Welcome to University Transplant Center at University Hospital in partnership with the University of Texas Health Science Center at San Antonio (UTHSCSA).

This guidebook was created to help provide you and your family with a better understanding of the transplant process. Please read over this information carefully and write down any additional questions you may have for our team.

Our History
The Kidney Transplant Program was started in 1968, with the first pediatric case performed in 1988. Our highly skilled transplant surgeons have performed over 1,300 kidney transplants, including 200 pediatric kidney transplants and many successful living-donor transplants. According to data reports, our patient survival rates at one year have consistently met or exceeded national expectations.

Please refer to the Scientific Registry for Transplant Recipients web site to view our patient outcomes and survival rates. New reports are available every 6 months at www.srtr.org.
THE KIDNEYS

The kidneys are located on either side of the spine near your waistline. They are about the size of your fist and are bean-shaped.

The kidneys:
- Remove waste products
- Control body fluid by balancing water and salt
- Control body potassium, phosphorus and other electrolytes
- Help keep blood pressure steady
- Help make strong bones and red blood cells that carry oxygen through the body

Signs and symptoms of kidney disease:
- Abnormal blood or urine test results
- High blood pressure
- Fluid build up in the face, legs, ankles or hands
- Shortness of breath
- Mental confusion
- Headache
- Extreme tiredness

If your child needs a kidney transplant

Some children are born with problems or develop diseases that can damage the kidneys. If the damage is severe or continues for a long time, he/she may have kidney failure that will eventually require dialysis. Dialysis is a procedure that uses a machine to remove waste products from the blood. Before or after dialysis has begun, you may be told your child is in need of a transplant. This option may feel scary but know that you are not alone. Your child’s medical team will help you through the process. A successful transplant could help a child with kidney failure avoid dialysis and can make him/her feel stronger and healthier.
A kidney transplant is a treatment option to improve your child’s quality of life and will not cure the underlying cause of kidney disease.

**Treatment Options**

I. Dialysis

- Hemodialysis – treatment usually done in a hospital or clinic
- Peritoneal dialysis – treatment done at home

II. Transplant

- Living donor types
  - Related (such as a parent, brother, sister, aunt, or uncle)
  - Unrelated (such as a family friend, stepparent, or adoptive parent)
  - Altruistic (a person who wants to donate an organ and does not know the recipient)
- Paired donation (diagram shown on page 11)
- Deceased donor – someone who does not survive an accident or illness, and their family makes the decision to offer their loved one’s organs to help others who need a transplant.
YOUR CHILD’S FIRST VISIT

Your child was referred for a kidney transplant evaluation because he or she is experiencing symptoms of kidney failure.

The process begins with lots of tests and meetings with specialists to determine if a transplant is right for your child. This may be tiring and confusing; therefore we encourage you to bring another adult along. It also helps to write notes and have someone else there to help you remember what was said.

The purpose of the evaluation is to:

- Introduce you to all members of the transplant team
- Confirm the diagnosis of the kidney disease (in most cases, the referring doctor already has made the diagnosis)
- Determine if your child would benefit from a kidney transplant
- Explain kidney disease, transplant surgical risks and benefits
- Discuss options such as living donation

We ask that you not bring other children to this visit. You will need to pay close attention to the information provided by many team members.

Please bring the following with you to the evaluation:

- All insurance cards including prescription plan
- Your child’s medications and medication list
- Any new test results not sent to the transplant team
- Up-to-date immunization records
- Contact information for all your child’s doctors, including: dentist, eye doctor and pediatrician
- Contact information for your child’s school
- Contact information for any potential living donors
  (Donors can begin the donor screening process at any time)
- List of questions to ask the transplant team
Preparing for the Evaluation

Children and adults alike feel better when they know what to expect. Learning as much as you can about transplant and the process may help your child with a speedier recovery.

