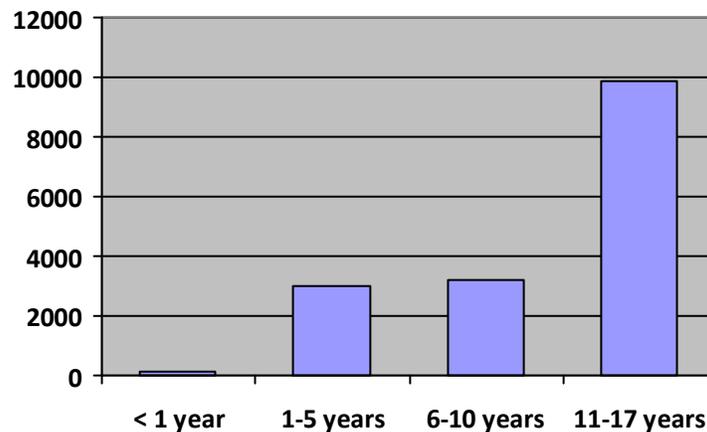

KIDNEY TRANSPLANT PROCESS FOR CHILDREN

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U.S. Pediatric Transplants by Age

The chart below shows **total** pediatric transplants performed in the United States organized by recipient age to date.



Based on current OPTN data as reported on August 13, 2010. Data subject to change based on future data submission or correction. Source: <http://optn.transplant.hrsa.gov/>

I. Overview

Kidney transplantation is the most successful treatment option for children with kidney failure – but the process can be confusing and intimidating for parents and such young patients. The following information, presented in an easy-to-read Q & A format, is intended to educate you and your loved ones on the kidney transplant process and what it may mean for your child. All content has been edited and reviewed by pediatric transplant surgeons and parents of children who have gone through kidney transplants. If you have any questions, please let us know at contact@kidneylink.org.

Why do children need kidney transplants?

Children can experience kidney problems – and kidney failure – for a number of reasons, including:

- Congenital urinary tract or kidney disorders;
- Inherited kidney disorders such as autosomal recessive polycystic kidney disease (ARPKD) (typically children with ARPKD will need a kidney transplant by the age of 10);
- Acquired kidney disorders such as focal segmental glomerulosclerosis (FSGS); and
- Other diseases that can destroy the kidney such as vasculitis, autoimmune diseases, or hemolytic uremic syndrome (HUS).

Stable kidney function can often be maintained successfully with medications and/or surgery before a kidney transplant is needed, but when kidney failure progresses it can cause growth issues, decreased school performance, bleeding issues, decreased appetite and lower energy levels in children. For these reasons, kidney transplantation is preferably performed before the child requires dialysis, which is called preemptive transplantation. In children, hemodialysis or peritoneal dialysis is considered only as a bridge to transplantation,

What are the benefits of a kidney transplant?

Successful kidney transplantation can almost restore a child's normal life.

What are the potential risks and complications?

As with any medical or surgical treatment, there are potential complications involved. Potential risks and complications include the following situations:

- In some cases, the transplanted kidney will fail to work or be rejected by the recipient's body at any time. Then the recipient would need to have another kidney transplant or be on dialysis and while waiting for another kidney transplant.
- Anti-rejection medications need to be taken for as the life of the transplanted kidney. These medications have many possible side effects, and the long-term expense of these medications is an important factor for families to consider.
- In some patients the original kidney disease can return after transplant. Transplant candidates must discuss their individual risk for recurrence with a nephrologist.
- If a living donor is not available, there is often a long waiting period for a deceased donor kidney in adults, but is much shorter in children.

How is a kidney transplant for a child different than for an adult?

Transplantation in children differs from adult transplantation. Not only are children smaller than adults, but they also have special emotional and medical needs. So that children can reach their full potential, their care must be focused on the fact that they are constantly growing and developing. That is why it is important that professionals who are trained in pediatric care perform pediatric transplantation. Other differences include:

- Children typically must be a certain age and size. Children undergoing transplants receive adult kidneys – kidneys they can “grow into.” For this reason, it's important for there to be enough space in the abdomen to hold an organ larger than is typical for a child. Many

centers prefer to wait until a child is 18 months old or 22 pounds; however, transplants have been successfully performed in children weighing as little as 18 pounds, but that depends on the underlying condition of the child, as well as the expertise of the surgeon. The more experience a transplant center has, the higher the success rate.

