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Welcome

Welcome to Children's Healthcare of Atlanta Transplant Services. We offer pre and post-transplant services for children that get a kidney, heart or liver transplant. Our focus is on the children we care for and their families. We want to create a friendly, family-centered experience for you and your child.

In addition to our clinical areas, the transplant unit includes a:

- Playroom for patients.
- Kitchen with a stove and refrigerator.
- Laundry room with washer and dryer.
- Consult room to meet with medical teams.

The hospital family services include a:

- Family amenities area with sleep rooms, lounge areas and tables to work.
- Family library.
- Parent business center.
- Coffee shop.
- Gift shop.

Kidney Transplant Services includes a transplant stepdown unit (TSU) and the pediatric intensive care unit (PICU) for care of our patients. We have an outpatient transplant clinic at Arthur M. Blank Hospital in the South tower on the 5th floor.

Our promise to you

The Children's Healthcare of Atlanta Kidney Transplant team wants to provide you and your child with high-quality, family-centered care. Our team can help support you during your child's treatment. Our goal is to have a nurturing and caring environment during each admission and visit.

Please call us if you have any questions or concerns about your admission or visit. We look forward to caring for you and your child.

About the handbook

This handbook helps you learn more about kidney transplants. It also includes information about resources. Visit choa.org/transplant or call the Transplant Information Line at 800-605-6175 for more information about the Children's Kidney Transplant Program.

This handbook should not replace instructions given to you by your child's doctor and healthcare team. It is not meant to be medical advice or a complete source of all information about this subject. Your child's doctor is the best source of information about what is best for your child's treatment and care.

Call 911 or go to the nearest emergency department right away in case of an urgent concern or emergency.

Important contacts and phone numbers

Children's Transplant Center at Arthur M. Blank Hospital	800-605-6175
Kidney transplant team*	404-785-1405
Nights, weekends and holidays	404-785-5437
Billing and finance	404-785-6478
Kidney transplant social worker	404-785-6047
Clinic visits	404-785-1400
After hours call center**	404-785-KIDS (5437)
Kidney transplant team email	kidneytransplantemails@choa.org

PLEASE NOTE:

* All transplant questions should be addressed by the kidney transplant team.

**This is the phone number for the call center. If your call is after hours, ask that they page the on-call kidney transplant team member.

General information sheet

Child's name ____

Medical condition ____

Your child's transplant team

Please write down the name and phone number of each person you meet. Ask them how to spell their names and what they do.

- **Transplant surgeon:** The doctor that does the transplant surgery.
- **Nephrologist:** A doctor that takes care of patients with kidney disease before and after a transplant.
- **Anesthesiologist:** A doctor that monitors your child during surgery. They will give your child special medicine (anesthesia) that puts them in a deep sleep so they cannot see, hear or feel anything.
- **Physician assistant and nurse practitioner:** Clinical staff that assist your child's doctor. They are supervised by doctors and help take care of your child before, during and after a transplant.
- **Transplant coordinator:** A nurse that helps you and your family plan your child's care and treatment before and after the transplant.
- **Intensive care unit (ICU) and patient floor nurses:** Nurses that care for your child while they are in the intensive care unit (ICU) and on the patient floor.
- **Respiratory therapists:** Clinical staff that check and treat any breathing issues.
- **Registered dietitians (nutritionists):** Clinical staff that help check your child’s diet, food and nutrition needs.
- **Transplant pharmacist:** A pharmacist who has special training with transplant medicines. They check your child's medicines, teach you what you need to know about them and help with research studies.

- **Psychologist:** Clinical staff that helps you and your child cope with feelings about having a kidney transplant. The psychologist helps with the transplant evaluation.

- **Child life specialists:** Clinical staff that teaches you, your child and your family about the hospital and procedures. They can help answer you and your child’s questions and provide medical play.

- **Social workers:** Clinical staff that help provide guidance, counseling and coping skills for you and your family. They help you get the services and resources you and your child need while in and out of the hospital.