Here is a list of tests and exams that may be performed during your child’s kidney transplant evaluation:

- Physical exam, complete medical review and surgical history.
- Electrocardiogram (EKG or ECG) – Evaluates the electrical system of the heart that controls rate and rhythm and may reveal heart damage that was previously undetected.
- Echocardiogram – An ultrasound of the heart that will show how well your child’s heart “pumps.”
- Chest X-ray – Determines if your child’s lungs and heart are healthy.
- Bladder Studies – An x-ray and/or camera examination of your child’s bladder.
- Nutrition Assessment – A dietitian will ask questions to determine your child’s eating and exercise habits. They want to help your child be as healthy as possible before and after transplant.
- Blood Tests – Your child’s blood count, blood type, blood chemistries, blood for viruses and immune system function will all be checked.
- Urology Assessment - A urologist will diagnose, treat, and manage your child’s ureters and bladder.
- Dental Evaluation – A dentist must check your child’s teeth and gums to make sure they are healthy before transplantation. (This may or may not be covered by your child’s insurance.)
- Panel Reactive Antibody (PRA) – Determines whether your child has antibodies that would cause your child to reject certain kidneys.
- Tissue Typing – Test used to find a matching organ.
- Social Work Assessment – To discuss and determine your family/friend support system before and after the transplant and to identify any additional resources that will be needed.
MEETING THE TRANSPLANT TEAM

The transplant team is a group of healthcare professionals here to help you care for your child before and after transplant.

Transplant Nephrologists
Our pediatric nephrologists are kidney doctors who specialize in transplant. They will review your child’s medical history and examine your child to help determine if they are a candidate for transplantation.

Transplant Surgeons
A transplant surgeon will go over the surgical procedure with you and your child, and answer any questions you may have about the operation.

Transplant Social Worker
A social worker will assist you with any non-medical issues. They will also provide important information regarding various insurance and assistance programs. Your child’s social worker helps also with discharge planning and counseling support, if needed.

Dietitian
Our pediatric dietitian provides nutritional advice to help your child remain as healthy as possible. What your child eats and drinks is very important to their overall health and healing.

Transplant Nurse Coordinators
Your child’s pre-transplant nurse coordinator is a registered nurse responsible for managing your child’s transplant evaluation schedule and keeping you informed of your child’s progress toward transplantation. They also provide additional education and support while your child is in the hospital.

After your child’s transplant, he/she will meet his/her post-transplant coordinator who will manage your child’s care.

Transplant Pharmacist
Transplant pharmacists help make sure your child is on the best medications to avoid unwanted side effects and medication interactions. They will educate you and your child about the medications he or she will be taking.

They work with local specialty pharmacies which carry the transplant medications your child will need after transplant.
Primary Care Physician (PCP) or Pediatrician
Your child should continue keeping appointments with their primary doctor before and after their kidney transplant. Your child’s primary doctors are a very important part of your child’s healthcare team and will manage your child’s non-transplant related health issues, such as ear aches, immunizations, wellness checks and the common cold. We will be available if they have any questions regarding your child’s transplant plan of care.

Spiritual Services
University Hospital’s Peveto Center for Pastoral Care offers spiritual services to help promote healing and to meet the spiritual, emotional, and religious needs of all patients and their families. The Peveto Center is open 24 hours a day and may be reached at (210) 358-4000.

Child Life Specialist
Child life specialists are clinical staff members who assist children and families in the hospital cope with the experience of transplant, child development and emotional well-being.

Family and Friends
You and your child cannot go through this process alone. Everyone will come to a point where he or she needs help and encouragement to make the journey. A strong support system produces the best outcome. This means you must have family or friends who are willing and available to help you drive your child to and from appointments and help take care of he/she before and after transplant.

Along the way, you and your child will also meet:
- Transplant Nurse Practitioner
- Respiratory Therapists
- Anesthesiologist
- Resident Physicians
- Physical Therapist
- Administrative Assistant
- Staff Nurse

Receiving a kidney transplant is a gift of life and a lifetime commitment. The success of a transplant is directly related to how well you and your child follow the plan of care given by the transplant team.
WHAT HAPPENS NEXT?

