Pre-transplant Pediatric Kidney Patient Education Handbook

Department of Transplant Services
History of Kidney Transplantation

Physicians began experimentation in kidney transplantation in the early 1900s. In 1954 the first successful kidney transplant was performed. The donor and recipient were identical twins. In 1967 we began performing kidney transplants at the University of Virginia, and today over 1,900 patients have received a kidney transplant here. The UVA transplant center does approximately 80 kidney transplant surgeries each year (5-10 of them are pediatric).

Where do Kidneys Come From

Kidneys for transplant surgery can come from two different sources. One is a deceased donor the other is a living donor. A deceased donor is someone who has suffered a catastrophic injury to their brain, for example from a car accident or a stroke. A deceased donor is a previously healthy person who has suffered brain death despite advanced life support. All thinking portions of the person’s brain, as well as the brainstem, have been destroyed. When an individual meets strict clinical criteria establishing brain death, they can become and organ donor.

Living donors are another option for kidney transplant and for many patients, the best option. A living donor may be someone related to you by blood or someone unrelated. The individual ideally has a blood type compatible with yours however, if there are no blood type compatible donors, there still may be opportunities for that individual to be a donor. Due to the large number of persons waiting for kidney transplant and the shortage of donor organs available, we encourage you to explore the option of living donor transplant if it is available to you. Living donors go through a thorough evaluation to assure that they are healthy and that they have two kidneys that function well. One kidney can perform the function of two if it is a healthy one. There is an educational handbook with detailed information regarding Living Kidney Donation that will be provided to you if you choose to investigate this option.
UVA Physician Coverage Plan
The University of Virginia, as an academic medical center meets all the national regulatory body requirements to provide appropriate medical staff coverage for all patient care needs. This coverage is provided 365, 24/7 by dedicated transplant surgeons and physicians along with support from house staff, fellows, nurse practitioners, and nurse coordinators. All physicians are routinely available to cover their respective service on a rotational basis. This coverage is for all aspects of the transplant program activity including organ procurement and transplant surgery as well as patient management.

Should circumstances related to coverage change patients will be notified via mail and/or any additional communication necessary.

The Evaluation Process
Your child has been referred to the University of Virginia for evaluation for kidney transplant. In some cases your local doctor or dialysis unit has referred you. Prior to the appointment, we ask that medical information and recent diagnostic testing be forwarded to us. We will review this in order to prepare for your child's clinic visit.

On the day of the appointment, we ask that you arrive 30 minutes early for registration in the Pediatric Specialty Clinic. Your child's evaluation will take place over several visits as the Pediatric Nephrology team will discuss transplant. We have a multidisciplinary team with a social worker, pharmacist, transplant nurse coordinator, education consultant and pediatric surgeon.

Transplant Nurse Coordinator – The Nurse Coordinator provides education regarding the transplant evaluation process, listing for transplant and patient responsibilities before and after transplant. Meeting with the coordinator is intended to provide you with an opportunity to ask questions and become fully informed about the kidney transplant process.

Pediatric Surgeon – the transplant surgeon’s role is to assess your child's appropriateness for transplant based on the information obtained during your evaluation. The surgeon also discusses with you the significance of undertaking kidney transplant, details about the procedure and the risks/possible complications associated with surgery.

Pediatric Nephrologist – the pediatric Nephrologist meets with you to discuss many of the disease processes that have contributed to your child’s kidney failure. He reviews your child’s medical history to determine medical tests that should be performed in addition to the standard evaluation tests required during the evaluation.

Social Worker – the transplant social worker’s role is to evaluate the transplant candidates ability to cope with the stress of transplantation and their ability to follow a rigorous treatment plan, both before and after transplantation. Patient and family/guardian commitment is necessary and the social worker will help you identify your support group. He will also discuss with you the costs associated with transplant and with medications required post transplant. He will help you understand your insurance coverage and what costs may not be covered by insurance.

Nutritionist – the transplant nutritionist will perform a nutrition assessment and provide nutrition education when needed.

Pharmacist – the transplant pharmacist will review your current medications and identify concerns or possible complications with medications required post transplant.