- **Physical therapists:** Clinical staff that help your child with movement and exercises to make them stronger before and after transplant. Physical therapists can also teach you what you can do at home to help your child regain strength.

- **Chaplains:** Hospital staff that help meet your family's spiritual needs. A chaplain can work with your pastor or religious leader to provide spiritual support. Hospital chaplains also lead interfaith services in the hospital chapel.

- **School program teachers:** Certified teachers in the hospital that help your child keep up with their schoolwork so the transition between hospital, home and school will be easier. There is a school room at the hospital.

- **Transplant financial counselors:** Financial counselors help you learn about your insurance plan and how to reduce your expenses for your child's care. A financial counselor can help your family set up a long-term payment plan if needed.

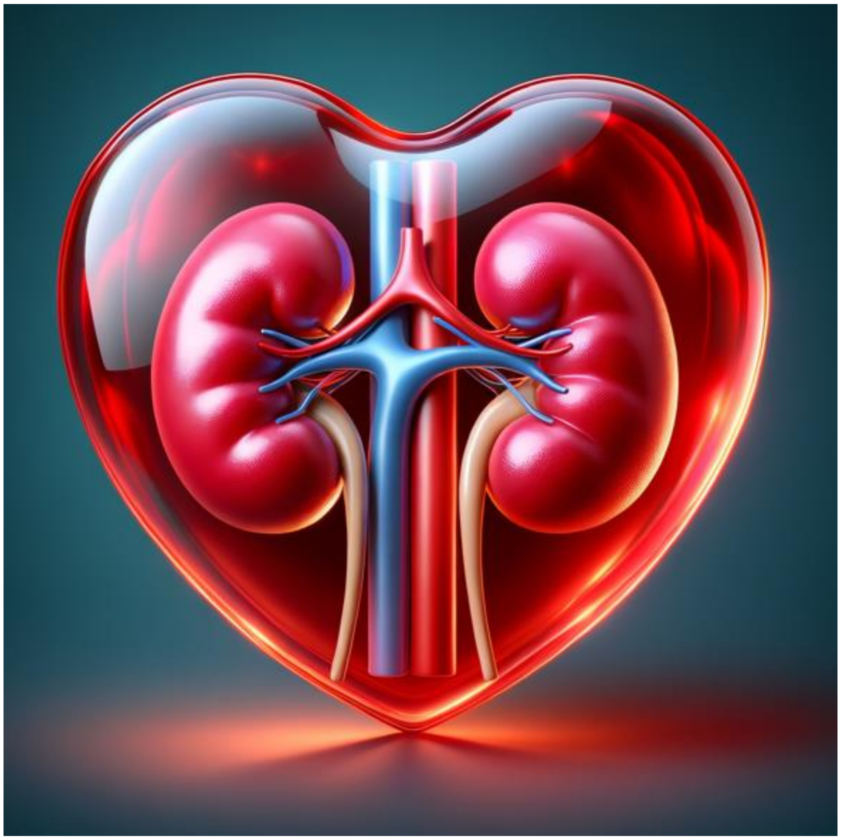
Kidney Transplant

What are kidneys?

The kidneys are:

- Positioned in the upper back. There is 1 on each side of the back.
- About the size of your fist and weigh about 4 to 6 ounces each. Most people have 2 kidneys.
- Shaped like a bean and are a reddish brown color.

Kidneys and renal blood vessels



What do the kidneys do?

The kidneys are organs that have a lot of jobs. People can live a normal, healthy life with just 1 kidney. You cannot live without at least 1 working kidney. The main functions of the kidneys are listed in the chart below.

What do the kidneys do?	
Filter the body's blood.	• Remove extra sodium, potassium and urea (waste). • Reabsorbs useful substances for the body.
Maintain fluid balance.	• Removes or reabsorbs water to keep the right amount of fluids in the body.
Excrete acid.	• Removes acids to help maintain the body's acid and base balance.
Makes the hormone erythropoietin.	• Erythropoietin tells the bone marrow to make red blood cells. • Your child may have low red blood cells (anemia) if their kidneys are not making erythropoietin.
Activate vitamin D.	• Vitamin D helps the body absorb calcium and makes healthy bones. • Vitamin D also helps make a strong immune system.