- Once your child’s transplant evaluation is complete and all test results have been received, the transplant team will have a selection committee meeting to determine the risks and benefits of transplantation.

- The selection committee will make one of the following three decisions:
  - **Accept** - the committee recommends your child be placed on the waiting list and/or proceed with living donor kidney transplantation.
  - **Defer** - the committee decides to request additional information or testing before a decision can be made.
  - **Decline** - the committee decides transplantation is not a treatment option for your child at this time.

- The referring physician will continue to monitor your child. A summary of your child’s evaluation will be sent directly to them as they continue to be involved in your child’s care.

- Some children are too well for transplant but may be seen again by the team if their condition changes.

- If transplantation is recommended, you will have the final decision on whether your child’s name is added to the waiting list.

- Your child’s transplant coordinator will contact you by phone and/or correspondence to inform you that your child has been placed on the list. ONLY after you receive such correspondence is your child officially on the transplant list.

- Your child has the option to also be placed on the waiting list at other centers (multiple listing).

- Any potential living donors that have not completed their testing/screening, may do so at this time.

- Patients have the option to refuse transplantation at any time.
CONTACTING YOUR TRANSPLANT TEAM

You may contact any member of the transplant team at any time. Continue to see your child’s local doctor or specialist who can also communicate with our transplant team. We will work together to provide your child the best care.

Please remember that you or a family member must inform the Transplant Nurse Coordinator or transplant team if your child becomes ill or is admitted into a hospital. Clear, direct, and honest communication among all family members and your transplant team will help the transplant process run smoother.

Contacting your Coordinator

Call (210) 567-5777

For non-emergencies, during weekends, holidays, or after hours your call will be answered by our voicemail. Leave your name and telephone number plus a detailed message on the recorder. Your call will be returned as soon as your child’s coordinator becomes available.

NurseLink

For medical questions or concerns after hours, weekends, or holidays, contact NurseLink at (210) 358-3000.

In an Emergency – Call 911

In the event your child is experiencing a life-threatening emergency, such as chest pain, unresponsiveness, breathing problems, or bleeding, call 911 immediately and they will take your child to the NEAREST hospital emergency room. You may ask the physicians in the emergency room to call University Transplant Center to inform the transplant team of the incident.
WAITING FOR A TRANSPLANT

The most difficult part of the transplant process is the waiting period. It is unknown when an organ will become available. Please be prepared for the call at any time. In the meantime, your child should be living a healthy, active, as normal life as possible. This may be a stressful time. Stay calm and don’t be afraid to discuss these issues with your child’s transplant team, clergy, social worker, or counselor. There are support groups and people who are willing to help.

Finding a Donor

The waiting list is a national computerized network. This list is managed by the United Network for Organ Sharing (UNOS).

You may contact them at (888) 894-6361 or visit their website at www.unos.org for more information.

Several factors are considered when determining who will receive the available kidney:

- Blood Type – Every person is a blood type A, B, AB, or O. For deceased donors and living donors, the blood type must be compatible.
- Tissue Type – Genetic matching is done to determine which donors are appropriate for your child. If a perfect match is not available, the recipient will be based on the closest match and time on the waiting list.
- Cross Match – A test which makes sure your child doesn’t have antibodies in his or her blood that would cause him or her to reject certain donor kidneys very quickly.

Children are given priority for deceased donor kidneys in the national sharing system. The average wait times are much shorter than adults with the same blood types.

Average pediatric wait times by blood type:

- O: 2-4 Months
- A: 1-4 Months
- B: 2-7 Months
- AB: N/A - 1 Month

Average wait times are based on transplants performed between 2013-2014 at University Transplant Center. If you would like to compare wait times from other centers, please visit www.srtr.org.

