KIDNEY TRANSPLANT

A Guide for Patients and Families

Children's Hospital of Philadelphia®
Transplant Center

Tzivya, 8,
kidney transplant patient

WELCOME TO THE PEDIATRIC KIDNEY TRANSPLANT PROGRAM

at Children's Hospital of Philadelphia (CHOP)

Olivia, 2,
transplant patient

The healthcare team has told you that your child may need a kidney transplant. The thought of a transplant can be overwhelming. The goal of kidney transplantation is to provide patients with a longer and better quality of life.

Healthcare providers believe that a kidney transplant is the best treatment for chronic kidney disease (CKD) in children. All children with CKD are candidates for kidney transplant evaluation. Nephrologists refer patients to our program for a transplant evaluation before a kidney transplant. The goal of the transplant evaluation is to make sure that transplant will be safe and effective for your child. The evaluation process is comprehensive and involves testing, consults and education.

Wait times for transplant are unpredictable. It is best to start the process before the need for a transplant becomes an emergency. A kidney transplant is not a cure for kidney disease, but rather a treatment option.

This pamphlet will provide you with general information about kidney transplant and explanations of the pre-transplant process, the transplant procedure and the post-transplant phase.

What do the kidneys do?

- Remove waste products from the blood (such as urea, uric acid and creatinine).
- Control the amount of water in the body. A healthy kidney will make urine to get rid of extra water.
- Regulate electrolytes in the body (such as potassium and sodium/salt). Electrolytes are in food and drinks. Kidneys get rid of what the body does not need.
- Balance the body's amount of acid, which is produced when we breathe or digest food. Kidneys get rid of extra acid in the body, and so a decrease in kidney function can cause acid build-up.
- Help to manage blood pressure.
- Help the body make red blood cells, which provide the body with oxygen.
- Help to change inactive vitamin D — which we get from the sun and through certain foods — into an active form that helps the body absorb calcium. Without vitamin D, bones can become weak.

A kidney transplant is a surgery that gives someone with failing kidneys a functioning kidney without the need for dialysis. A new kidney will allow a child to grow and feel better.

OUR TRANSPLANT TEAM

The first adult kidney transplant was in 1954. The Pediatric Kidney Transplant Program at CHOP started in 1993. We are one of the most active pediatric kidney transplant programs in the United States. Our transplant team has the experience and skill to care for children with many different causes of kidney failure. A multidisciplinary team will partner to care for you and your child throughout the transplant process.

Transplant Surgeon: A doctor who performs the kidney transplant surgery and will follow your child's progress while in the hospital. This doctor works with the nephrologist.

Nephrologist: A doctor who specializes in kidney disease. They can diagnose and treat kidney disease with medications and diet changes. They will be involved in your child's care before and after transplant.

Anesthesiologist: A doctor who helps your child stay comfortable during surgery and other procedures. They will give your child medication (anesthesia) to allow your child to fall asleep. Your child will not be able to see, hear or feel anything during the surgery.

Transplant Advanced Practice Provider: A nurse practitioner or physician assistant who has advanced education in the healthcare of children. They work closely with the nephrologist to care for your child before and after transplant. They will follow your child's progress in the hospital and during outpatient visits.

Kidney Transplant Coordinator: A nurse who will coordinate your child's transplant evaluation, manage transplant listing and provide education.

Transplant Clinical Pharmacist: An expert in medications who will help you understand and adhere to medical treatments before and after transplant. The pharmacist assists the medical team to manage medications. The pharmacist will provide you with medication education before your child goes home.

Dietitian: An expert in nutrition who will see your child before and after transplant to make sure a proper diet is being followed and your child is growing well. Children with kidney disease may have a difficult time maintaining a healthy nutritional status. A dietitian will work with you to create the best plan for your child.

Social Worker: A healthcare professional who helps patients and families access services and resources that you and your child may need while in and out of the hospital. Services include psychosocial assessments, coordination of educational services, Family Medical Leave Act assistance, health insurance questions, transportation and lodging assistance, financial assistance applications, and referrals to outside services.