At the end of the evaluation, you should have a good idea of what risks and benefits are associated with kidney transplant and whether it is a good option for you. At any time either before or after your clinic appointments, please feel free to contact us with any questions or concerns. We are here to help you.
Evaluation of the Kidney Transplant Recipient

In order to be considered to be a transplant recipient an individual must have kidney function less than 20 ml per minute which is roughly the same as 20% function or less. Not every patient with end stage renal failure is a suitable candidate for kidney transplantation. The selection decision is most dependent upon a patient’s physical condition. Each case is evaluated individually. There are some factors that exclude patients from receiving a transplant. Such factors include chronic infection, liver disease, extensive vascular disease, morbid obesity, severe respiratory disease, cancer, and severe psychosocial instability. A thorough evaluation is essential to clearly identify risks associated with transplantation. We will also help you and your local doctor correct or stabilize conditions that may lead to complications following transplant.

The routine evaluation for any potential kidney recipient includes the following diagnostic tests:

- Blood tests will help determine the extent and/or cause of your child’s kidney disease. Other tests performed will be for typing and identification or specific viruses. Complete Blood Count (CBC), Chemistry tests, Coagulation tests, Blood and Tissue Typing, Hepatitis testing and Viral Screening tests including CMV, EBV, VZV and HIV.
- Cardiac evaluation: EKG and other diagnostic tests the Transplant Nephrologist feels are necessary, which may include an Echocardiogram. This test will show how well your child’s heart is beating and the function of his/her heart valves. This will help your physicians in deciding if your child’s heart function is strong enough for transplant surgery.
- Chest x-ray helps your physician identify any problems with your child’s lungs
- Urine test, may be used to screen for the presence of drugs and alcohol
- TB skin test
- Social Work Evaluation
- Nutrition Assessment

The Transplant Nephrologist may request additional studies to determine if your child is a suitable candidate for renal transplantation.

We also may request neuropsychological testing. After your child’s initial visit, we will contact you to let you know when your next appointment is and how things are. Working closely with the Transplant team will help the evaluation go smoothly.

Evaluation of the Living Donor

A living kidney donor must go through a thorough evaluation to ensure that kidney donation is safe for him/her. Blood tests are done to determine his/her blood type, blood chemistries, viral studies and blood count. If the donor and recipient have compatible blood types, tissue typing is obtained. Here are the blood types and which are compatible:

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The Rh factor, negative (-) or positive (+), is not important for organ transplants.

It is still possible to have a living donor who is a different blood type. We can test your child’s blood type to see if it is possible to modulate the blood type by giving your child special medications before transplant.

Each of us inherits certain genetic markers from our parents. Tissue typing determines how closely one’s markers match those of someone else. For instance, you and a sibling may have all six markers match, or only half will match, or none will match. These results are obtained through a blood test.
When a potential donor contacts our Living Donor Coordinator, a health screening is completed over the telephone to determine if there are any obvious health issues that would preclude kidney donation. The donor will then have lab studies completed to confirm blood type and determine the adequacy of their kidney function. If these results are acceptable, the donor is worked up further.

All expenses associated with living kidney donation are paid through a special account and eventually are billed to the recipient’s insurance. There is no compensation to the donor for time lost from work or costs incurred coming to and from the transplant center. Hospitalization and treatment of any complication arising from the donor’s surgery are covered.

If your child has a potential living donor, he/she must contact the transplant office. We will not call donors to solicit their interest.

**Evaluation of the Cadaveric Donor**

The evaluation of a cadaveric donor begins when brain death is declared and the donor’s family gives consent for organ donation. Chemistry tests are done to determine if the kidneys are functioning normally. Blood typing and tissue typing are also completed. The donor is tested for hepatitis, HIV and other viruses. The donor family is interviewed to determine if the donor exhibited any high-risk behavior that would make infection with hepatitis B or HIV likely. Although donor organs are tested there is still a small risk (less than 1%) to the transplant recipient of contracting HIV, hepatitis or other viruses if the donor is infected but the infection is not detectable at the time of donation.