Should your child turn 18 prior to being placed on the list, they will not receive the same priority as a patient who turned 18 while already on the waiting list.
LIVING KIDNEY DONATION

A living donation is the quickest way to transplantation.
A family member, friend or other unrelated healthy person may be able to donate one of their kidneys to your child. Nearly everyone is born with two kidneys, but we can live a healthy normal life with just one. In many cases, living donors are the better option. If you have a potential living donor, please ask your child’s Transplant Nurse Coordinator for further information about this option. We can begin screening potential living donors right away, even before your child’s first appointment!

Your child’s living donor does not need to be an exact match.
Many of our living donors are tested and are not compatible (not an exact match) to the person they hoped to donate to. If that happens, the donor can still help your child through a paired donor exchange. We can help arrange an exchange in which your child’s donor gives his or her kidney to an unrelated, compatible recipient, and your child receives a kidney from another living donor who is the right match for your child. Sometimes, more than two compatible pairs can be matched. So your child’s one donor could actually help save more than two people waiting for life-saving transplants.
WHILE ON THE WAITING LIST

- Keep your child as healthy as possible (good nutrition and a low-salt diet will help your child’s recovery time after transplant)
- Try new activities as a family to keep your child active and positive
- Encourage your child to walk and stay in shape with age-appropriate exercise (they should not exercise if they feel dizzy, nauseous, unusually short of breath or outside on days that are extremely cold, hot or humid).
- Your child should participate in physical education (PE) class at school (Talk to your child’s pediatrician or PCP before participating in any contact sport.)
- Have your child see the dentist regularly to avoid serious infections after transplant
- Keep in contact with the transplant team
- Have your child follow the recommended nutrition plan
- Keep your child’s follow-up appointments with the Transplant Clinic
- Notify your child’s Transplant Coordinator of any telephone, address or insurance changes
- Have a small suitcase packed with comfortable clothing, robe, slippers, etc. (see page 15)
- Contact the transplant team if your child is going out of town and tell them he/she can be reached
- Contact the transplant team if your child has had a blood transfusion, immunizations, or is being treated for an infection
- Plan for financial expenses during the time your child is in the hospital. This includes hotel stay, food, transportation and medication cost upon discharge

Changes on the Waiting List
Your child can be made “inactive” while he/she is on the waiting list. This means, they will temporarily not be eligible to get a transplant.

Factors that will change your child’s listing status include:
- Loss or change in insurance
- Non-adherence/compliance
- Loss of contact with the program
- An illness which would result in a poor transplant outcome

Keep all of your child’s vaccines up-to-date.
PLAN AHEAD

Answer the following questions as a family:

- How will your child get to the hospital once you get the call?

- Who will be the primary caregiver after transplant?

- Where will your family stay while your child is in the hospital?

- How will your child get to follow-up appointments?

- Who will care for your child while he/she cannot attend school for 8 weeks?

- How will you pay for expenses while out of work to care for your child?

- Who will pay the bills and take care of the household chores while you are away?

- Who will take care of other children, elderly relatives, and/or pets?
GETTING THE CALL

- A Transplant Nurse Coordinator will call you with specific instructions
- Have a designated driver and a back-up plan on how to get your child to the hospital
- Bring his or her health insurance information
- Your child will be instructed to not have anything to eat or drink once they are called for a transplant unless the Transplant Nurse Coordinator advises otherwise
- Assign one family member the task of calling the rest of your family and friends

Changes after the call
Your child’s transplant could be cancelled or postponed if:

- Your child has any signs of infection.
- The donor kidney has any problems.
- A new medical problem exists.
  
  *It is important to inform our Center if your child develops a new medical problem as soon as it occurs.*

- Final cross match is positive (if your child has antibodies against the donor kidney that may cause rejection).