Psychologist: A healthcare professional trained in supporting and counseling children and their families throughout the transplant process. They will help you develop coping skills, assess how your child is doing in school, and assess how you will manage complex care after discharge. Psychologists can provide emotional support or refer you to counselors.

Child Life Specialist: A professional who helps children and families cope with the healthcare experience by providing developmentally appropriate activities, education and preparation for medical procedures, and emotional support. They can answer questions about your child's development, adjustment to hospitalization and ability to cope.

Immunogenetics and Clinical Laboratories: These perform blood tests to identify your child's blood type and makes sure that blood between a child and their donor is compatible. This process helps ensure that the team finds the best donor kidney for your child.

Financial Counselor: A financial counselor will help you learn about your insurance plan and the cost of your child's care. They work with your insurance company to request approvals for hospitalizations and procedures, including the transplant surgery.

THE PRE-TRANSPLANT PROCESS

There are many steps in the transplant process The following sections will provide information on each step.

Transplant Evaluation

The purpose of this evaluation is to perform a comprehensive assessment and provide education about the transplant.

The transplant evaluation includes:

1. Meetings with members of the multidisciplinary team
    - *Family meeting:* The transplant coordinator or advanced practice provider will provide education about the transplant process, obtain consent for the evaluation process and answer any questions or concerns.
    - *Social work and psychology team* members will conduct a separate meeting with your family to ensure you have the supports and resources needed so that transplant is safe and effective for your child.
    - *Infectious disease team* members will review your child's vaccination records and risk for infections. Vaccines need to be updated to make sure that your child is protected from any preventable illnesses. The following are community-acquired infections that our team will monitor for post-transplant:
        - Cytomegalovirus (CMV)
        - Epstein-Barr virus (EBV)
        - BK virus
    - Meet with surgeon, dietitian, financial counselor and pharmacist
2. Other appointments
    - *Dentist:* The dentist will check for cavities or infections. Because post-transplant medications may decrease your child's ability to fight a tooth infection, you should make an appointment with your family dentist before transplant.
    - *Eye doctor*: The eye doctor will check the health of the eyes. Make this appointment with an ophthalmologist.
    - *Anesthesia resource center:* Before any surgery, children need to be checked by a member of our anesthesia team. These are doctors and advanced practice providers that will help your child stay asleep and comfortable during surgery. They will review your child's medical history, examine your child and explain how their team cares for your child during surgery.
    - *Radiology:* Your child will have an echocardiogram (ultrasound that takes moving pictures of the heart and blood flow).
    - There may be other consults depending on your child's diagnosis and clinical status. These may include pulmonary (lungs), cardiology (heart) neurology (brain) or urology (bladder).
    - Scientific Registry of Transplant Recipients (SRTR) reviews the outcomes of patients who have transplants at our center and at other pediatric centers. During your first transplant family meeting, we will give you a copy of the SRTR data. Once on the waitlist, we will send you this data each time it is updated, approximately every six months. You can also access the most current data on the national transplant website: **www.ustransplant.org.**

Necessary Blood Tests

1. *Blood Type:* For a transplant to work, it is important that we find a donor who has a blood type that matches your child's blood type. This is called ABO compatibility.

Your child's blood type	Donor's blood type
A	A, O
B	B, O
AB	A, B, AB or O
O	O

2. *Human leukocyte antigen (HLA) testing:* This is how we test for a "good match." HLA is a group of proteins on bone marrow cells that can trigger an immune response. There are six major human leukocyte antigens.
3. *Crossmatch:* A crossmatch is a test that is done when there is a potential donor for a transplant recipient. The crossmatch looks at the HLA testing to determine how well the donor's HLA matches the recipient's HLA. A donor's and a recipient's HLA type should match as closely as possible to decrease the risk that the recipient's immune system will attack the donor's kidney. This attack can result in rejection. A parent would be a half match or better, so a "good" donor would match 3 out of the 6 major antigens. Another donor may match all 6 (the "best case" scenario) or may not match at all. A "bad match" might not rule a donor out, but is a factor in choosing a donor.