What happens when the kidneys do not work?

It is called renal failure when the kidneys do not work. These things can happen:

- Harmful waste builds up in the blood and causes headaches, nausea and vomiting.
- Extra fluid collects in the body and causes swelling in the legs and feet. This is called edema.
- High blood pressure. This is called hypertension.
- Anemia. This is when there are not enough red blood cells in the body. This causes your child to feel weak and tired.
- Insomnia. This is when your child has trouble sleeping.
- Delays in growth and development.

Causes of kidney failure

Medical name	What this means	How this hurts the kidneys
Dysplastic or cystic kidneys	Cysts grow in the kidneys.They are most often present at birth.	Cysts are fluid-filled sacs that preventthe kidneys from working well.
Urinary reflux or posterior urethral valves	Blockage in the urinary system. These are the kidneys, bladder and connecting tubes that make and store urine.	Kidneys become infected and damaged when urine cannot flow through the system.
Glomerulonephritis	A disease that damages the part of the kidneys that filters blood.	The kidneys are not able to filter outharmful substances from the blood. The body loses large amounts of protein through the urine.
Nephrotic syndrome	A disease that can damage the part of the kidneys that filters blood.	The kidneys are not able to filter outharmful substances from the blood. The body loses large amounts of protein through the urine.
Nephropathy	Kidney damage caused by high blood glucose (blood sugar) levels from diabetes.	High blood glucose damages the filteringsystem of the kidneys. The body loses large amounts of protein through the urine.
Lupus erythematosus or Goodpasture's syndrome	These are autoimmune diseases. The immune system is the body's defense against harmful substances such as bacteria or viruses. Autoimmune diseases happen when the immune system destroys normal body tissues.	These autoimmune diseases cause inflammation of the filtering systemand lining in the kidneys.
Hemolytic uremic syndrome (HUS)	Condition that affects the blood and blood vessels.	This causes kidney failure due to damage to very small blood vessels in the kidneys.
A/port syndrome	An inherited disease (passed from parent to child) that affects the glomeruli, tiny blood vessels in the kidneys that filter waste from the blood.	Kidneys are not able to filter out harmful substances from the blood.The body loses large amounts of protein through the urine.
Wegener's syndrome	A rare disorder that causes inflammation of blood vessels in the kidneys and lungs. It may be an autoimmune disease.	Kidneys are not able to filter out harmful substances from the blood.The body loses large amounts of protein through the urine.

If you do not understand why your child's kidneys are failing, please ask their nurse or doctor to write down the name of the problem here:

____

____

____

____

____

Treatment for kidney failure

Your child's kidney failure may have happened over a long period of time (chronic) or suddenly (acute). A nephrologist (kidney doctor) will tell you about treatment options that may include dialysis or a kidney transplant.

Dialysis does the work of healthy kidneys by using a machine to filter body fluid and waste. Dialysis can:

- Remove waste, extra salt and water.
- Maintain a normal level of salts such as potassium, sodium and chloride.
- Help control blood pressure.

Dialysis is a long-term treatment for kidney failure. Dialysis happens multiple times each week. There are 2 types of dialysis: hemodialysis and peritoneal dialysis.

- **Hemodialysis** uses a man-made filter called a dialyzer to remove wastes and return salts to the body. These treatments can take 4 hours each time. They happen most often 3 times a week. Hemodialysis is most often done in a hospital or clinic.
- **Peritoneal dialysis** uses the body's own filter, a thin covering on the inside of the abdomen (belly) to filter the blood. Peritoneal dialysis can be done at home. The 2 types of peritoneal dialysis are:
    - CCPD (continuous cycle peritoneal dialysis): This uses a machine and often done at night. A parent needs to help with this type of dialysis. It is best for young children.
    - CAPD (continuous ambulatory peritoneal dialysis): This is often done during the day. It can be done by the child and may be better for an older child.