- Finding a donor before a child's kidneys fail can be tough, especially since doctors avoid putting a child on dialysis and prefer preemptive kidney transplants. There is no one sure and fast way to know when this will occur. End-state renal failure occurs at different times for different children.
- Some children with ARPKD have such large cystic kidneys that one or both will need to be removed before a new kidney can fit in the abdomen. This is called a nephrectomy.

II. Preparing Your Child for a Transplant

Kidney transplantation involves more than simply an operation. Preparation and evaluation, waiting for transplant and recovery following surgery are all part of a long journey for the transplant candidate and family. Even after full recovery, some lifestyle changes are necessary for continued health after transplantation.

How is a child evaluated for a transplant? What's this process like?

The pediatric nephrologist determines when the timing for transplantation is optimal. At that point, the kidney transplant candidates need to undergo an evaluation by the pediatric transplant team to determine whether transplantation is likely to be a safe and beneficial treatment option. This pre-transplant evaluation commonly involves:

- Blood tests, including blood group and tissue type analysis;
- Chest X-ray;
- Electrocardiogram and other heart testing in some cases;
- Meeting with endocrinologists if diabetes is present or growth is delayed;
- Meeting with urologists if there is a history of bladder or ureter problems; and
- Meeting with a transplant surgeon.

Once a child is approved for kidney transplantation, the child is activated on the deceased donor transplant list, even if he or she has a living donor who is being worked up in preparation for kidney donation. It sometimes happens that the child is called for a deceased donor kidney, which is available before the living donor is ready for donation. While living donor kidneys have a better outcome, individual circumstances may sometimes make the family and transplant team choose to accept the kidney instead of waiting until the donor is ready. The decision is never made on a unilateral basis.

The transplant team monitors each child's medical status closely and verifies that all immunizations are up to date before a transplant.

Who is part of a child's transplant team?

Medical professionals involved in a pediatric kidney transplant – the transplant team – typically include:

- Pediatric nephrologist;

- Pediatric transplant surgeon;
- Social workers;
- Child psychiatrists;
- Dietitians;
- Physicians, and
- Nurses.

What should parents do while waiting for the transplant?

- Every patient on a kidney transplant list has to have a blood sample sent to the transplant center on a monthly basis. This is to assess whether the patient developed new antibodies against potential donors of kidneys in the region. The higher the number of antibodies, the less likely it is for a patient to get a kidney transplant soon. Blood transfusions are the most common culprits for the development of new antibodies. This is why it is very important to keep the anemia controlled with medications and iron supplements, as needed.
- Keep in touch! While a child waits for a cadaver (deceased) kidney transplant, it is important to remain in close contact with the transplant team. Because the transplant team may need to reach a candidate's family at any time of the day or night, the transplant center will typically ask for home and work phone numbers and may give the family a beeper. Once a cadaver kidney becomes available, the child must come to the transplant center as quickly as possible, usually within eight hours of notification.
- Let your transplant team know immediately if your child becomes sick. Depending on the severity of the illness, transplant surgery may need to be postponed until the child is healthy enough for surgery.
- Stay near the transplant center or at least be available to travel with little notice.

How should parents help their child prepare for a kidney transplant?

As children differ in age and maturity levels, the approach at discussing transplantation should vary as well. The following guidelines were provided by Transplant Living, a United Network of Organ Sharing (UNOS) program:

Infants and Toddlers: It is very difficult to prepare an infant for a medical procedure. Older toddlers, however, may understand simple explanations. Regardless of age, the importance of creating a familiar and comfortable atmosphere in the hospital is crucial. While away from home, infants and toddlers will benefit from having family members with them as much as possible. Having familiar toys, videos or a favorite blanket can also help the child feel more at home.