4. *Serology:* This blood work looks to see if your child's body has built up protection against Measles, Mumps, Rubella, and Varicella (chicken pox). If your child does not have enough protection, he will need to get these vaccines. These are live virus vaccines, so your child needs to get them before the transplant. We will also check to see if your child has been exposed to CMV, EBV, HIV, Hepatitis A, Hepatitis B, Hepatitis C, tuberculosis (TB), and others as needed.

Other Possible Studies

Depending on your child's medical needs, additional studies could include:

- Kidney or bladder ultrasound (pictures of the kidney or bladder)
- EKG (checks the rhythm of the heart)
- Lung function test (tests breathing function)

Kidney Transplant Patient Selection Criteria

There are a few serious medical conditions that would prevent or delay a child from getting a transplant. Please refer to the policy "Kidney Transplant Selection Criteria." This will be reviewed during the family meeting.

Other Treatment Options

If your child does not qualify for transplant at this time or you choose not to pursue a transplant, the Kidney Transplant Team may suggest dialysis.

Dialysis is a procedure that takes the place of your kidney to clean blood.

There are two types of dialysis:

- Chronic maintenance hemodialysis is performed in a dialysis unit at the hospital three to four days a week.
- Chronic maintenance peritoneal dialysis is performed at home by a machine while the child sleeps. The process takes 8 to 12 hours, depending on the size of the child.

Some children need dialysis before their transplant. Your child's nephrologist will discuss if this is needed for your child. If necessary, a family meeting will be scheduled with a dialysis nurse to talk about the different types of dialysis.

