



A patient's guide to
**PEDIATRIC
KIDNEY TRANSPLANT**

Transplant Institute
4502 Medical Drive, MS 18-1
San Antonio, TX 78229
Mainline: 210-567-5777 or 1-888-336-9633
Referral Fax: 210-358-0402
UniversityTransplant.com



THE KIDNEY

RESOURCES

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

The Kidneys:

- Remove waste products
- Control body fluid by balancing water and salt
- Help keep blood pressure steady
- Help make strong bones and red blood cells that carry oxygen through the body



When Your Child Needs a Kidney Transplant

Being told your child needs a transplant is a scary feeling but know that you are not alone. 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, they may have kidney failure that will eventually require dialysis. Dialysis is a machine that works to remove waste products from the blood. At this time, a kidney transplant may be an option for your child. A successful transplant could help your child avoid needing dialysis and can make them feel stronger and healthier.

Common Causes of Kidney Failure in Children

- Renal dysplasia
- Focal Segmental Glomerulosclerosis (FSGS)
- Reflux nephropathy
- Hemolytic uremic syndrome
- Cortical necrosis
- Hyperoxaluria
- Chronic inflammation in the kidney (glomerulonephritis)
- Polycystic kidney disease
- Recurrent infections
- Chronic obstruction - blockage of the flow of urine

Signs of Kidney Disease

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

United Network for Organ Sharing (UNOS)

1-888-894-6361 | unos.org

Transplants for Children

210-949-1212 | transplantforchildren.org

National Kidney Foundation

1-800-622-9010 | kidney.org

US Department of Health and Human Services

Access to the Government's information on organ and tissue donation and transplantation.
organdonor.gov

Texas Organ Sharing Alliance (TOSA)

210-614-7030 | txorgansharing.org

Transplant Living

A website with information and resources for transplant recipients.
transplantliving.org | trasplantesyvida.org

Renal Info

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

State of Texas Kidney Foundation

210-739-9778 | txkidney.org

GENERAL INFORMATION

University Health Transplant Institute

4502 Medical Drive, MS 18-1
San Antonio, Texas 78229

Office Telephone Numbers

210-567-5777 | 888-336-9633
Fax: 210-358-0408

Office Hours

Monday through Friday
8 a.m. to 4:30 p.m.
Closed on holidays and weekends

After Hours, Weekends, or Holidays

Main Hospital Line: 210-358-4000
NurseLink: 210-358-3000
For medical emergencies, please call 911.

Other Important Phone Numbers

Pediatric Intensive Care Unit: 210-743-3190
Pediatric Intermediate Care: 210-743-2252
Hematology/Oncology Transplant Unit: 210-743-2182
Chaplain Services: 210-743-3300

Living Donor Health Questionnaire

UTCLivingDonor.com

UniversityTransplant.com

Transplant Institute of Pediatric Clinic

4502 Medical Drive, Rio Tower, 5th Floor
San Antonio, Texas 78229

Clinic Mainline

210-358-5437
Fax: 210-702-4143

Clinic Hours

Monday through Friday
8 a.m. to 4 p.m.
Closed on holidays and weekends

THE TRANSPLANT TEAM

Kidney transplantation is a treatment option to improve your child's quality of life and increase overall life expectancy.