Preschool: Preschool children can benefit from pre-hospitalization teaching. When explaining medical procedures to preschoolers, it is important to use reassuring vocabulary and simple explanations. In addition, because children are very aware of their parent's feelings, it is important to stay positive. Play therapists, nurses and other members of your transplant team can also assist in helping your pre-school age child understand certain topics and cope with the varying stress related to illness and transplantation. It may be useful to keep a diary that records your child's tests and operations to show them when they are older.

School-age: School-age children can benefit from pre-hospitalization teaching. In addition, because young children sometimes think an illness is punishment for something they have done, it is important to let young children know that the illness is not their fault.

When preparing your child for their medical procedure, it is important that you always answer their questions simply and truthfully, and unless they ask, not overload them with too many details.

- Encourage your child and their siblings to ask questions about anything that is worrying them.
- Take tours of the clinic, hospital room and ICU.
- Allow your child to meet and speak to personnel from these areas can help to alleviate fears of the unknown
- Inform your child about the types of tubes that will be used, what the incision will look like, what the typical hospital stay is like and what types of medication they will take after transplantation

Adolescents: Dealing with an illness, in addition to helping your child handle stress associated with the transition from childhood to adulthood, can be very difficult. That's why supportive communication and careful preparation with this age group is especially important.

- Encourage your child to talk about his or her feelings. Listen when your child is talking and acknowledge his or her feelings as being real.
- Don't be afraid to ask your doctors and nurses to simplify complicated medical jargon and draw pictures if necessary.
- Prepare your child for the reactions of others. Parents can help their children by suggesting various simple and concise explanations.
- Additional help, like a therapist or psychologist, can often engage your child in conversation that they may not share with you.
- Encourage your child to tell their friends about the upcoming surgery so they can be a source of support.
- During the hospitalization, encourage friends, classmates and family members to visit or write to maintain communication.

III. Transplantation

What are the options for children in need of a kidney transplant?

Like with adults, children in need of a kidney have two main options: a living donor kidney transplant and a deceased donor kidney transplant. A pediatric nephrologist and a transplant surgeon will discuss both types of kidney transplants with the family to help determine which approach is more suitable for their situation.

What's a living donor kidney transplant?

In a living-donor transplant, an adult (18 or older) gives one kidney to the child. The donor can be either a family member or someone unrelated, such as an adult family friend. The potential donor will first undergo a series of tests to measure compatibility. When it is determined that it

is time for the transplant to take place, both the donor and recipient will undergo surgery almost simultaneously; the donor kidney is removed in one room and then transferred to another to be placed in the child. Living donors can continue to lead a healthy and normal life with their one remaining healthy kidney. These types of transplants can be scheduled to best suit issues of health, school and convenience for both the donor and recipient. Of the more than 12,000 kidney transplants performed in the United States during 1999, slightly more than one third were from living donors.

What's a deceased donor kidney transplant?

In a deceased donor transplant, the child receives a kidney from a healthy person who has died suddenly (usually accidents). In this situation, the deceased person's family has agreed to donate the kidneys for transplantation. The physician caring for the deceased person and a transplant surgeon will determine whether the kidney is suitable for the transplant recipient. It is not possible to predict when a deceased donor kidney will become available. Transplant candidates may wait for months or years for an opportunity to receive a deceased donor kidney. Some children may end up going on dialysis if their kidneys fail before a good match is found.

What are some benefits of a living donor kidney transplant?

Live donor grafts typically last longer than that of a cadaveric transplant; however, both can have great success. Another benefit of the living donor is the ability to plan ahead and ideally get the transplant as soon as it is needed, making logistics simpler and also increasing the likelihood of staying off of dialysis.

What happens before the kidney transplant?

Transplant candidates should arrive a day or two before transplantation to undergo a physical examination by the pediatric nephrologist and some additional medical tests, including blood work, chest X-ray, urine test and an EKG. For a scheduled living donor transplant, the child is usually admitted to the hospital the evening before surgery.

What should families bring to the hospital?

