and in front of the vagina in women.



Kidney Failure Leading to Transplantation

When your kidneys are unable to perform their normal functions you have kidney failure, also known as renal failure. Some of the primary causes of end stage kidney failure include:

- Hypertension
- Glomerulonephritis
- Hereditary diseases such as polycystic kidney disease or Alport's syndrome
- Metabolic diseases such as diabetes mellitus or inborn errors of metabolism like oxalosis or cystinosis
- Obstructive uropathy
- Medication toxicities
- Multisystem diseases such as vasculitis, amyloidosis or systemic lupus erythematosus
- Congenital malformations including vesical ureteral reflux, hypoplasia or dysplasia
- Other forms of irreversible acquired renal failure

Diseased kidneys do not do a good job of filtering toxins or removing water from the body. To stay healthy, people with diseased kidneys will need dialysis or a kidney transplant. Kidney transplantation improves the length and quality of life of people whose own kidneys have failed.

Kidneys for Transplantation – Where Do They Come From?

All kidneys available for transplantation are a result of a gift from one person to another. Kidneys can come from either deceased or living donors.

Deceased Donor Kidneys

Deceased donor kidneys (and other organs) are donated after the death of the donor. The suitability of the donor is determined by many factors. These include many of the same criteria used for living donors such as medical history, general health, habits and so forth.

As of January 2015, there were 101,600 persons awaiting a kidney transplant in the United States. At the University of Michigan alone, there were 944 patients waiting. Unfortunately, in the year 2012 only 16,487 kidney transplants were performed in the United States and 4,903 persons died waiting for a transplant. Because of a severe national organ shortage, alternative solutions to using deceased donor organs have been sought.

Donation After Brain Death (DBD)

Most deceased organ donors are brain dead. They have suffered complete and irreversible loss of all brain function, and are clinically and legally dead. Mechanical ventilation and medications keeps their heart beating and blood flowing to their organs.

Donation After Cardiac Death (DCD)

Some people with non-survivable injuries to the brain never become brain dead because they retain some minor brain stem function. If such individuals made the decision to be donors or their families are interested, organ donation may be an option. Donation in such cases involves taking the patient off the ventilator, typically in the operating room. Once the patient's heart stops beating, the doctor declares the patient dead and organs can be removed.

High-Risk Donors

Some donors have been determined to have high-risk behaviors, either now or in the past, such as IV drug abuse, long-term stay in a correctional facility, prostitution, etc. These donors are determined to be at higher risk of transmission of certain diseases (i.e., HIV, hepatitis C, hepatitis B) to a recipient. All donors, whether they are high-risk or not, are tested for disease. These tests can detect a donor infection as recently as one week prior. The results of these tests are back before the organs are donated. High-risk donors who test negative and are not currently engaging in high-risk behaviors carry a very low risk of transmission of infection and are therefore used as kidney or pancreas donors. The true risk of transmission is not known but is probably much less than 1%. If a kidney from a high-risk donor is offered to your child, this will be discussed with you and your child at the time of the offer. While we generally recommend accepting such an offer, you and your child will have the option to accept or decline.

Living Kidney Donation

There are several advantages for a transplant candidate receiving a living kidney transplant as opposed to receiving a kidney from a deceased donor. The major advantage is that the recipient does not have to wait as long for a transplant. In some cases the transplant can occur before the patient begins dialysis. Another advantage of living donor kidney transplantation is that it can give patients the chance to receive a transplant before the onset of debilitating complications of their kidney disease, or before they become too ill to have a transplant.

Related and Unrelated

Living donors may be related or unrelated to the recipient. Individuals who wish to be considered as a living kidney donor **must** contact the transplant donor coordinator to indicate their interest. The transplant donor coordinator will review the process with the interested party before setting up an evaluation appointment.

Living donors are prohibited by law from being paid or receiving any other financial incentives to donate. Living donors must be 18 years of age or older.