Notes

The Kidney Transplant

How transplants work

- A kidney transplant provides your child with a healthy kidney from a donor.
  - The donor is a person who gives your child a kidney.
  - There are 2 types of kidney transplants: **deceased donor** and **living donor.**
- The new kidney does the work of failed kidneys.
- Your child may need their own kidneys removed. Your doctor can explain this based on your child's medical condition.

Deceased donor

- A deceased donor is a person who has recently died and donated their kidneys.
- Children on the United Network for Organ Sharing (UNOS) list get a kidney from a deceased donor. UNOS matches deceased donors and patients waiting for a kidney.

Living donor

- A living donor is a person who volunteers to give your child 1 of their kidneys.
- Most living donors recover well and live full lives with 1 kidney.
- A family member is often the best match for your child. But many living donors are not related to the person who gets their kidney. Aunts, friends, firefighters and teachers have all volunteered as donors.

Steps for a kidney transplant

The kidney transplant team will discuss each step with you, your child and your family.

Step 1

Your child's doctor refers them to the Children's Kidney Transplant Program. They must state your child's medical need for a transplant.

Step 2

Our financial counselors get financial approval for your child's pre-transplant evaluation and for the transplant.

Step 3

The transplant team will call you to schedule a pre-transplant evaluation. A pre-transplant evaluation is a series of tests. Your child will see many people from the transplant team:

- Nephrologist
- Surgeon
- Psychologist
- Social worker
- Pharmacist
- Transplant coordinator

The tests help the kidney transplant team decide if a transplant is the best option for your child. The transplant team will help you through this process.

Step 4

Your child has a pre-transplant evaluation at Arthur M. Blank Hospital. This is most often a 1 day outpatient visit unless your child needs 2 organs.

Step 5

The kidney transplant surgeon and team will decide if a transplant is the best option for your child based on the test results. If approved, these next steps happen:

- **Deceased donor transplant**
    - Your child's name is placed on the UNOS list if there is not a living donor for them.
    - This process can take 2 to 3 weeks.
- **Living donor transplant**
    - You should tell the transplant coordinator as soon as possible if there is a living donor volunteer. During their evaluation our staff can provide information about living donation.
    - The volunteer who wants to be a living donor should call Emory Hospital Living Donor Services or complete registration at emory.donorscreen.org/register/donate-kidney or call 855-366-7989. The kidney transplant team will not call the volunteer first.
    - The donor will be referred to Emory University Hospital after financial approval is complete. Emory's Living Donor Coordinator will contact the donor with a date for the evaluation.
    - If the donor is not approved due to medical or other reasons, your child can be put on the UNOS list.
    - If a second volunteer donor becomes available, the process starts over. Only 1 donor can be evaluated at a time.

Step 6

If the living donor is approved the donor's surgery is scheduled at Emory University Hospital. Your child's surgery will be at Arthur M. Blank Hospital.

Step 7

Your child has their transplant surgery. They will stay in the hospital for 7 to 10 days.

Step 8

Your child will receive follow-up care at Arthur M. Blank Hospital outpatient transplant clinic in the South Tower

Pre-transplant evaluation

The pre-transplant evaluation (eval) is a series of tests that helps decide if a kidney transplant is the best option for your child.

- The kidney transplant coordinator will schedule your child's eval. This will be an outpatient visit to Arthur M. Blank Hospital.
- The coordinator will schedule tests and appointments with the kidney transplant team during your visit. They will work closely with you during the process.
- Please plan to stay for the entire day or days of eval.

How do we prepare for the eval?