- Medical equipment your child uses, such as a blood pressure cuff/machine, any dialysis equipment and enough dialysis solution for one week.
- Comfortable, loose-fitting clothes for your child to wear after surgery, as well as slippers for use in the hospital.
- Favorite toys, stuffed animals, games, mylar balloons, videos and anything else to make your child comfortable and happy during the hospital stay.
- Other family members for support.
- Medical history if the child is not being transplanted in his/her regular hospital.
- Snacks, books, cell phone and charger, laptop and anything else parents, family and friends may need during the hospital stay.

What shouldn't be brought to the hospital?

Latex balloons and fresh flowers and plants are not allowed in the hospital room. Often, children can't eat many snacks or treats after their surgery either.

What happens the day of the surgery?

For a living donor kidney transplant, patients are often admitted the evening before the surgery. They should arrive on an empty stomach.

What happens during the kidney transplant operation?

Kidney transplantation involves surgically placing another person's kidney (the donor) into a child's lower abdomen, usually on the lower right side. The transplanted kidney is placed in the pelvic area, not where the original kidneys are. In small children, the kidney is placed in the middle of the abdomen, also referred to as "intraperitoneal".

Surgeons usually attach the donor ureter (the tube through which urine flows) to the child's bladder, allowing urine from the new kidney to flow in the normal manner. The child's own kidneys are usually not removed. The transplant surgery typically takes about four hours. The donor kidney should begin to function immediately. Sometimes the new kidney is palpable on the outside.

What are parents doing during the surgery?

Often, parents are able to go into the OR with their child and stay there while the patient is given a mask for initial anesthesia before being put completely under.

IV. Post-Transplant**What happens immediately after the transplant surgery?**

Following surgery, children are moved to a recovery room for a few hours before moving to their room in the Intensive Care Unit. Depending on the transplant center, parents may be able to join their child in the recovery room. Otherwise, parents can meet their child in the ICU. Visiting rules also vary, but immediate family are generally allowed access to the patient in small numbers just hours after the surgery. The length of time spent in the ICU will also vary, depending on the center and situation for that particular child. As with any surgery, it may take some time for the child to be clear and able to communicate and certainly pain medications will already be started so there should not be any immediate issues with comfort.

How long do children stay in the hospital after a transplant?

Typically, children remain in the hospital for about one week after a kidney transplant. Some children require more time to recover.

What happens during this time?

While hospitalized, the child will have a central line catheter in place for blood work and administering certain medications. If the child was on hemodialysis before the transplantation, the hemodialysis catheter will be used for that purpose. A urinary catheter will also be in place for about five days. Daily blood tests will also be required. The first two days after the transplant, blood tests may be necessary several times a day. During recovery, as the discomfort around the incision lessens, the child can move around more and gradually return normal activities. In most cases, the child can get out of bed and take short walks the day after surgery. Pain medications will change once the child is past the immediate recovery stage and will be closely watched to

ensure the child does not have to endure too much discomfort. Water and then food are slowly introduced. Nurses will assist the child with daily walking and deep breathing exercises, which are an important part of the recovery period. Different members of the transplant team will also help the child and family members learn more details about the medications needed to prevent the transplanted kidney from rejection. Some children may require dialysis after the transplant until the new kidney picks up the job. This is more common with deceased donor kidneys than with living kidneys.

V. Life Post-Transplant – What’s Next?

What happens in the weeks following the transplant?

Patients typically need twice to trice-weekly blood tests during the first 4-8 weeks after leaving the hospital and less frequently thereafter. Transplant recipients from out-of-town are typically asked to stay near the transplant center for at least eight weeks of testing. A pediatric nephrologist and the transplant coordinator will review the blood test results and, if necessary, make medication adjustments and answer specific questions patients and their families might have. The transplant team will also educate children and their families on:

- Good hand-washing technique;
- Adequate fluid intake;
- Regular toileting schedules; and
- Diet and exercise.

What happens once children and families return home?

As with any surgery, it will take some time to get fully recovered and back into regular activities. In addition, the immunosuppressant regimen is most intense in the weeks directly following the surgery so most children do not return to school for a month or so as they would be overly susceptible to any germs or illnesses. Some children may also require a transition period to get back into full days of school, depending how fatigued they may feel. While children should resume participation in physical education classes gradually, over time, most children should be able to participate in school, play sports and feel energetic.