Parents, children, siblings, other relatives, as well as in-laws and friends can be considered for living kidney donation. The potential donor and recipient must have compatible blood types and they must have a negative crossmatch. Please refer to “The Immune System” on page 5 of this section for more information on the immune system, antigens, antibodies, matching, tissue typing and crossmatching.

Some health circumstances prevent an individual from donating a kidney. For instance, individuals with a current history of diabetes or cancer may not be eligible to donate. The transplant team may review the data on potential donors with a relevant history before scheduling an evaluation appointment.



Desensitization

Many patients who are waiting for a kidney transplant may not be able to receive one because they are considered “sensitized.” Other patients cannot receive a kidney transplant because their blood is incompatible with the donor. Sensitization and blood incompatibility are caused by antibodies against human cells or blood types. Antibodies are proteins made by white blood cells generally used to help the body fight infection.

Antibodies are also made any time your immune system finds a protein it considers “foreign.” A person can develop antibodies from previous transplants, blood transfusions or pregnancy. Antibodies against blood types are developed after birth, which is a normal body response.

This normal immune response requires careful matching of compatible blood types between the transplant donor and the transplant recipient.

If a kidney transplant is performed in a patient with antibodies against human cell or blood types, the antibodies will bind to the transplant causing severe rejection and destruction of the kidney.

A process called “desensitization” provides an opportunity for sensitized and blood type incompatible patients to receive a kidney transplant. Desensitization removes unwanted antibodies from the blood stream using medications and a process similar to dialysis (dialysis removes chemicals from the blood, while desensitization removes harmful antibodies). The process prepares the patient for a successful transplant and occurs as a monthly infusion process for the first six months followed by two additional infusions at nine months and one year after treatment begins.

Insurance approval is required before desensitization can begin. Please contact your financial coordinator to see if your child is a candidate for, and are interested in pursuing, desensitization.

The success of desensitization depends on the amount of antibodies. Patients with very high levels of antibodies are likely to fail this treatment and, as a better option, may benefit from the Kidney Paired Donation Program (KPD). This program offers the matching of incompatible living donor/recipient pairs to others with a complementary incompatibility until a compatible or better suited donor is identified.

Paired Donation

Occasionally a healthy and suitable individual comes forward to donate for his/her loved one only to find he/she is not a match (either by blood type or positive crossmatch) for the loved one – yet he/she still wants to donate. Paired kidney donation is aimed at providing transplant opportunities for these potential donors and recipients. This program identifies “pairs” where the donor from one pair donates his/her kidney to the recipient of the second pair and vice versa.

Paired donation is only available to recipients who are actively listed for a kidney transplant. For more information, please see page 1 of the Living Donor section.

If you have questions about the paired donation program, please ask your transplant coordinator.

The Immune System

The job of the immune system is to fight infections and to keep us from getting cancer. The immune system does this by recognizing antigens, which are small particles found on the surface of all cells of the body, viruses and bacteria. The cells of your body have the same antigens that your immune system has. Your immune system leaves them alone. A cancer, virus, bacteria or transplanted tissue may not have the same antigens as your immune system. The immune system will attack these “foreign” antigens and make antibodies against them.

Understanding the Immune System

What is an Antigen?

An antigen can be a “self” or “foreign” protein. When the immune system recognizes an antigen as “foreign” it will develop antibodies specific to the antigen.

What are Antibodies?

Antibodies are proteins formed by the immune system of the “self” in response to the “foreign” antigen. They function to neutralize the antigen. When they interact, a reaction occurs that can cause destruction of tissue. When the antigen is present in a kidney transplant, the reaction between antibodies and antigen can cause rejection.