To help ensure that the pre-transplant eval goes as smoothly as possible:

- Bring a copy of your insurance benefits and insurance I.D. card with your deductible and co-payment amounts and social security card.
- Your child must have a pediatrician. Bring the doctor's name and phone number with you to the eval.
- Arrive on time. We may need to reschedule your visit if you are late.
- Please leave young siblings at home. Your focus needs to be learning about the transplant. We do want your family to be part of follow-up clinic visits.
- Call your pediatrician to make sure that your child's immunization records (vaccines) are up to date. Bring your child's records along with their doctor's name and phone number to the eval.
- Write a list of questions to ask the team. Share your concerns and fears with them.

What happens during the eval?

You will spend most of the day in the transplant clinic at Arthur M. Blank Hospital in the South tower. Your child will have some tests that may include:

- **A routine medical exam**. This includes your child's height and weight, family history of long-term diseases and surgery history. Bring these items with you:
  - A written record of your child's medical history. Have it ready before you come to the eval to share with the doctors.
  - Your child's medicines.
  - A list of questions you have about your child's transplant or eval.
- **Blood tests** to check your child's:
  - Blood type. This test checks your child's blood to see if it is type A, B, AB or O.
  - Blood chemistries, such as BUN, creatinine, sodium and potassium.
  - Blood counts, such as red and white blood cell counts.
  - Blood for viruses, such as Epstein-Barr virus (EBV), Cytomegalovirus (CMV) and BK virus.
- **Other lab tests if needed.**
- **Radiology and imaging tests** such as:
  - Chest X-ray to check your child's lungs.
  - Ultrasound with doppler exam. This test checks the blood flow through the major blood vessels. It is often done before and after a kidney transplant.
- **Echocardiogram (echo)**. This test may be done if your child has a history of heart disease or high blood pressure.
- **Other evaluations** may include meeting with:
  - Other doctors. Your child may see other doctors such as a urologist. These doctors care for the urinary system. A cardiologist (heart doctor) may help your child's doctor coordinate care.
  - A psychologist. Your family will talk with them to make sure you all learn about the emotional aspects of a kidney transplant.
  - A dietitian. You and your child will meet with the dietitian (nutritionist). They will check your child’s weight and diet during treatment.
  - A transplant pharmacist. You will meet with 1 of our transplant pharmacists. They will review all the medicines your child will need after the kidney transplant. They will also review your child's current vaccine history and make recommendations.
  - A social worker. You will meet with the transplant social worker. The social worker will give you resources and ensure that you have the resources needed to be successful after the kidney transplant.

Note: Your child may not need all of these things. The transplant team will decide what your child needs.

Blood tests

Your child will have blood tests (labs) to help the doctors check if the kidneys are working. The team will check these blood tests during your child's pre-transplant eval and during and after their transplant.

Blood test	**Change with kidney disease**
Albumin • Albumin is a protein in the blood made by the liver. It helps move substances in the blood and helps with blood pressure. • Kidney disease causes albumin to be filtered out in the urine.	Low
BUN (blood urea nitrogen) • Urea is made when the kidneys break down protein. It is a waste product that is removed from the body in the urine. • Urea is high in the blood when the kidneys do not work well.	High
Creatinine • Creatinine is made when the body uses muscle and energy. It is removed from the body by the kidneys. • Creatinine is high when the kidneys do not work well.	High
Potassium • Potassium is salt in the cells. It is needed for nerves and muscles to work. Kidneys remove extra potassium through the urine. • Potassium is high when the kidneys do not work well.	High
Hemoglobin • Hemoglobin carries oxygen to the body in red blood cells. • Hemoglobin is low when iron in the blood is low, which happens with kidney failure. This is called anemia.	Low
Hematocrit • Hematocrit measures the number of red blood cells in the blood. • A low hematocrit level can show anemia or blood loss.	Low
Glucose • This is a test to measure the sugar level in the blood. • Stress and medicines can cause glucose to be high in the blood. • The team may add other medicines if your child’s body cannot control glucose levels.	High

Deceased donor kidney transplant

What are the steps for a deceased donor transplant?

There are several steps for a deceased donor transplant. The kidney transplant team can answer your questions during the process.