In fact, energy and activity can improve so dramatically that parents often express concern about that their child has become hyperactive or participates in aggressive play that may seem too rough. Parents need to be prepared to set reasonable limits on their child's play. Because this task may be difficult, pre-operative discussions about physical activity limitations with the transplant team and your child may be helpful.

Physical therapy may also begin while your child is in the hospital. A physical therapist will work together with you and your child to develop a program that integrates your child's needs, goals and activity preferences and help them attain the usual developmental milestones.

Are there any special arrangements/preparations parents should make for the return home?

If the child's bedroom is upstairs, some might be more comfortable making a bed on the ground floor where stairs are not involved until the abdominal incision has healed a bit. As for bathing, it's important to keep the incision dry.

What are the signs a child's body may be rejecting the new kidney?

In the past, symptoms of rejection included the following:

- Pain or tenderness over the transplant site
- Fever
- Flu-like symptoms such as chills, nausea, vomiting, diarrhea, tiredness, headache, dizziness and body aches and pains

However, nowadays, the immunosuppressants have become much stronger and they tend to mask any physical signs of rejection. Symptoms such as the following are LATE SIGNS!

- Change in pulse rate
- Weight gain
- Swelling
- Less urine

Only regular blood tests can reveal rejection in a timely fashion, allowing for medical intervention and salvage of the kidney.

How long will the transplanted kidney – the new healthy one – last?

On average, transplanted kidneys last 10 to 12 years. According to the latest data from the Organ Procurement and Transplantation Network,

- 95 percent of children who receive a kidney transplant have a functioning kidney after one year.
- After three years, that rate is about 85 percent.

The percentages provided are average statistical values. Infants and young children tend to have much better kidney transplant survival times and adolescents have worse outcomes. This is solely due to the difference in compliance with the medication regimen in the two groups.

What can be done to help the transplanted kidney last as long as possible?

Transplant recipients of every age should always maintain regular scheduled doctors appointments and take all prescribed medications on time. They should also be aware of ways to combat germs and be sure to call their doctors at any sign of infection. Because the risk of bacterial and fungal infection is greatest in the first few weeks after your surgery, it may be necessary to take the following precautions:

- Avoid indoor crowded places like stores, movies, restaurants and churches in the first few months after transplantation.
- Avoid people with known infections or illnesses.
- Avoid taking care of animals.

- Avoid working outside or in your garden.
- Wash your hands frequently--it's a safe and effective way to stop some infections before they start.
- Good dental care is important. You should brush and floss daily, and see the dentist regularly. You may also need an antibiotic before routine dental cleaning visits.
- If you get a cut or scrape, cleanse the wound and apply a clean, dry dressing. If any sign of infection develops (fever, pain swelling or redness), contact your doctor.
- Avoid buildings under construction or destruction.

How often should a child with a transplanted kidney get checked out by a doctor and for what?

The child with a transplanted kidney will always have somewhat regular doctors appointments to test for levels of medications, kidney function, and all other blood levels that help indicate the health of the transplant. Blood pressure and growth will continue to be watched closely. If there is a question about how well the graft is doing or there is a rise in the creatinine/GFR levels, a kidney biopsy may be ordered to get a closer look.

What type of doctor should a child see after a kidney transplant?

Most children who have undergone a kidney transplant continue to work with a pediatric nephrologist until they are 18 or older. At this point, they are transferred to a transplant nephrologist caring for adults.

What kinds of medications does a child take after a kidney transplant?

For the most part, all transplant recipients need life-long treatment with immunosuppressant medicines to prevent rejection of the transplanted kidney. These medications must be taken daily following surgery. Like so much else, the protocol of immunosuppressant medications varies with each hospital. There are certainly more medications at the very beginning; after a couple of months, the regimen will get more solidified as levels are determined. Most children start on two to three immunosuppressants in addition to a prophylactic antibiotic and a few others. Blood pressure medications are not given unless blood pressure continues to be a problem even post-transplant, which it is for some. Children put on steroids may react with huge appetites.

What else should parents know or expect about medications for their child?