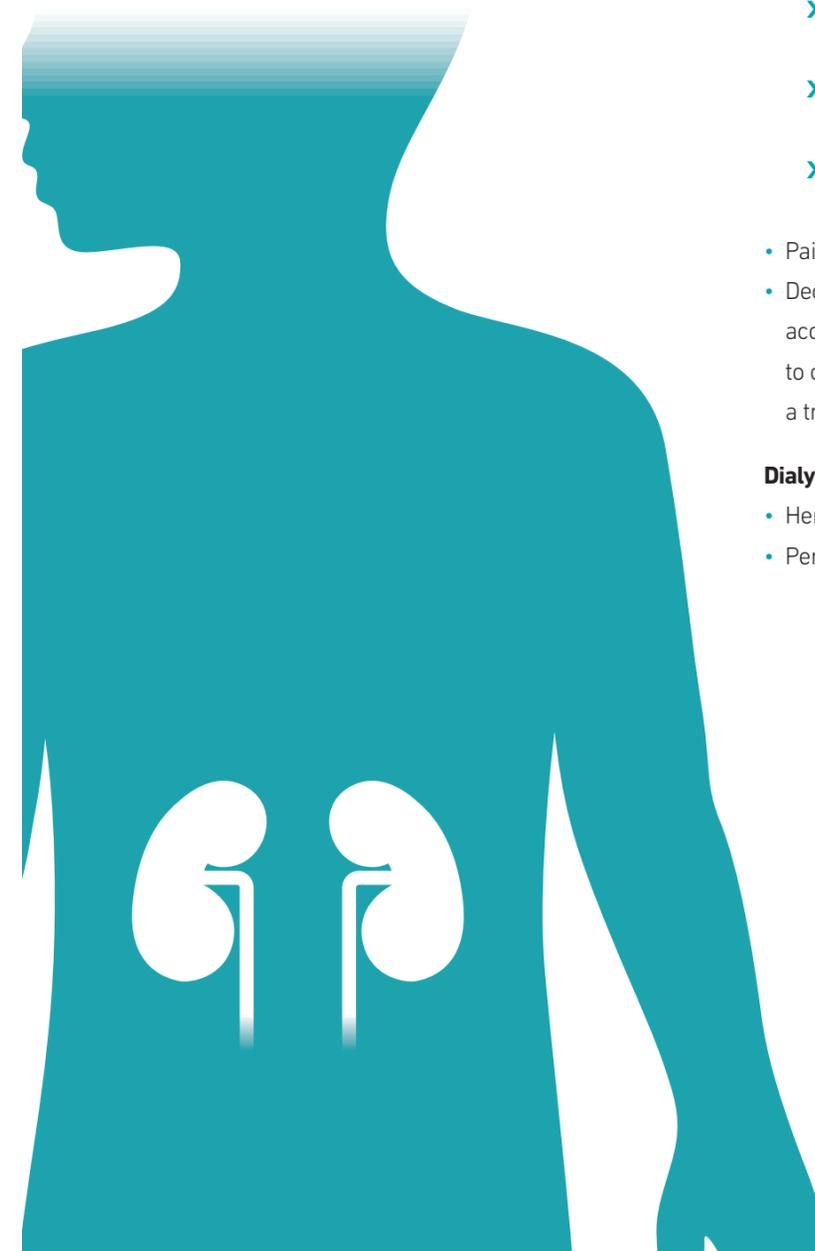
Treatment Options

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 wishes to donate an organ and does not know the recipient)
- Paired donation (diagram shown on page 12)
- 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

Dialysis

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



YOUR CHILD'S FIRST VISIT

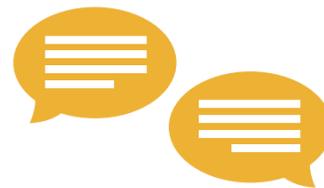
Your child was referred for a kidney transplant evaluation because they are experiencing symptoms of kidney failure.

The process begins with testing and meeting 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 the severity of the kidney disease
- Determine if your child would benefit from a kidney transplant
- Explain kidney disease, transplant surgical risks and benefits
- Discuss options such as living donation
- Give you and your family the opportunity to ask questions



Please make arrangements for the care of younger siblings as your focus will be on learning about the transplant process and meeting your child's transplant team.

Returning to School

Your child will be out of school for at least eight 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 they can resume to normal activities.

Medications after Transplantation

The body tries to get rid of anything that it considers foreign. After your child's transplant, their body will try to reject/attack the transplanted kidney. In order to prevent this rejection, we will give your child important medications that have to be taken daily, even when your child is feeling well.

These are some of the medications your child may take:

Immunosuppressant – or "anti-rejection" – special medications that are designed to suppress (or lower) their immune system

Steroids – first line of defense for rejection. These medications will quickly be reduced to low doses

Antibiotics – help prevent bacterial infections

Antivirals – help prevent viral infections

Antifungals – help prevent fungal infections

Antihypertensives – 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 their kidney fails.

Contacting the 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

The administrative staff in the main transplant office answers all calls between 8 a.m. and 4:30 p.m., Monday through Friday, except holidays and will transfer your call where necessary.

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.

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 Health Transplant Institute to inform the transplant team of the incident.

AFTER TRANSPLANT

After we discharge your child from the hospital, we will follow them closely in the pediatric transplant clinic.

- 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 new ureter).
- We will follow your child closely for the first few months.
- You should bring your child's medications and your 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.



Preparing for the Evaluation

To ensure a complete evaluation, please bring the following information with you to the appointment:

- All insurance cards, including prescription plan, to discuss deductible and co-payment amounts
- Your child's medications and medication list
- Any new testing results which have not been sent to the transplant team
- Name and contact information for your child's doctors including: dentist, eye doctor and pediatrician
- Up-to-date immunization records
- Contact information for your child's school
- Contact information for any potential living kidney donors (donors can begin the donor screening process at any time, even prior to your child's first appointment)



Ask Questions

Children and adults alike feel better when they know what to expect. Don't be afraid to ask questions. Bring a list. Learning as much as you can about transplant may help your child with a speedier recovery.

Some example questions to ask:

How should I talk to my child about transplant, their hospital stay and the surgery?

Is there assistance for a place to stay after transplant since we live more than 1.5 hours away from San Antonio?