How Antibodies Develop

People can develop antibodies to foreign antigens after being exposed, while they are being evaluated or while they are listed for transplant, through a pregnancy, transfusion, infection or transplant. If any of these happen to your child while they are being evaluated or while they are being listed for a transplant, it is important to send a blood sample to the tissue typing lab within seven to 14 days of the event. To request a kit (a tube and packaging material), call the tissue typing lab at **(734) 647-2774** and ask for a post-transfusion sample kit. Take this to your local lab and have your child’s blood drawn. Then, mail the specimen back to UMHS and let your child’s coordinator know.

Understanding the Matching Process

What is Matching?

When we speak of a donor and a recipient as being a “match,” it really means that their blood groups are compatible and that they have a negative crossmatch. Your child’s coordinator can answer any questions that you may have.

Blood Types

A suitable donor has a compatible blood type with the recipient. Human blood types are O, A, B and AB.

Blood Type		Blood Type
O	Can Receive Blood From	O
A		A or O
B		B or O
AB		A, B, AB or O

The Rh factor, positive or negative, is not part of kidney or pancreas matching.

Once it is known that your blood type is compatible with your donor, we obtain blood samples from both of you to determine your tissue types and crossmatch.

What is Tissue Typing?

Your white blood cells, also called leukocytes, have a special group of antigens on them called Human Leukocyte Antigens or HLA. Tissue typing is how we find out which ones you have. This is necessary information to have before a person can receive a kidney transplant.

Each person inherits two sets of HLA, one from each parent. Each set is called a haplotype. A haplotype contains three antigens. Brothers and sisters also have one haplotype from each parent. This is why parents and siblings have a better chance of a close match, than do unrelated donors. If two siblings have all six antigens exactly the same, then we call this a two-haplotype match. When the donor is not related to the recipient, the tissue typing terms change. Antigen matching is then expressed by the number of antigens out of six that are the same for the donor and the recipient. While there is some advantage in having a well matched donor, any healthy compatible donor is a “good donor” and the odds of a good result are high.

What is Crossmatching?

Crossmatching is done after blood and tissue typing are completed and a donor is identified. This test checks to see if the recipient has developed antibody against the donor. A small amount of the recipient’s blood is mixed with the potential donor’s white cells. If antibodies in the recipient’s blood attach to the donor white cell antigens, the white cells are injured. This is called a positive crossmatch. This means that if a transplant took place between this recipient and donor, the recipient’s immune system would attack the transplanted tissue. The crossmatch must be negative for the transplant to be done.

What is Antibody Screening?

Antibody screening is also called PRA (panel reactive antibody). This test can tell us if there are antibodies that a recipient has that would cause a reaction against certain donors.

Recipients can be exposed to different antigens through blood transfusions, other transplants or pregnancy. The body then protects itself from these “foreign” exposures mentioned above and makes antibodies. The body does not want to see that specific foreign antibody again or it will attack it. For example, if we transplanted a kidney with that specific foreign antibody, the body would attack that kidney. Antibody screening is performed monthly while the recipient is listed. This is done to monitor for any changes in the PRA level. The PRA score is given as a percentage and can be from 0% to 99%. The higher the PRA level, the harder it is to find a compatible kidney for the recipient.

Pre-Transplant Evaluation

Pre-Transplant Evaluation Appointment

A kidney transplant evaluation is actually a series of visits with several doctors and other members of the transplant team, all occurring on the same day. This appointment will take at least four to five hours. During the initial evaluation appointment your child will see a transplant coordinator, a physician assistant or nurse practitioner, a nephrologist (kidney doctor), a surgeon, a social worker, a registered nurse and a dietitian. Each member of the team has a specific role in the evaluation process. Please refer to the Transplant Team section of this guide for further information.

On the day of evaluation you and your child will attend a patient education session for patients and families of potential kidney recipients. There is much information shared during the evaluation appointment. We urge parents/caregivers to take notes and ask questions throughout the evaluation day.

Your child's evaluation appointment will include a history and physical exam in addition to other testing. After all the test results are compiled, the transplant team will meet to discuss whether transplantation is an appropriate treatment option for your child. It is important to remember that your child is **not** listed for a transplant at the end of the evaluation appointment.