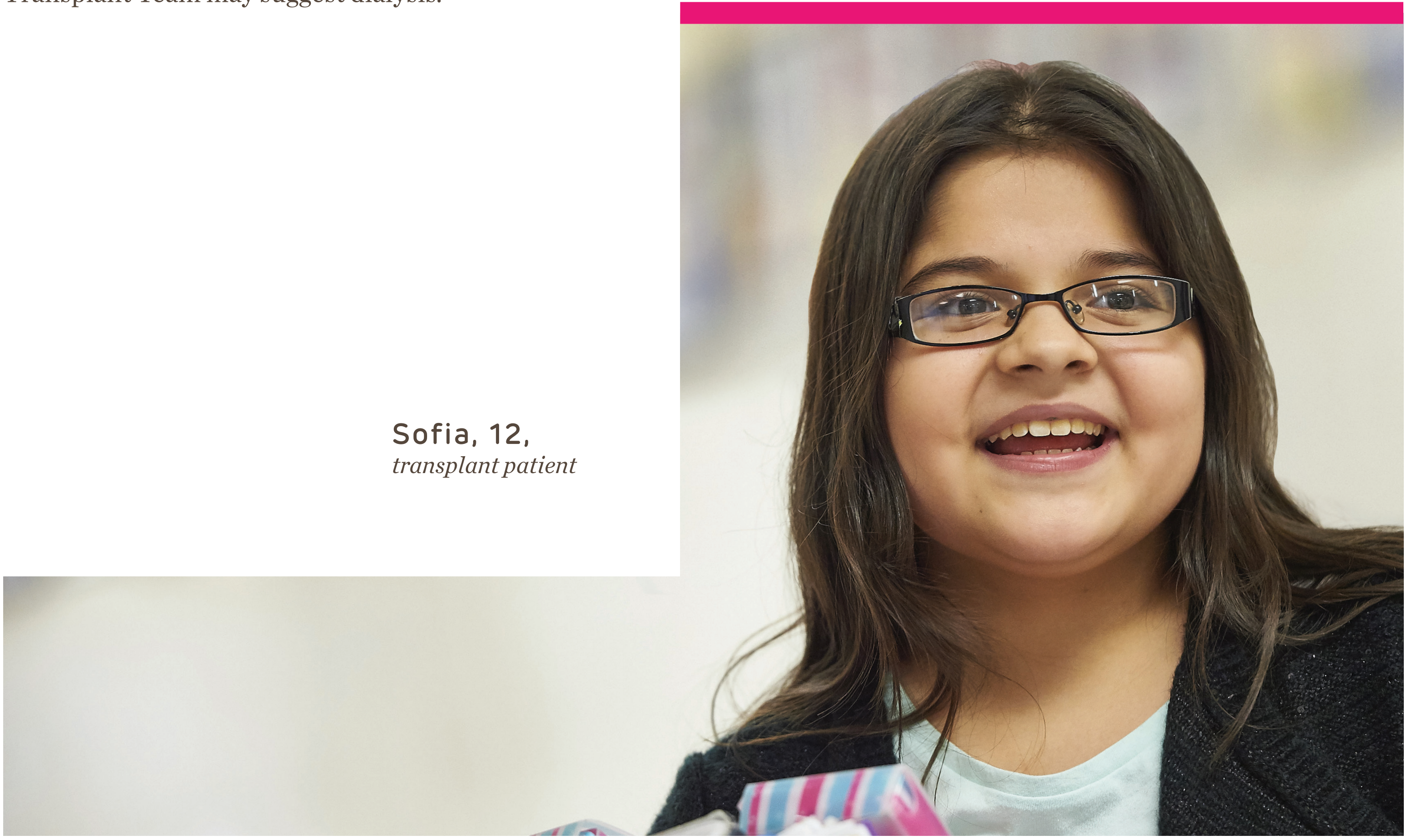
THE OPTIONS FOR KIDNEY DONORS

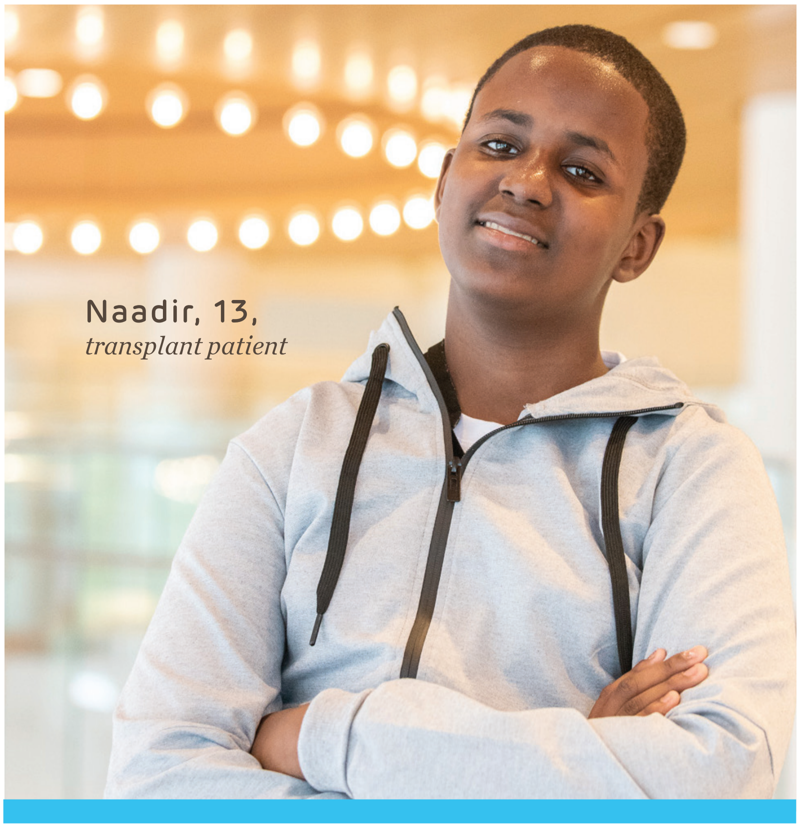
- Living kidney donors can be family, friends or people who want to donate their kidney to help someone in need.
- Deceased kidney donors are organ donors who have passed away.

What are the benefits of having a living kidney donor?

- Faster access to transplantation.
- Surgery can be scheduled at a time that is convenient for both the donor and your child.
- Improved long-term outcomes.