1. Your child is put on the UNOS waiting list to get a kidney from someone who recently died.
2. UNOS keeps a national list of people who are waiting for donated organs. They work with agencies to obtain organs. Your child stays on the list until they receive a kidney.
3. UNOS gives your child a score. It is based on age, length of time on the list and percent antibody.
4. Your child is matched with a kidney based on the score and their blood type. Waiting for a deceased donor kidney can take time. Talk with the kidney transplant team if you have questions.

The transplant team needs a reliable phone number where you can be reached when a kidney becomes available. Please tell the transplant team about all travel plans

How does the UNOS donor matching process work?

1. A kidney is donated from a person who just died.
2. The donor's medical information is put into the UNOS database.
3. Your child will show as a match to the donor’s information.
4. UNOS notifies Children's that a kidney is available.
5. The transplant surgeon and team review whether to accept or decline the organ. This is based on whether the kidney is the best match for your child.
6. The transplant coordinator calls you when a kidney is available.
7. To understand how patients are matched on the national waiting list:
    - Think of the list as a "pool" of patients.
    - When an organ is available, UNOS searches the entire “pool” for a match.

Other things that are considered include:

- Location of the kidney and the child.
- The amount of time that the child has been on the waiting list.
- Blood type. Your child can receive a kidney from a person with the same or with a compatible blood type. The 4 blood types are O, A, B and AB.

Blood type compatibility

If your child's blood type is:	**The donor's blood type can be:**
O	O
A	A or O
B	B or O
AB	AB, A, B or O

About the deceased donor

Families often want to know the age of the donor and how the donor died. Information about the donor is confidential. Your child's information is not given to the donor's family either. You can write a letter to the donor's family. A transplant coordinator will send the letter to Lifelink of Georgia. They forward it to the donor's family.

Living donor kidney transplant

A living donor transplant means doctors take a kidney from a living person to replace your child's unhealthy kidney.

The benefits of a living donor transplant include:

- The kidney comes from a person known to be healthy.
- Surgery can be scheduled. It can be worked around vacations or time off to allow for greater convenience in your child and family's life.
- The transplant can be done before your child becomes very ill. This can help with recovery.

Who can be a living donor?

A living donor can be a parent, family member or friend. A donor must meet health standards and have a donor evaluation. The kidney transplant team will decide if the donor is a good match for your child based on the tests. A donor must be:

- Older than 18 years of age.
- In good health. Some medical conditions can prevent a person from being a living donor. This is up to the transplant surgeon to decide. Examples include:
    - Kidney disease
    - High blood pressure
    - Diabetes
    - Heart, lung or breathing problems
    - Cancer

  - Urinary tract problems
  - Contagious diseases (a disease that can be passed from one person to another) such as HIV, hepatitis or tuberculosis (TB)
  - Obesity (very overweight)
- Willing to donate a kidney. The decision to donate must be made freely and without pressure from anyone.
- Admitted to Emory University Hospital for the evaluation and surgery.
- Able to take time away from work or school for some time. Stay in the hospital for an average of 2 to 3 days.

What are the steps to be a living donor?

A living donor must have a series of tests to make sure they are the best match for your child.

1. A person that wants to be a donor for your child's transplant will need to call Emory Kidney Living Donor Program at 855-366-7989, register online at emorylivingdonor.org or email livingdonor@emoryhealthcare.org.
2. The Children's financial counselor asks your insurance company for approval for the donor eval. Your insurance may pay for the donor's tests. If you do not have insurance, our financial counselors will work with you to set up a payment plan.
3. Your insurance company approves the donor eval. The living donor coordinator sets up the donor eval at Emory University Hospital.
4. A living donor's blood type must be correctly matched to your child's blood type.
   - If their blood types do not allow for donation, your child can enter the paired donor exchange. This involves 2 living donors and 2 recipients. It is like trading donors with someone else. If the recipient from 1 pair is compatible with the donor from the other pair, your donor will donate to that recipient and their donor will donate to your child. This allows your child to still receive a living donor transplant when your donor blood type does not match your child's.
5. The donor has their eval.
6. The donor will have an outpatient eval at Emory University Hospital. The donor's test results may take 6 weeks.
7. The transplant team reviews the donor test results and decides if the donor is a good match. If the donor is not a good match, new donors can be evaluated.