Tests and Procedures During Evaluation

Initial Testing

The following is a list of preliminary testing that can be expected in order to determine if your child is an appropriate candidate for kidney transplant. Many times all of the testing below can be accomplished on the day of evaluation.

- A complete history and physical exam to evaluate your child's general health is performed. It is very important that you be completely honest with us about your child's health history.
- Blood studies will include blood chemistries, blood counts, blood type, immune system function and tests for certain infectious diseases.
- A chest X-ray is taken to determine the health of your child's lungs and respiratory tract.
- An echocardiogram of your child's heart is done. Further diagnostic testing of your child's heart may be necessary.
- Dental exam required for every child over the age of 3
- Immunizations need to be current and updated as deemed necessary by the medical team.



Additional testing may be necessary depending on your child's individual medical history and consultations with other providers.

Additional Testing

Often the results of one test lead the team to request additional testing. When this occurs, the results from the additional testing are necessary before the team can make a determination about your child's candidacy for transplant. The transplant team wants to ensure your child is as healthy as possible for his/her transplant and that he/she will benefit from a transplant.

When additional tests are ordered, they can often be done by your child's primary care physician or local lab. Occasionally, we require a specific test be completed at a UMHS facility. You will receive written instructions for the tests that are needed.

If your child is asked for additional testing, do not be discouraged. Most people who get listed and transplanted are asked to have additional testing after their initial evaluation.

Testing Complete – Results Reported

It is important to note that all requested testing must be completed and the results must be obtained by the transplant team in order for your child's case to proceed to be reviewed at the evaluation meeting. Failure to complete the testing or get the results submitted can lead to delays in the process.

Health and Social Considerations for Listing

Smoking Policy

Tobacco use constricts the blood vessels, compromises blood flow to the extremities and is a risk factor in coronary artery disease. Transplant recipients who smoke and/or use smokeless tobacco products have worse survival of their transplant. They also have higher risks of infection and of developing cancer. Going through tobacco withdrawal at the time of surgery is an unnecessary stress. The University of Michigan Health System campus environment is smoke-free, therefore, no smoking is permitted on the grounds.

Transplant candidates are recommended to stop smoking and/or using smokeless tobacco products before transplant and to maintain abstinence from tobacco products after transplant.

Smoking cessation assistance can be received through primary care physicians or through the transplant social worker. Available smoking cessation programs include:

- UMHS Tobacco Consultation Service
(734) 998-6222
quitsmoking@med.umich.edu
- Michigan Tobacco Quitline
QUIT-NOW, (800) 784-8669

Alcohol and Drug Policy

Alcohol and illicit street drugs can cause serious health problems for the transplant recipient. Addiction to alcohol or drugs may cause a person to place more importance on getting their alcohol or drug than on caring for their transplant. Use of alcohol and drugs can make people forget to take medications, neglect lab work and doctor's appointments and can impact the ability to follow up on all aspects of pre- and post-transplant care. Use of alcohol or drugs as a way to deal with stress and worry is a possible sign of addiction.

Patients identified by the transplant team as having significant substance abuse issues will be expected to work with the transplant social worker to establish an appropriate treatment plan.

Insurance companies may withhold coverage for a transplant if there is evidence of untreated (past or present) alcohol or substance abuse.

Mental Health

Managing chronic illness can be stressful and challenging and some patients and families experience occasional or ongoing depression or anxiety. In addition, kidney transplant recipients are prescribed medication that may cause mood changes for a short time after transplant. If your child is dealing with depression, anxiety or any other mental health issues, the transplant team will discuss a plan for managing symptoms. This may include a referral to a mental health professional for therapy or medication management. If your child is already followed by a local therapist or psychiatrist, the transplant social worker will talk with you and your child about requesting a letter summarizing your child's care and treatment plan at the evaluation appointment.