Sofia, 12,
transplant patient





All living donors must have the following qualifications:

- Be at least 21 years old.
- Blood type and cross match compatible with your child.
- Be healthy, willing and able to give a kidney. The donor will complete medical and psychosocial evaluations at the Hospital of the University of Pennsylvania (HUP).

Factors that may affect a person's ability to donate a kidney:

- High blood pressure
- Diabetes
- Cancer
- Older than 55 years
- Obesity or body mass index (BMI) greater than 32
- Have an infectious disease
- Certain other medical or psychiatric conditions

Living Kidney Donor Screening and Evaluation

Potential kidney donors need to complete a comprehensive and multidisciplinary evaluation to make sure they are appropriate donors. The steps to complete this screening and evaluation include:

Step 1: Screening form:

- Includes medical history and blood type.
- Reviewed by the transplant surgeons.
- If acceptable, the donor moves to step 2.

Step 2: Bloodwork for HLA typing and crossmatch:

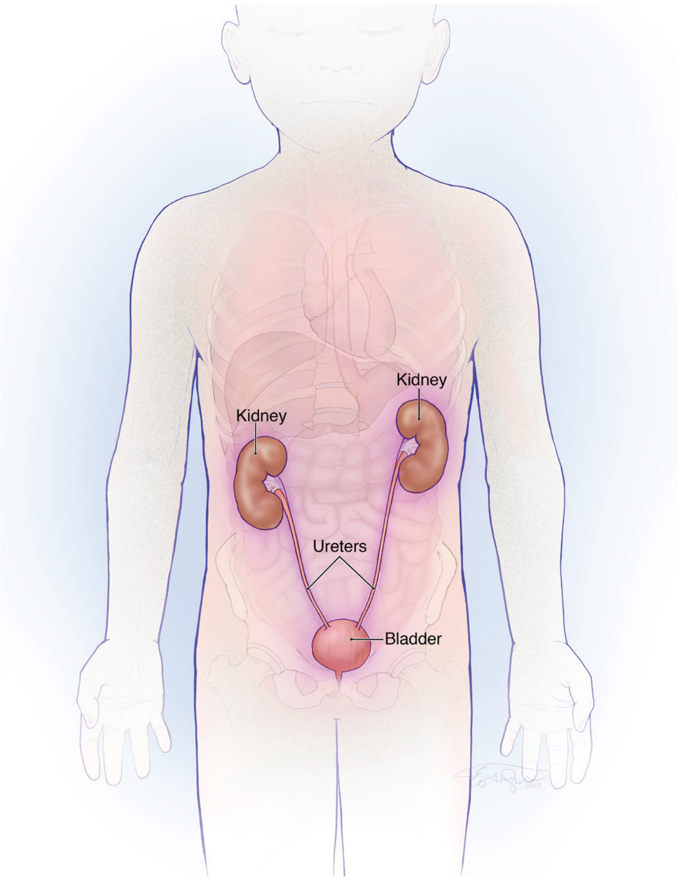
- Reviewed by the kidney transplant team at CHOP.
- If acceptable, the donor moves to step 3.

Step 3: Evaluation at HUP:

- The living donor team at the Hospital of the University of Pennsylvania will evaluate the potential donor.
- The role of the living donor team is to treat and evaluate the donor separately from the child.
- The HUP team will tell the CHOP team their findings.
- If donor is medically cleared, a transplant can be scheduled.

Kidney Paired Donation

This is an option for when a living donor does not match the blood type and HLA typing of the intended recipient. This option allows kidneys to be exchanged between two incompatible pairs to make two compatible living donor transplants.



The Waiting List: Deceased Donor

If your child is found to be a good candidate for kidney transplant and you decide you would like to pursue deceased donor transplant, your child will be placed on the United Network for Organ Sharing (UNOS) kidney transplant deceased donor waitlist.