If the kidneys are found to be suitable for donation, the donor is taken to the operating room where the kidneys are removed. Once removed, the kidneys are placed on ice and in a nutrient rich solution that helps to preserve their function. The kidney is transported to the location where the recipient operation will occur. Every effort is made to transplant the kidney(s) within 36 hours of being removed from the donor. Generally the longer the kidney has been out of a donor the more slowly normal function will recur in the recipient.

**Activation on the Kidney Transplant List**

Once your child’s evaluation is complete, the case will be discussed at Kidney Selection Conference. This is a multidisciplinary group that meets weekly. The group consists of the Pediatric Nephrologists, a Social Worker, Transplant Surgeon, Nurse Coordinator with input from pediatric surgery, urology nutrition and other services who have seen your child. You will be notified of the group’s decision. If the decision is made to activate your child on the list, information is provided to UNOS. UNOS, which stands for the United Network for Organ Sharing, is a federally regulated, private organization. They maintain the computer registry where all organ transplant candidates are listed. UNOS is responsible for establishing the policies that the transplant centers must follow and ensures that the sharing of organs is fair to all individuals. Patients are prioritized on the Kidney Transplant Wait list based on time with points added for being a child. This means that you must wait “in line” for a kidney to become available from a deceased donor. The kidney waiting list does not currently take into account the severity of your child’s illness or length of time on dialysis.

Your child’s name will be placed on the list along with blood type and the antigens that were identified as part of the blood tests. While active on the kidney transplant list, we will need a sample of your child’s blood each month. With this blood we are able to determine the PRA (preformed antibody level) and perform a preliminary crossmatch with potential donors that become available. If we do not receive this sample, your child won’t be able to receive a kidney transplant, since we need it to match with the donor. It is important to keep all appointments and complete lab tests so that your child is in the best possible shape for transplant when the time comes.

The waiting period for a transplant is a difficult time...
for most patients. You can anticipate a waiting time of approximately one year for a cadaveric kidney transplant for a child. During that time you need to be prepared to accept a kidney should one become available. While active on the transplant list, we will need to be able to reach you at all times. We will ask you for phone numbers of family or friends who could assist in helping us to locate you. It is extremely important that our office be able to contact you at any given time. Additionally, you should have a plan to be able to get to UVA for a transplant. This means someone to drive you if needed or to watch your other children or care for your home or animals. It is important to notify the transplant center of changes in your health or contact information.

When a kidney becomes available for your child, the Pediatric Nephrology Team must make contact with you within one hour, or the kidney will be offered to the next person on the list. We will then let you know when to arrive at the hospital. It may be necessary for your child to be dialyzed prior to surgery. If your child is active on the list, it is assumed that you are ready and willing to accept a kidney. If you change your mind about this, or your child becomes ill, please contact us so that we may temporarily remove your child’s name from the active list.

Multiple Listing & Wait time Transfer – Per UNOS patients can be listed on more than one waitlist which means that your child may be evaluated and listed for transplant at another transplant center. Visit www.transplantliving.org for more information.

Crossmatch

Just prior to both a living donor transplant and a cadaveric transplant, a critical blood test called a crossmatch will be performed. A sample of your child’s blood will be mixed with white blood cells from the potential donor to determine the presence of cytotoxic antibodies to the donor’s antigens. If this test is “positive,” indicating the presence of antibodies to the donor within your child’s blood, a transplant from that donor cannot be done. Your child’s body would quickly try to reject the kidney. This can be very disappointing for the living kidney donor and recipient when the transplant surgery has been scheduled and it must be cancelled due to positive crossmatch. You will be told at what point the crossmatch can be repeated and when the surgery may be rescheduled.