Social Support Plan

To ensure a successful transplant outcome, it is important to discuss the need for ongoing social support with family and friends. Your child's transplant social worker will require your family to have a plan for these specific tasks that you will need help with:

- **24/7 on-call driver:** Identify a friend or family member who can bring you to Ann Arbor when you receive the call for transplant. This call can come anytime, day or night.
- **Main support person while in the hospital:** The inpatient transplant team will want to provide education and instruction to you and your child before he/she is discharged. The team will educate you and your support person regarding medication instructions, follow-up clinic appointments and weekly labs. This information is important to remember after your child returns home.

Adherence to Medical Regimen

The biggest risk factor for loss of kidney transplant in teenagers and young adults is not following the post-transplant medical regimen. Missed medication will lead to rejection and graft loss. Following a medical regimen after transplant is complicated by the normal transition process during the teenage years. The transplant team will assess the family's and patient's ability to follow the medical regimen during the evaluation process.

Active Participation in Your Child's Healthcare

In order to have a successful transplant outcome, it is vital you and your child develop a positive relationship with the transplant team. The transplant experience can include both ups and downs and the team requires regular, consistent and accurate communication about all aspects of your child's care. This communication may be related to medications, symptoms, outside hospitalizations or tests and discussions about the plan for managing the health of your child's transplant. Some of this communication may be with the doctors or with nurses or other support staff. The entire transplant staff is committed to providing quality service and patient care. Please return all calls from the University of Michigan promptly.

Evaluation Meeting

Every patient case is discussed at the Kidney Transplant Evaluation Meeting at which time medical, surgical and psychosocial history are reviewed. The evaluation committee members review each patient's case and test results to determine whether there are any issues which need to be further addressed before the patient can be placed on the transplant list.

There are three potential decisions that may be made regarding a patient during the Kidney Transplant Evaluation Meeting:

- The patient meets the criteria and is approved to be listed
- The patient does not meet the criteria and cannot be listed
- More information or testing is needed to make the determination and the decision is deferred until the information can be obtained.

You will receive a letter within two weeks of the committee's decision informing you of the decision and any additional steps you and your child need to take.

Closing an Evaluation

The pediatric kidney transplant evaluation committee meets on a regular basis and reviews all the patients who are being considered for a kidney transplant. Sometimes during this review process, it is determined that a transplant evaluation should be closed. This does not mean that your child cannot be reevaluated in the future but instead, at the present time, your child is not a candidate for a kidney transplant at UMHS. There are several reasons that an evaluation may be closed. These include:

- Improvement/stabilization of kidney function such that the need for kidney transplant is not imminent
- Serious medical illness or condition that precludes current transplantation (some examples include recurrent infections, cancer, etc.)
- Failure to demonstrate adequate weight gain
- Refusal to obtain vaccinations required by the transplant team
- Your child is not cleared by other subspecialties involved in his care
- Social or psychological barriers to moving forward with transplant (some examples include CPS involvement, lack of stable housing plan, lack of social support, etc.)
- Inability to maintain a therapeutic relationship with your child's current care team or transplant care team
- Lack of follow through on the recommendations of the transplant team in a timely manner

After the initial transplant evaluation committee meeting, a list of requirements to proceed with the kidney transplant process is provided in writing to your family. It is very important that you make and keep the necessary appointments to meet these requirements. If your child is unable to make significant progress on these requirements within three months of the initial evaluation, the evaluation may be closed. After these three months, if the committee has concerns about this progress, you will receive a letter stating you have one month to move forward with the requirements otherwise your child's evaluation will be closed.

Again, this does not mean your child cannot be reevaluated in the future but instead, at the present time, your child is not a candidate for a kidney transplant at UMHS. You will be notified in writing if the transplant team feels it is in the best interest of your child to close the transplant evaluation.