- UNOS is the agency that oversees organ transplantation across the country.
- UNOS maintains a national computerized list of children and adults waiting for kidney transplants.
- UNOS works with Gift of Life, our local organ procurement organization, to recover organs.
- Once active on the waitlist, your child will be eligible for organ offers.
- Inactive (Status 7): In some situations, our team makes children inactive on the waitlist for a period of time. You will be notified if your child is made inactive on the waitlist. During the time that your child is on the inactive waitlist, they will gain wait time but will not receive organ offers.
- Dialysis patients have special consideration with waiting time on the list.

The UNOS Donor Matching Process

The following results in an organ match:

- CHOP will receive a notification that kidneys are available for one of our patients on the waitlist. Kidneys are offered based on:
  - Donor/recipient blood type match and compatibility
  - Time on the waitlist
- The transplant nephrologist and surgeon review the information about the donor kidney and decide whether to accept the organ.
- If our team accepts the organ, you and your family will be notified.

If your child is on the CHOP waitlist but not cared for by a CHOP nephrologist, your child should be seen by a CHOP transplant nephrologist at least every three months.

Children can be listed in more than one area of the country. This may increase the chance of getting a deceased donor kidney sooner. We will explain more about this option at the transplant meeting.

A transplant coordinator is always on call to receive offers for deceased donor kidneys. When your child is listed, we will make a plan to contact you if a kidney becomes available. The transplant coordinator must be able to reach you within one hour. We need to make sure that your child is available, not sick and does not have an infection.

A surgeon and nephrologist are available 24 hours a day, 365 days a year. We have several nephrologists and surgeons, and they are “on call” for transplants. When your child is offered a kidney, a surgeon and transplant nephrologist will review the information about the donor kidney and decide whether to accept the organ. They will speak with you about the condition of the kidney and any risks of accepting the kidney for your child.

An organ is not guaranteed until final review by the surgeon.

We can shared limited information about the donor if it is related to the safety and effectiveness of the transplant. There is a process through which you can reach out to your donor family after the transplant. Our team will provide you with additional information.

THE TRANSPLANT PHASE

Preparing for Surgery

Your child will need:

- blood work
- chest X-ray
- EKG
- Nothing to eat or drink for 6 hours before surgery

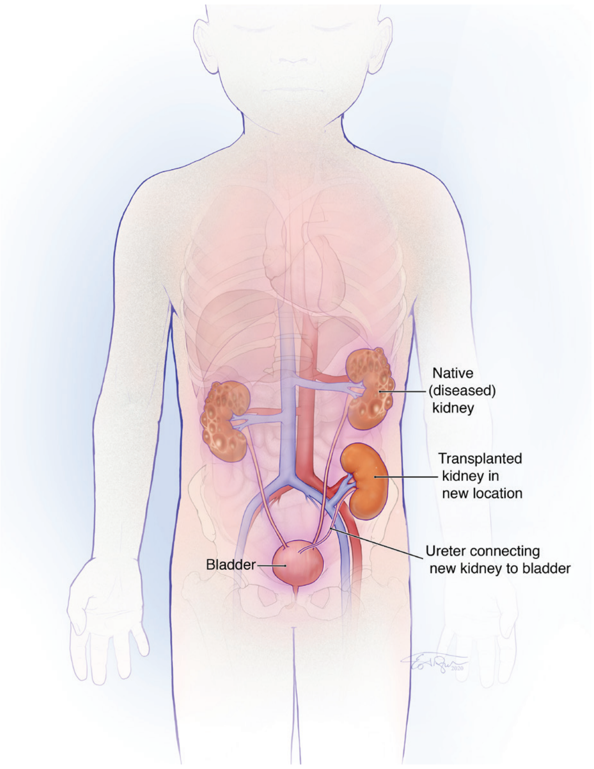
Most children coming in for kidney transplant are admitted to the Nephrology Unit. The nurses on this unit are trained in the care of a kidney transplant patient. You will meet nurses, doctors, anesthesia providers, transplant nephrologists, transplant advanced practice providers and the surgeon. They will answer all of your questions. You will sign the consent for surgery.