What if I want to become a living donor?

A person must clearly state their interest in being a living donor.

- Call for an appointment with the Emory Transplant Living donor program 855-366-7989. You can start the process by going to emorylivingdonor.org.
- Exercise often. Activities such as walking, swimming or biking are strongly advised for donors. This helps the donor recover better after surgery.
- Follow a healthy diet.

- Stop drinking alcohol and smoking.
- You may need to stop some medicines. Talk with your doctor and the kidney transplant team before you stop any medicine. Herbs, vitamins and nutritional supplements are medicines.

The living donor evaluation

The living donor eval may include these tests:

- Screening tests. All female donors must have a pap smear and mammogram. Men must have a prostate specific antigen (PSA test).
- A routine medical exam. This includes the donors':
    - Height and weight
    - Blood pressure
    - Family history of heart, kidney or other chronic disease
    - History of smoking or obesity
    - Alcohol or drug use
    - Any prior surgeries
    - Blood tests. These may include a complete blood count and tests for hepatitis, drugs, HIV and pregnancy. The transplant surgeon decides which blood tests the donor needs.
- Chest X-ray and electrocardiogram (EKG). These tests check the donor's lungs and heart.
- CT scan. This checks the size and shape of the donor's kidney and the amount of kidney tissue.
- You may need an angiogram. This checks the size of the donor's blood vessels around the kidney to see if there are any blockages. Dye is injected into the artery, so the blood vessels show up on X-ray.
- Psychosocial evaluation. The donor will talk with a social worker and psychologist to make sure they understand the emotional parts of living donation. The psychosocial exam makes sure that the donor wants to donate their kidney without any outside pressure from family or friends.

A donor may need more tests if their medical history is complex. The next step is to schedule the donor surgery. The entire process, from referral to scheduling, can take several months.

Questions to ask the transplant team

You should be able to answer the questions below after meeting with the kidney transplant team. Please ask the team to explain anything that you do not understand.

1. Why does my child need a transplant?

2. What are the risks of a transplant?

3. How long is the transplant process from beginning to end?

4. What are options for my child if they do not get a transplant?

5. Questions that have not been answered yet:

Preparing for your child's transplant

While you wait for a deceased donor

Here are some steps you and your family can take while your child waits for a deceased donor transplant:

- Stay in touch and always be ready.
    - Make sure the transplant coordinator can always reach you. Give the team phone numbers for school, work and family members. This ensures that the transplant team can contact you right away.
    - Tell us if your phone number or address changes. The kidney will be given to another person if we cannot reach you.
    - Contact the transplant financial counselor if your family has a change in work status or insurance coverage.
- Have a plan to get to the hospital on the day of the transplant. The transplant coordinator will tell you when your child must arrive at Arthur M. Blank Hospital.
    - Make sure your car works well and is ready for your trip at any time.
    - Have a plan for the care of siblings during the transplant.
- Make sure your child is ready.
    - Tell the transplant team about all illnesses and infections. The transplant will be canceled if your child is sick.
    - Your child should get treatment for any sickness. This helps ensure they will be ready for the transplant when a donor kidney is available.
    - Tell the transplant team about any changes in your child's health.
- Help your child be in good physical shape for the transplant.
    - Your child should follow diet instructions from the dietitians.
    - Your child should be as active as possible.
- Spend time with your child. Talk with them about the transplant.
    - Let them express feelings, fears or concerns.
    - Let them ask questions and be truthful with your answers.
    - The transplant team will be happy to help you with concerns and questions.
- Keep your child in school and get involved in activities if possible. Try to keep your child's routines normal and balanced.