Remember, if we cannot find you, the kidney will go to another person. Provide us with as many contact numbers as possible.
WHAT TO BRING
PACK A SMALL SUITCASE

For your child:
• Two sets of comfortable clothing such as: pull-on pants, sleepwear, shoes/slippers, robe
• Favorite blanket, stuffed animal or toy. Make sure the item has been washed well. (Child Life can provide other toys, crafts, books, games, etc.)
• Family photos (be sure to include the pets)
• Personal hygiene items
• List and bottles of medications your child currently takes
• List of important medical conditions, prior surgery(s) or hospitalization(s)
• Peritoneal dialysis supplies for one exchange

For parents or caregiver:
• Keep extra checks, deposit slips, and your ATM/debit/credit card on hand.
• All insurance cards and current photo ID
• Comfortable clothing and shoes
• Prescription medications
• Phone numbers and addresses of family, friends, employers, neighbors, your child’s school and medical care providers.
• A good book, magazine or small craft project
• A camera, phone, laptop and/or iPads (University Hospital offers free wifi “att wifi”)
• Chargers for your electronic devices

WHAT NOT TO BRING

• Jewelry
• Plants or pets
• Fresh fruit/vegetables
• Latex balloons
• A large suitcase

All valuables you bring should be kept on you and not in the hospital room.
TIME FOR TRANSPLANT

Once your child arrives at University Hospital, report to the Emergency Department for further assistance.

Once your child is given a temporary room to prepare for surgery, members of our transplant team will administer the following:

- Physical examination & evaluation review
- Blood work
- Chest x-ray
- Electrocardiogram (EKG)
- Provide fluids and medicines through an IV
- Dialysis (if needed)
- Final cross match

The doctor will answer your questions prior to surgery and ask you to sign a surgical consent.
ABOUT THE SURGERY

Your child will be under general anesthesia. Anesthesia is special medicine that allows your child to be in deep sleep so he/she does not see, hear or feel anything during surgery, not even pain. Surgery is about 2 to 4 hours long.

The incision is approximately 6 inches long just above the groin on the right or left side, or in the center for smaller children.

The artery and vein of the new kidney will be attached to one of your child’s arteries and veins.

The new kidney’s ureter (the tube that carries urine to the bladder) will be attached to your child’s bladder. A small tube called a stent will be placed in the ureter to protect it while the incision / connection is healing.

Complications from Surgery
Remember that most transplant surgeries are successful, however, complications may occur after a kidney transplant, including:

- Infection
- Bleeding (that may require a blood transfusion)
- Urine leak
- Urine obstruction with hydronephrosis (enlarged kidney)
- Rejection
- Problems breathing
- Death
AFTER SURGERY

- Your child will wake up in the Pediatric Intensive Care Unit (PICU).
- Your child will have some pain around the incision/surgical site.
- Your child will receive medication to relieve his/her pain.
- In order to clear your child’s lungs, the transplant staff will ask him/her to take deep breaths and cough.
- Medications and fluid will be given to your child through an IV for the first few days after transplant.
- A catheter will be inserted in your child’s bladder for about four days to help him/her pass urine, even if they are in diapers.
- Many patients need dialysis for a short time after transplant, if the donor kidney does not work right away.
- The transplant team will go over your child’s medications and how to care for the transplanted kidney.
- The average time in the hospital after an uncomplicated kidney transplant is five to six days.

You will be given a new, in depth, transplant education book to help you and your child through his/her hospital stay and after transplant plan of care.

DURING YOUR CHILD’S HOSPITAL STAY

A multidisciplinary team will be responsible for your child’s care. They meet daily and will visit your child each week day in his/her hospital room. They are dedicated to answering you and your family’s questions and to help your child recover as quickly as possible. The transplant coordinators will teach you and your family how to care for your child at home, explain each medication and how important they are to take even when your child is feeling well, their side effects, and life after transplant.
Immunosuppressant – or “anti-rejection” – special medications that are designed to weaken his/her immune system
Steroids – first line of defense for rejection. These medications will quickly be reduced to low doses
Antibiotics – help prevent bacterial infections
Antiviral – help prevent viral infections
Antifungals – help prevent fungal infections
Antihypertensive – these medications, although used to treat high blood pressure, will improve blood flow to the new kidney
Vitamins and minerals
Medications to help prevent stomach ulcers

Please remember, patients that do not take their medications correctly are not considered for another transplant if his/her kidney fails.