Day of Surgery

Your child will be transferred to the pre-operative area. You will meet members of the transplant team. During the surgery, you can wait in the surgical waiting area. A member of the team will provide updates during the surgery.

What Happens During the Surgery?

- The surgery usually takes about 4 to 5 hours but may take longer.
- For younger children, the kidney is placed in the lower abdomen. There will be a scar in the middle of the abdomen.
- For older children and teenagers, the kidney is placed in the area to the right or left of the belly button. See figure below.
- Your child will receive fluids and medications through an intravenous (IV) line during surgery. This allows the kidneys to receive blood flow. Your child may look a bit "puffy" after surgery due to the IV fluids. The puffiness will go away.



AFTER THE SURGERY

After transplant, your child will recover in the Pediatric Intensive Care Unit (PICU).

- You will be able to stay with your child.
- We will monitor your child's fluid intake.
- We will monitor your child's urine output.
- Your child will receive IV fluids for at least the first 24 hours after surgery.
- Your child may have a tube in place to help them breathe.
- Your child will have a catheter (soft tube) in place to drain urine.
- The transplant surgeon will decide when your child can eat or drink.
- The transplant surgeon will provide follow-up care for the incision.
- The transplant surgeon will decide when the urine catheter can be removed.
- The kidney transplant team will manage the medicines and the fluids that your child receives.
- The kidney transplant team may consult the pain team for pain management.
- Your child will be transferred from the PICU to the Nephrology Unit when stable.
- On the Nephrology Unit, the medical team will work with the kidney transplant team to manage your child's care and prepare to go home.

Before You Go Home

The kidney transplant team will answer your questions and concerns prior to discharge.

After transplant, your child will take immunosuppression medications for the rest of their life. These medications prevent the body from recognizing your child's new kidney as foreign and attacking it. This process is called rejection. It is very important that your child take these medications as prescribed. Missing doses or taking them off schedule can lead to rejection. The kidney transplant team will monitor the level of medications in your child's blood to ensure your child is getting enough medicine to prevent rejection.

In addition to immunosuppression medications, your child will go home on multiple other medications after transplant. As your child recovers, these medications will decrease.

When your child is ready for discharge, the nurses, pharmacist and the transplant advanced practice providers will meet with you to answer your questions and concerns. The kidney transplant team will provide prescriptions for all of your child's medications.

THE POST-TRANSPLANT PHASE

Complications After Surgery

The two most common complications are rejection and infection.

Rejection occurs when the body's immune system recognizes that the kidney is new to the body. Since the "new" kidney is not part of your child's body, your child's immune system will try to fight it. It is very important that your child takes the immunosuppression medications. The kidney transplant team monitors for rejection by routinely testing your child's blood and urine. If there is concern for rejection, we may obtain a kidney biopsy. A biopsy is performed by collecting a tiny piece of kidney tissue with a needle, which we can then look at under the microscope.

Infection is caused by germs. Taking immunosuppressive medicines can decrease your child's ability to fight infections. To prevent infections, your child should not return to school or visit public places for at least 6 weeks after transplant. It is important to practice good hand hygiene and infection prevention measures to avoid infections. We will test your child for common viruses during your clinic visits.

Other potential complications:

- The new kidney may not work right away (delayed graft function). We may perform an ultrasound to make sure that blood is flowing to the kidney. We will check kidney function by measuring the creatinine in your child's blood. The lower the creatinine level, the better the kidney is working. It may take a while for the creatinine to decrease. Your child may need to have dialysis until the new kidney is working.
- The kidney may clot (thrombosis). This is a very rare complication and is more common when the child is small. If this happens, the donor kidney will need to be removed.

Post-Transplant Clinic Visits

Clinic Visit Schedule	
Transplant - 6 weeks	2 times per week
6 weeks - 12 weeks	1 time per week
3 months - 6 months	Every 2 weeks
6 months - 12 months	1 time a month
1 year - 2 years	Every 4-6 weeks
2 years post-transplant until transition to adult care	Visit every 3 months Labwork every 6 weeks

If there are complications or clinical concerns, your child will be seen more often. Expect the following procedures at each clinic visit:

- Blood work to check for signs of infection and rejection, kidney function, and levels of immunosuppression medication
- Urine sample
- Vital signs
- Physical exam

The transplant psychologist and social worker are available to help with any behavioral or coping concerns. Other members of the transplant team, such as the dietitian and clinical pharmacist, are also available to meet with you and your child.