Getting Listed

If it is determined that your child is an appropriate candidate for placement on the transplant list, your child has completed all the appropriate tests and has received authorization from the insurance company, your child is then listed for kidney transplant. At that time, you and your child's referring doctors will receive a letter about the transplant committee's decision.

To Remain Active on the Waiting List

To remain active on the waiting list, your child must keep up with the listing requirements which include:

- **Your child will have 6-month follow up visits with the transplant team.** These are much shorter than the evaluation appointment. At these visits, we will update your child's health information, ensure that transplant is still a good option, and review any testing that will be needed in the coming year.
- **Send in your child's monthly blood sample without fail.** This sample is used to repeat antibody screening before a transplant and is required to maintain active status on the transplant list. If you do not receive a blood draw kit, call the transplant office so that one can be sent to you. Without a current blood sample your child **cannot** be considered for any deceased donor kidney.

Being Placed on Hold

If the above requirements are not met, your child may be placed "on hold." Patients on hold cannot be offered donated organs, but continue to accrue waiting time. Your child must meet the requirements before he/she will be eligible to receive organ offers. It is in your child's best interest to keep their testing current when listed. **It is you and your child's responsibility to make sure testing is completed and the results are sent to our office. You should contact your child's transplant coordinator to review results.**

Other medical issues can cause a patient to be placed on hold, such as infections, other significant illness or significant operations, and blood transfusion. Your child will be placed on hold for three months after a blood transfusion. Patients may be placed on hold for non-medical reasons too, including change or loss of insurance, social support issues,

compliance issues, substance abuse issues, untreated psychiatric issues and/or the patient's going out of town. Transplant social workers are available to help patients remove barriers to transplantation and will work with you, your family and your dialysis center toward this goal.

Please keep the transplant team informed of any changes in your child's health, insurance or personal situation.

Maintaining Health While Waiting for Transplant

Maintain a Healthy Lifestyle

Staying as healthy as possible, physically and emotionally, before transplantation is very important. We recommend you and your child learn all you can about his/her disease, testing, medications and the transplantation process before the operation.

Staying physically healthy includes the following;

- **Stay as active as possible.** A daily program of moderate exercise, as well as participating in normal activities can help maintain general strength and energy levels, and help to maintain stable lab values.
- **Follow recommended diet.** While waiting for a kidney transplant, it is important to follow the special diet recommended by your child's doctors and registered dietitian. When kidneys are not working well, waste products can build up from the foods and drinks consumed. People with kidney disease are often told to adjust protein, sodium, potassium, phosphorus, calcium and fluids in their diet.
- **Patients who smoke should quit.** It has been shown that smoking decreases the survival of the transplant, in addition to causing other health issues. Our team can help locate resources to help patients quit.
- **Female patients should avoid pregnancy while waiting for a transplant.** Some patients are interested in the possibility of becoming pregnant and having a baby after a transplant; this is often possible. For more information on this topic refer to page 11 in the Medicines section.
- **Talk with your child's transplant coordinator** if you or your child have any questions about maintaining a healthy lifestyle.

Staying Emotionally Healthy is Very Important

Transplant social workers are trained to help patients and their loved ones to cope with the challenges of chronic illness and the specific challenges of kidney transplant and ongoing care. Here are some suggestions from our social work team about emotional health:

- **Share your feelings.** The wait for a kidney transplant can take years and it is common to have feelings of frustration, anxiety and sadness during your child's time on the waiting list. If you or your child begins to feel overwhelmed by these or other emotions, we encourage you to talk to the transplant social worker, dialysis social worker, or a friend or family member. If these emotions are making it difficult for you or your child to function on a daily basis, individual counseling might be helpful. Your child's social worker can further discuss any resources that may be of assistance.
- **Stay involved.** Keeping life as normal as possible helps maintain stability during the waiting period. Your child should try to stay involved in school and leisure activities as his/her health will allow. If your child's health limits his/her ability to continue to work or participate in some activities, be creative and find new outlets or interests to focus on.
- **Learn to relax.** You should identify those activities that your child finds relaxing and make a commitment to do at least one relaxing activity each day. Some activities that help reduce stress are taking a walk, listening to or playing music, reading, relaxation classes, talking with friends or family, writing, drawing, painting, as well as many other activities. Avoid unhealthy outlets of stress such as abusing drugs or alcohol, overeating, or isolation from friends and family.
- **Engage in activities that promote spiritual well-being.** For patients who turn to faith or spirituality as a source of strength, you and your child may find that connecting with your spiritual community for prayer and comfort may ease the mind, body and spirit.