Incompatible ABO Kidney transplant

In some cases a living donor kidney transplant can still work even with a positive crossmatch. Prior to transplant, your child will receive medication treatments that can alter the immune system so your child’s body can accept the incompatible kidney. These medications, Rituxan and IVIG, take several hours to infuse and are given several times. The treatment, plasmapheresis, is similar to dialysis, but removes antibodies from the immune system instead of toxins. If it is decided that this treatment option is right for your child, you will need to come to Charlottesville 3 days a week for 2–3 weeks prior to transplant to complete the treatments.
Kidney Transplant: Surgical Procedure

When it is determined that the crossmatch is negative and that there are not any other concerning medical issues with the recipient, he/she will be taken to the operating room. The surgical procedure lasts approximately four hours. The kidney is placed in either the right or left lower abdomen near the hipbone. An incision, approximately 10 inches in length, is made in the lower abdomen. The renal artery and vein are connected to the hypogastric or iliac artery and vein. After blood flow is established, the donor ureter is implanted on the recipient bladder. The recipient’s native kidneys, or his/her own kidneys, will remain in place unless they are causing problems or are infected. The recipient is then taken to the Pediatric Intensive Care Unit. A transplant surgeon will discuss with you in detail risks associated with transplant including:

Medical Risks:
- Bleeding requiring transfusions, 5 in 100
- Infection, 1 in 20
- Wound Infection, 1 in 20
- Pneumonia, 1 in 20
- Pain or discomfort usually lasting 1-8 weeks
- Blood clots (that are symptomatic) in legs, 1 in 33
- Damage to abdominal organs, including the spleen and intestines, 1 in 100
- Incisional hernia, 1 in 20
- Urine Leak, 5 in 100
- Kidney Thrombosis, 1 in 100
- Delayed Graft Function, 50 in 100 Cadaveric Donors; 5 in 100 Living Donors
- Re-operation for bleeding, 5 in 100
- Acute Re-transplant, 3 in 100
- Neuropraxia (arm pain/nerve compression due positioning in the OR), 1 in 5

- Arrhythmia, 1 in 100
- Cardiovascular collapse, 1 in 100
- Multi-organ failure, 1 in 100
- Major anesthetic complication such as heart attack and/or stroke, 2 in 100
- Death 1 in 100
- Other risks (for example pleural effusion, pneumonia, allergic reactions to medications)

Psychosocial risks:
- Depression
- Post Traumatic Stress Disorder (PTSD)
- Generalized anxiety
- Anxiety regarding dependence on others
- Possible feelings of guilt
Immunosuppressive Medicine

While in the hospital after receiving a kidney transplant, it will be very important for you to learn about the medications your child will be on. The success of your child’s kidney transplant is dependent on how effectively we are able to suppress your child’s immune system. In order to prevent your child’s body from rejecting the transplanted kidney, we need to alter the immune system through the use of immunosuppressive drugs. If your child stops taking medicines after transplant, he/she will reject the kidney. It is critical that you realize this BEFORE your child is transplanted. You are making a commitment to life-long immunosuppression for your child. These medications have side effects that you should be aware of as you decide whether transplant is a good option for you.

The following drugs are used in combination to prevent rejection. You will also find other medicines listed which will be needed in conjunction with the anti-rejection drugs. The most frequent side effects are listed for each.

### Prednisone

1. Mood Swings
2. Stomach Ulcers
3. Bone Loss
4. Muscle Weakening
5. Diabetes
6. Weight gain
7. Moon face

### Prograf

1. Tremors
2. High Blood Pressure
3. High Potassium levels
4. Headache
5. Diabetes
6. Nausea

### Cellcept

1. Nausea
2. Low White Blood Cell Count
3. Vomiting
4. Diarrhea
5. Diabetes
6. Nausea

Bactrim is used to prevent pneumocystis pneumonia, a rare lung infection that affects persons who are immunosuppressed. Your child will take this drug twice each week.

Nystatin or Mycelex are anti-fungal medicines that prevent the overgrowth of yeast in the mouth, which can occur because of immunosuppression. Your child will use this daily during the first three months after transplant.

Anti-ulcer medications are given to protect your child’s stomach while taking prednisone.

Your child’s doctor may feel that other medications are needed to treat rejection or infection. Listed below are other medicines that may be prescribed.

Ganciclovir or Valganciclovir is used to prevent or treat CMV infections.