What resources are available for our family if we need financial or spiritual support?

How much should we expect to pay after the operation and on a monthly basis for medications?

What pharmacies carry the medications needed for my child?

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.

Professional:	Description:
Transplant Nephrologists	Our 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 Nurse Practitioner	A nurse practitioner will work closely with the nephrologists and surgeons to evaluate your child's health and will visit daily (Monday - Friday) during your child's hospital stay. They will inform you of changes to your child's condition and plan of care.
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. <i>Post-transplant coordinators are responsible for your child's care in the clinic, as well as yearly follow-up care.</i>
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 Social Worker	A social worker can assist you with any non-medical issues. They can 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.
Transplant Financial Coordinators	Financial coordinators will help you obtain preauthorization for your child's evaluation exams, kidney transplant surgery and follow-up care. They can also answer any questions you may have regarding your child's healthcare coverage.
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 they will be taking. They work with local specialty pharmacies which carry the transplant medications your child will need after transplant.
Administrative Assistant	Your child's transplant coordinator will have an administrative assistant who provides support for all team members, schedules all new patient evaluations; and assists with obtaining medical records, lab results, tests and procedures.

TIME FOR TRANSPLANT

Once your child arrives to University Hospital, report to the Pediatric Transitional Unit (PTU)

Members of our transplant team will administer the following exams:

- Physical examination & evaluation review
- Blood work
- Chest X-ray
- Electrocardiogram (EKG)



- Provide fluids and medicines through an IV
- Dialysis (if needed)
- Final cross match



After your Child's Transplant

- Your child will wake up in the Pediatric Intensive Care Unit (PICU).
- Your child will have some mild discomfort.
- Your child will receive medication to relieve their pain.
- In order to clear their lungs, the transplant staff will ask your child to take deep breaths and cough.
- Medications and fluid will be given to your child through an IV for the first few days after their transplant.
- A catheter will be inserted in your child's bladder for about four days to help your child pass urine, even if they are in diapers.
- Many patients need dialysis for a short time after the 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.

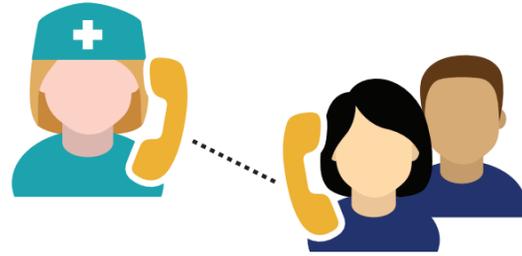
Complications from Surgery

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

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



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 your child's 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

What to Bring



For your Child:

- Two sets of comfortable clothing such as: pull on pants, sleep wear, 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 of medications your child currently takes
- List of important conditions or surgery
- Peritoneal dialysis supplies for one exchange



For Parents or Caregiver:

- Keep extra checks, deposit slips, and your ATM/debit/credit on hand
- All insurance cards and current photo ID
- Comfortable clothing and shoes
- Your child's and your own prescription medications
- Phone numbers and addresses of family, friends, employers, neighbors, your child's school and child's medical care providers
- A good book or small craft project
- A camera
- Phone, laptop or iPads
- Chargers for any electronic devices

What NOT to Bring

- Jewelry
- Flowers/plants/pets
- Fresh fruit/vegetables
- Latex balloons
- A large suitcase

Remember that any valuables you bring should be kept on you and not in the hospital room.

Professional:	Description:
Primary Care Physician (PCP) or Primary Nephrologist	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.
Resident Physicians	Resident physicians are doctors who practice medicine and are training under the supervision of fully licensed physicians at University Hospital. They will be working closely with the attending doctors caring for your child.
Respiratory Therapists	During your child's stay with us, they may be visited by a respiratory therapist who specializes in helping children with their breathing.
Physical Therapist	Physical therapists and their assistants are available to help your child restore physical function and a level of independence immediately following their transplant.
Anesthesiologist	An anesthesiologist will be monitoring your child and administering special medicine (anesthesia) that allows them to be in a deep sleep so they do not see, hear or feel anything during surgery, not even pain.
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.
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 .
Family and Friends	You and your child cannot go through this process alone. Everyone will come to a point where they need 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 them before and after transplant.

Receiving a kidney transplant is a gift of life and a lifetime commitment. The success of a transplant is directly related to how well your child follows instructions given by the transplant team.

TRANSPLANT EVALUATION EXAMS

You will be provided a schedule of appointments required for your child's kidney transplant evaluation. Here is a list of tests and exams that may be performed:

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. Makes sure your child doesn't have any old infections that would get worse after transplant.

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.

Dental Evaluation

A dentist must check your child's teeth and gums to make sure they are healthy before transplantation. Your child will also need to be checked by their dentist every six months while waiting for a transplant to make sure there are no infections (this may or may not be covered by your child's insurance).