Noah, 5,
kidney transplant patient

There needs to be a 12-hour period between the time your child takes certain medications and the time we perform blood work. We will tell you which medications your child should not take before your clinic visit. Bring these medications to clinic so that they can be taken after the blood work.

Returning to School

Your child's immune system is weak after transplant. We require that they stay out of school for the first 6 weeks after surgery. During this time, we will help you set up a home education plan. When your child is ready to return to school, we will send the school a letter explaining the following:

- Your child's immune system is weak.
- Your child cannot receive live vaccines.
- The school should notify the transplant team of any outbreaks of infectious diseases (such as chicken pox) in the school.
- We provide emergency contact numbers for the transplant team.

Physical Activity

After transplant, your child cannot compete in high-contact sports. Lower-contact sports can be played as long as a kidney protector is worn. A kidney protector is a device that is fitted to the abdomen over the area of the new kidney. Your child can be fitted 6 weeks after transplant. Speak with your nephrologist about restrictions on physical activity. We will provide a list of sports that are considered high and low contact.

Surveillance Biopsy

There may be dysfunction in the transplanted kidney that cannot be seen with blood work, urine testing or a physical exam. In order to look for these changes, we will perform a "surveillance biopsy" at 6 months, 1 year and 2 years after transplant. We will talk more about the details and obtain your consent before the biopsy.

Hypertension Clinic

Due to the significant relationship between heart health and kidney health, beginning one year after transplant, your child will attend a combined Hypertension/Kidney Transplant Clinic. This will replace a regular clinic visit. Your child may have an echocardiogram performed. This is a picture of the heart and tells us about heart function. They also may have an ambulatory blood pressure monitor placed, which is a blood pressure monitor worn at home for 24 hours. This gives our team more information about home blood pressure readings. Your child will attend Hypertension Clinic each year, unless otherwise indicated.

Teen Clinic and Transition to Adult Care

When your child becomes a teenager, they will attend our Teen Clinic twice a year. This will also replace a regular clinic visit. During Teen Clinic, they will meet with a multidisciplinary team and learn how to become responsible for their health and manage their own care. We will work with your family to help prepare your teenager for transition to an adult nephrologist. This should happen by 21 years of age or earlier. There are many adult kidney transplant programs in the country, and we will help you find one.

For More Information on the Transplant Process and Donation

United Network for Organ Sharing (UNOS)
www.unos.org

Gift of Life Donor Program
www.donors1.org

The National Kidney Foundation (NKF)
www.kidney.org

Donate Life America
www.donatelife.net/

U.S. Government Information on Organ Donation and Transplantation
www.organdonor.gov/

Penn Living Kidney Donor Transplant Program
www.pennmedicine.org/for-patients-and-visitors/find-a-program-or-service/transplant-institute/living-kidney-donor-transplant

The Connelly Resource Center for Families: 215-590-4968

Located on the eighth floor of the Main Building, the Connelly Center was designed to provide support to parents, caretakers, siblings and other relatives of our patients. Inside the center, families will find a family and children's library, a learning center, kitchen area, laundry room with three washers and dryers, five sleep rooms, a cell phone charging station and a comfortable place to take a break.

KIDNEY TRANSPLANT CLINIC (NOTES)

IMPORTANT PHONE NUMBERS

If you have questions or concerns:

- Monday to Friday, 8 a.m. to 5 p.m.: Call the Kidney Transplant Office at **215-590-3913**
- After 5 p.m. and on weekends: Call CHOP's main number at **215-590-1000** and ask for nephrology fellow on call.

Learn more:
CHOP.EDU/TRANSPLANT

Children's Hospital of Philadelphia®