Your child may also need to be on other medications to control blood pressure or to treat other medical problems. The side effects experienced will be most prominent in the first six months after transplant. As your child progress after transplant we will be able to decrease the medications.
Rejection

Rejection of an organ can occur after any kind of transplant. Your child may experience rejection in the first three months. It is important to know that rejection is treatable. At the first sign of rejection, we will treat your child with medicine to reverse it. Your child will be given steroids in a large dose initially. If treatment with steroids does not reverse the rejection, other very potent immunosuppressive drugs will be given.

We will monitor your child for rejection through laboratory values. There are also physical symptoms to watch for. Those symptoms may include fever, high blood pressure, weight gain, decrease in urine output, swelling of arms and/or legs, general tiredness or aches, or pain over the transplanted kidney. If you notice any of these symptoms, you should contact Pediatric Nephrology immediately. In many circumstances, we will notice rejection through lab values before you notice symptoms. That is why it is critical that you attend clinic visits as requested.

Follow-up Care After Kidney Transplant

We will follow lab values closely in order to help you maintain your child’s transplanted kidney.

We will need to see your child in the pediatric nephrology clinic approximately 3X/week for the first 2 weeks after discharge from the hospital, then 2X/week the next 2 weeks. We then try to limit the visits to weekly weaning to every other week but this will depend on how your child is progressing. By one year post, the transplant your child should be seen every 1-2 months.

Financial Concerns

Medicare covers most patients who have End Stage Renal Disease and are on dialysis. Medicare will cover the costs involved with kidney transplant. Medicare also covers 80% of the cost of immunosuppressive medicines only for the first three years after transplant. After three years, Medicare may no longer pay for any transplant medications. It is essential to explore the potential options for obtaining transplant medications prior to undergoing kidney transplant. Transplant medications are very expensive. It is also important to understand that if an individual has a transplant surgery at a center that is not Medicare approved, it may affect his/her ability to get their immunosuppressive drugs paid for under Medicare Part B. The UVA Transplant Center is a Medicare approved transplant center. The Social Worker will work with you during your evaluation to determine how you may be able to obtain medications after your Medicare coverage ends.

If it has been determined that you are Medicare eligible OR you already have Medicare because of your kidney disease: YOU SHOULD NOT RECEIVE ANY BILLS FOR ANY PART OF YOUR EVALUATION, NOR SHOULD YOUR INSURANCE BE BILLED.
UVA Patient Rights and Responsibilities

What You Can Expect

UVA Health System provides quality health care while respecting the rights of our patients and their families. During your visit you can expect:

- Information you can understand about your illness and planned treatments.
- To take part in making care decisions including why you need a treatment and what will happen if you do not have it.
- To know the name of the doctors and all staff taking care of you.
- To have your family or doctor to be told when you are admitted to the hospital, if you wish.
- To receive care in a safe environment and to be free from any form of abuse or harassment.
- To have personal privacy and to have your health care information treated confidentially.
- To access information in your medical record.
- The chance to write down your wishes for future medical care (using an Advance Directives form). We will follow your expressed wishes.
- To have your pain assessed and managed.
- To be free from restraints unless needed to keep you or others safe.
- The option to agree to or refuse any research study or experiment.
- The chance to review your bills and have any questions answered.
- A timely reply to any concerns or complaints.

To provide you the best possible care, we ask that you and your family:

- Tell us correct and complete information about your health, wishes for your care, changes in your condition, and your concerns.
- Ask questions when anything is unclear.
- Follow your care plan or accept the risks if you make another choice.
- Show respect for all patients, visitors, staff as well as the hospital rules.
- Pay your bills promptly. If you are unable to pay for your care you may receive help. Ask us for information about our financial assistance program.

Please feel free to ask any questions or talk about any concerns with your health care team.

If you are not satisfied, please call our Patient Representative Department at 434.924.8315.