Blood Tests

Your child's blood count, blood type, blood chemistries, blood for viruses and immune system function will all be checked.

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.

PLAN AHEAD

Answer the following questions as a family:

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

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

• Who will care for your child while they cannot attend school for eight weeks?

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

• Who will be the primary care giver after transplant?

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

• How will you pay for expenses while out of work?

• Who will take care of the pets?

Changes in Listing Status

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

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 Institute 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 may go to another child.
Provide us with as many contact numbers as possible.**

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 class at school (no contact sports like football or wrestling)



- Have them see the dentist regularly to avoid serious infections after transplant



- Keep in contact with the transplant team



- Keep all of your child's vaccines up-to-date



- Have your child follow the recommended diet



- 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.



- Contact the transplant team if you are going out of town and how you can be reached



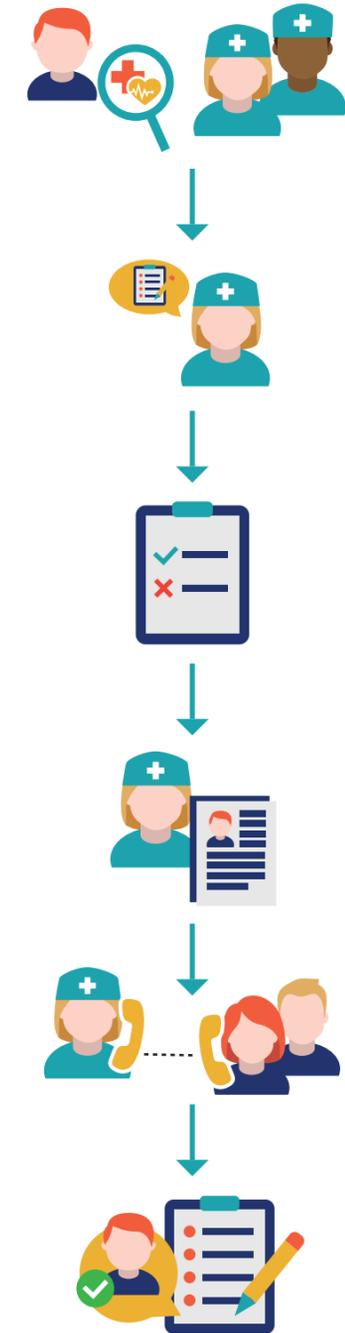
- Contact the transplant team if your child has had a blood transfusion, immunizations or is being treated for an infection



- Plan for financial expenses during the time your child is in the hospital. This includes hotel stay, food, transportation and medication cost upon discharge

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 meeting to determine the risks and benefits of transplantation.
- If this is the right time for your child, the team will recommend your child be placed on the waiting list. If more information is needed to make a decision, additional testing may be requested.
- You will be informed of the transplant committee's decision within ten business days.
- 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.
- It is also possible transplantation may be considered too risky if your child has other medical issues, such as severe heart disease.
- 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 listings).
- Any potential living donors can work to complete their testing/screening at this time.
- Patients have the option to refuse transplantation at any time.



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, and 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.

A living donation is the quickest way to transplantation.

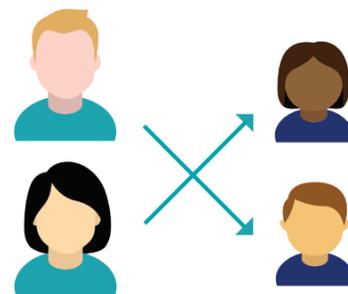
A family member, friend or other unrelated healthy person may be able to donate one of their kidneys to your child. Nearly everyone is born with two kidneys, but we can live a healthy normal life with just one.



Of all potential donors, 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. Almost half of the living donor transplants we do are through paired exchange. We can help arrange an exchange in which your child's donor gives their 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.

Finding a Donor

The waiting list is a national computerized network. This list is managed by the United Network for Organ Sharing (UNOS). UNOS is supervised by the federal government to help ensure that patients receive healthy organs as they become available. You may contact them at **1-888-894-6361** or visit their website at www.unos.org for more information.

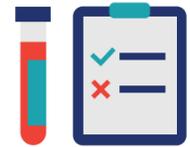
Several factors are considered when determining who will receive the available kidney:



- **Blood Type** – Every person is a blood type A, B, AB, or O. For deceased donors, the blood type must be the same. For 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 their blood that would cause them 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: 1-2 year wait
- A: 4 months - 1 year wait
- B: 1-3 year wait
- AB: 4 months - 1 year wait

Should your young adult turn 18 prior to being placed on the list, they will not receive the same priority as a young person who turned 18 while already on the waiting list.

Mandatory National Sharing – Zero mismatch can happen anytime.