Your child/family’s willingness to work hard and follow the transplant team’s plan of care is directly related to how well your child will do after transplant.
CONGRATULATIONS!

Your child is ready to be discharged from the hospital and return to living a full life with family and friends.

We will follow him/her closely in the Pediatric Transplant Clinic. Here are a couple of points to keep in mind.

- You will receive an appointment card for your child’s next visit in the Transplant Clinic and for a procedure to remove the ureteral stent (the tube placed in your child’s ureter).
- The transplant team will be checking your child to see how well they are doing with his/her new organ and adjust his/her medications accordingly.
- You should bring your child’s medications and Transplant Manual to ALL of your child’s appointments.
- We will give you instructions for lab work or other tests that your child might need. The purpose of these tests is to monitor your child’s progress and identify complications as soon as possible.
- Your child will be seen in the clinic twice weekly for the first month.
- The visits will gradually decrease over the next few months.

Returning to school:
Your child will be out of school for at least 8 weeks. The transplant team will help you arrange for a teacher to come to your house to see your child during this time. Your child’s transplant doctors will let you know when he/she can resume to normal activities.

It is the responsibility of the parent or caregiver to contact your child’s school prior to and at the time of transplant. The school will provide forms for your child to continue classes at home during recovery.

Once your child returns to school, he/she should avoid contact with sick children. Please instruct them not to share drinking glasses or eating utensils with others at school and at home. Physical Education (PE) is acceptable. Contact sports like football or wrestling are NOT recommended.
SPREADING AWARENESS

Transplantation provides hope to thousands of children and adults with organ failure by giving them a new chance at a healthy and normal life. Transplantation is made possible by the commitment from organ, eye and tissue donors. Unfortunately, the need for donors is much greater than the number of people who donate. You can help spread awareness by sharing your story with those around you and encouraging them to register to become a life-saving donor.

You have the power to save lives. Here is how.

Steps to sharing your story:

- Introduce yourself and speak about how personal transplantation is to you and your family.
- In 2015, 21 people died each day awaiting a life-saving transplant due to a shortage of donors. (Share the facts about donation.)
- Make a point to share how important donation is to “life” and how it affects your child and your family.
- Encourage others to register online at www.DonateLife.net or by completing the donation section on their driver’s license or renewal application form at the DMV.

Facts about donation:

- Organ donation is only considered after all efforts to save your life have failed and death has been declared.
- Anyone can register, regardless of age, gender, ethnic background or current health status.
- All major religions support donation.
- There is no cost directly related to donation.
- Donation does not prevent an open casket funeral.

A single donor can improve the lives of more than 50 people through organ, eye, and tissue donation.
RESOURCES

United Network for Organ Sharing (UNOS)
(888) 894-6361 or UNOS.org

Transplants for Children
(210) 949-1212 or transplantsforchildren.org

State of Texas Kidney Foundation
(210) 739-9778 or txkidney.org

National Kidney Foundation
(800) 622-9010 or kidney.org

US Department of Health and Human Services
Access to the Government’s information on organ, eye, and tissue donation.
organdonor.gov

Texas Organ Sharing Alliance (TOSA)
(210) 614-7030 or txorgansharing.org

Transplant Living
A website with information and resources for transplant recipients
transplantliving.org or trasplantesyvida.org

Renal Info
A website with support and resources for people with kidney disease
renalinfo.com

Encourage others to sign up and become registered donors.
Volunteer opportunities available.

Stay Connected with University Transplant Center