- Understand that there may be many different types of medications that need to be taken more than once a day
- Realize that managing medication is stressful and may create conflicts with your child
- Become familiar with the names of the medications, the reason for their use and how they are given.
- Tell the transplant team if any of the medications bother the child so they can plan the best combination of medicines.
- Provide age-appropriate support and supervision to assure that medications are taken as prescribed.

Other recommendations include:

- Develop a system that is easy to follow.

- Make sure you have enough medication at home and get prescriptions filled early so you don't run out.
- Stay with one pharmacy. If your insurance only covers generic drugs and there is a change in the company providing the drug to the pharmacy, your child will need to undergo blood tests to ensure that there is no significant change in the blood drug level.
- If your child misses a dose of any of the medications, for any reason, notify the transplant team coordinator or your transplant physician.
- Because many medicines interact with transplant medicines and may increase side effects or make the transplant medicine weaker so the child is at greater risk of rejection, never give your child new medications until you discuss it with your transplant team. That includes over-the-counter medications and herbal supplements.

How will my child's growth be affected by the transplant?

As a part of feeling well, a transplanted child's appetite will likely improve dramatically. This change can be very confusing to the children and their parents unless clearly discussed prior to transplantation. In fact, parents of children who have already had a kidney transplant – especially those who have been put on steroids – suggest locking up the cupboards and watching what food is in the house! This huge increase in appetite should settle down as the dose decreases; however, children with new healthy kidneys often gain a better appetite and a few inches and pounds. Growth, which may have been previously stunted, can really take off.

In addition, because immunosuppressant medications may cause weight gain, salt retention, potassium loss, high blood sugar and high blood pressure, it is often helpful to work with a nutritionist to design an appropriate diet plan for your child. Talk to your doctor about your child's specific needs.

On the other hand, while many kids will start to grow well and even catch-up post transplant, some do not. Doctors often wait a year before considering (re)starting a child on growth hormone.

Do children have a difficult time adjusting to the transplant socially and emotionally?

Parents and doctors agree social adjustment/readjustment can be a huge issue for children following transplantation, although this varies from child to child. Every effort should be made by both the parents and the transplant team to identify if a child is having problems coping with their changes and fears following transplantation. Here's how:

- Parents and doctors need to reassure the child that physical changes which typically occur from the steroids, will improve with time.
- Parents can help their child manage these differences by planning ahead with the school
- Parents should emphasize the child's good physical attributes.
- Parents should stress that the long-term outcome of many of the physical changes will be minimal

Additional advice for parents and other caregivers:

- Focus on the joys and accomplishments of today.
- Join a support group or form a relationship with a family facing a similar situation.
- Research and ask questions to learn all you can about your child's condition and potential therapies.
- Be easy on yourself when you've had a bad day.
- Learn about your child's special financial and educational needs.
- Don't be afraid to ask for help.
- Schedule and spend special time with your spouse and other children

Should parents worry about their children in the sun?

Sun sensitivity is one of the more common side effects associated with some immunosuppressants, so it's important to protect your child from exposure to the sun. Sunscreen, hats and shirts should be used when outside for any period of time in the sun, which is also true for any other child.

Is it OK for children to be around pets?

It is important that you discuss plans for new pets with your transplant team. In addition, due to the higher risk of infection, it is not recommended for your child to be cleaning pet cages or changing litter boxes.

How soon can families take a vacation or trip?

Due to complex follow-up care, it is important that your family not make any travel plans for the first three to six months after the transplant.

What other issues might children (or parents) may have to deal with later in childhood or life because of the transplant or medications?

- Problems, such as delayed puberty arise from the chronic kidney disease. Just like stunted growth, this is not always reversed by transplantation. An endocrinologist can be consulted to help improve the body image of the adolescent by providing hormones that make him or her "look like other kids my age".
- Some of the medications interfere with reproduction or may be dangerous for the unborn child. It is important for the patient to discuss this with the doctor and make the team aware of his/her interest in having children in the very near future (within one year). Several medications may have to be replaced by equivalent ones with a different side-effect profile, which allows carrying out a pregnancy, for instance.