Where and Who to Call When You're Sick – Before Transplant

Many problems may occur while waiting for a transplant. It is extremely important to remain in contact with your child's transplant coordinator.

Call if:

- Your child is hospitalized outside the University of Michigan Hospital
- Your child's medical condition changes or he/she becomes ill
- Your telephone numbers change

Pediatric Kidney Transplant

Call (734) 615-2040

Hours: Monday – Friday,
8 a.m. – 4:30 p.m.

Closed holidays.



- Your medical insurance changes
- Your child needs to travel out of town
- You, your child or your family have questions or concerns
- Your care and support plan and those you planned to help you are no longer available

The Call Comes When An Organ Becomes Available

The call advising of an available organ being offered for your child can come at any time. The first notification comes to the transplant coordinator, who works in collaboration with the surgeon.

The transplant coordinator on call has one hour to accept or decline the organ offer. In this time when the kidney becomes available, they need to be able to find your child and to review current information with the surgeon. To ensure the organ can be considered for your child, take the following precautions:

- **Keep transplant team informed about how to reach you.** We need to be able to reach you 24 hours a day. Make sure that the transplant coordinators have phone numbers for family, friends, places of employment or anyone who might know your whereabouts if you are not home. If you have privacy manager on your telephone, we recommend that you remove it. The University of Michigan does not identify itself on these machines. If you don't pick up our call or answer quickly, you may miss your chance for a kidney. If you have an answering machine on your phone, be sure to turn the machine off at night.
- **If you use a pager or a cell phone, answer it even if you do not recognize the telephone number calling.** You may not recognize the number, but it may well be one of the coordinators trying to reach you. Do not start for the hospital without actually speaking to a coordinator. With the number of pagers being used, it is also possible you have received a *misdialed* page. If you have any question about who paged you, call the hospital page operator at **(734) 936-6267**, and ask for the kidney transplant coordinator on call. One of them will return your page, no matter what time of the day or night.
- **If you plan to leave home for business or vacation, call the Transplant Office** to give your destination. Should a kidney become available, we will do our best to locate your child and offer the chance to return for the transplant.
- **It is important to realize that even after you arrive at the hospital, the transplant team may determine that the donor organ is not suitable.** While this can be very disappointing, remember that sometimes this cannot be determined until the last minute, and the transplant team is committed to giving your child the best possible outcome.

Transportation to the Hospital

The transplant coordinator on call makes the necessary arrangements for the transplant operation. You will have adequate time to travel to the hospital. Your travel time has been considered in making the arrangements for the operation. Drive safely. Wear a seat belt.

What to Bring When You Come to the Hospital

It is a good idea to be prepared for your child's hospitalization by having a bag packed with the things your child will need to bring to the hospital. In addition to personal clothing and toiletry items, we suggest you bring the following:

- Patient Education Guide (this manual). This will be used throughout the inpatient stay to continue education on medications and care following transplant.
- Personal items, clothing for discharge
- Glasses
- Formula
- Current medications
- Money for parking and meals
- Phone numbers of family and friends who will be caring for you and your child during recovery
- Canes or other walking devices

When You Arrive at the Hospital

When you arrive at the hospital, go directly to the Mott Children's Hospital Information Desk identified by the transplant coordinator.