You have the right to contact an agency listed below:

Office of Licensure and Certification Virginia Department of Health Office of Quality Monitoring
Phone: 800.955.1819 or 804.367.2106
Fax: 804.527.4503

The Joint Commission Office of Quality Monitoring
Phone: 800.994.6610 | Fax: 630.792.5636
UVA Transplant Patient Rights & Responsibilities

What You Can Expect

Rights

Quality Care:
- Access to quality medical and psychosocial care regardless of ethnic background, national origin, religion, or age
- Access to transplant physicians, nurses, social workers, and other specialists as needed.
- To expect coordination of effort between my transplant team and primary care provider

Respect and Personal Dignity:
- To be treated with respect, dignity, courtesy, compassion, and cultural sensitivity
- To have privacy and confidential handling of all medical records and communication

A Voice in Decision-Making:
- To be consulted for my view of “quality of life”
- To participate as a full partner with my health-care team and to have my opinions heard and valued in the development of a plan of care
- To have treatment options, possible complications and self-care requirements explained in an understandable manner, with sufficient time to ask questions and have them answered
- To appeal decisions made by a physicians, hospital staff, managed care plan, or other health-care provider
- To obtain a second opinion and/or accept or refuse medical treatment
- To change physicians

Information:
- To have family members or significant others, I designate, be kept informed of my medical condition during hospitalizations
- To know the identity and profession of any individual providing a service to me
- To timely communication regarding lab work results, medical tests, and advice of my medical team, and to have access to all medical records
- To receive a complete explanation of the total bill for services rendered.

Emotional Support:
- To have feelings respected and, when appropriate, addressed by my health-care team
- To have a comprehensive psychosocial plan developed and updated by an appropriately trained mental health provider
- To have correspondence forwarded to the family of my donor, provided the donor family has expressed a willingness to receive communication from the recipient.

Responsibilities

 Maintain Long-Term Health:
- To schedule appointments and tests at appropriate intervals with the transplant team
- To be prompt in attending appointments and when canceling, to give notice as early as possible of the need to reschedule
- To adhere to transplant medical instructions and to inform the transplant team when unable to do so
- To learn the names, dosages, and reasons for taking all prescribed medications and to report all adverse reactions to the transplant team
- To learn and identify signs and symptoms of rejection and infection and know when to report such signs and symptoms
To maintain primary health care needs (dental, urology, dermatology, etc.) and to know when to report any abnormalities

To ask questions and obtain clarification to ensure understanding of all communication from the transplant team

Provide Information:

- To inform the transplant team if my address, insurance or phone number change
- To inform the transplant team about any changes in my health condition including: desire to take new medication (including herbal, vitamins, alternative, or over-the-counter); any change in my daily activity (such as stopping or starting exercise regimen); or any other situation that may have an impact on my emotional or physical well-being
- To provide information from other treating physicians to the transplant center by giving written permission for records to be sent to the transplant office
- To provide the transplant team with the names and contact information of designated family or significant others who should receive updates on my medical and psychosocial condition
- To request results of my medical and lab tests if these are not provided in a timely fashion

Display Mutual Respect:

- To treat all health care professionals with respect and courtesy
- To cooperate and follow UVA Health System rules regarding patient conduct

Meet Financial Obligations:

- To understand that UVA will NOT pay for my child’s medical care or medications needed after transplant
- To give UVA any information needed for insurance to pay for my child’s transplant and to pay for my medical care and medications after transplant
- To apply, if needed, for financial help to pay for the cost of transplant and for medical care after transplant
- To submit any financial verification information required by assistance agencies (State or private)
- To understand that insurance and/or Medicare does not pay for the cost of my child’s transplant or for the drugs after transplant that I am responsible for paying for all of these costs
- To understand that changing health insurance may mean that a new insurance will not cover pre-existing conditions such as transplant medications, etc.
- To understand the limits of Medicare and/or other insurance (including deductibles and co-payments)
- To notify the transplant office of any insurance changes before or after transplant
- To accept responsibility for the cost of transplant surgery if insurance denies coverage due to my failure to notify UVA of insurance changes

Summary

Kidney transplantation is one treatment option available to persons with end stage renal disease. There are risks and benefits associated with kidney transplant. We look forward to seeing you through the transplant process if this is a good option for you. Please contact us at 434.924.2096 with any questions you may have either before or after your clinic appointment.