When the call comes

The transplant coordinator will call you when UNOS finds a donor kidney. Your child must get to Arthur M. Blank Hospital as quickly and safely as possible. Your child should stop eating and drinking as soon as you get the call. Their stomach should be empty before surgery.

Bring these with you:

- List of your child's medicines
- List of drug allergies
- Your child's health information
- Your health insurance card

Make sure your child takes all their medicine as prescribed to help prevent problems. It is OK to swallow small sips of water with their medicine.

Transportation

You need to get to the hospital as quickly and safely as possible. If you live far from Atlanta, you and your family should be ready to fly here for the transplant.

Transplant surgery

A deceased donor transplant

1. The transplant coordinator calls you when a donor kidney is ready. Be sure to call us back as quickly as possible. We will tell you when to come to the hospital.
2. Go to admissions at Arthur M. Blank Hospital.
3. Staff will direct you to your child's room. The inpatient team prepares your child for surgery.
4. The kidney transplant team will do a medical review in the next few hours that may include a:
    - Complete history and physical exam.
    - Review of your child's current medicines. Please have a complete list of all the medicines your child is taking.
    - Review of any health problems that your child has had lately such as a sore throat, cold, infections, rashes, cold sores or contact with people who have infections.
    - Chest X-ray.

    Note: Your child’s surgery may be canceled if your child is sick or if an emergency happens.

5. The anesthesiologist will visit you and your child to talk about anesthesia.
    - An anesthesiologist is a doctor who monitors your child during surgery.
    - Anesthesia is medicine that puts your child in a deep sleep so they cannot see, hear or feel anything during surgery.
6. The transplant surgeon will come and talk with you about your child's surgery. You will be asked to sign a consent form (permission) for surgery after the transplant surgeon has explained the surgery and possible risks.

7. The transplant surgery will take place.
   - The surgery may take 4 to 6 hours.
   - There is room for you and your family to wait.
   - The transplant coordinator, an operating room (OR) nurse or a child life specialist will give you updates about your child.
   - The surgeon will talk with you after your child's surgery.
   - Please tell your coordinator if you leave the hospital. Give them a number where you can be reached.
8. Your child will go to the pediatric intensive care unit (PICU) after surgery.
9. Your child will go to the transplant stepdown unit (TSU) when the doctor says they are ready. This is often 2 to 3 days after the transplant.

A living donor transplant

1. The transplant surgery is scheduled. Your child should go to Arthur M. Blank Hospital the afternoon before surgery. Your child's surgery may be canceled if your child is sick or if an emergency happens.
2. The anesthesiologist will visit you and your child to talk about anesthesia.
   - An anesthesiologist is a doctor who monitors your child during surgery.
   - Anesthesia is medicine that puts your child in a deep sleep so they cannot see, hear or feel anything during surgery.
3. The transplant surgeon will come and talk with you about your child's surgery. You will be asked to sign a consent form (permission) for surgery after the transplant surgeon has explained the surgery and possible risks.
4. The transplant surgery will take place.
   - The surgery may take 4 to 6 hours.
   - There is room for you and your family to wait.
   - The transplant coordinator, an operating room (OR) nurse or a child life specialist will give you updates about your child.
   - The surgeon will talk with you after your child's surgery.
   - Please tell your coordinator if you leave the hospital. Give them a number where you can be reached.
5. Your child will go to the pediatric intensive care unit (PICU) after surgery.
6. Your child will go to the transplant stepdown unit (TSU) when the doctor says they are ready. This is often 2 to 3 days after the transplant.

The donor's surgery

1. The donor's surgery is scheduled at Emory University Hospital.

2. The Emory transplant coordinator gives the donor information about pre-registration and when to stop eating and drinking the day before surgery.
3. The donor is admitted to Emory University Hospital.
4. The living donor will arrive at Emory University Hospital the morning of surgery.
5. After surgery, the donor will recover at Emory University Hospital.

Notes

After the Transplant

In the hospital

PICU

Your child will go to the pediatric intensive care unit (PICU) after surgery.

- Your child will be sleepy from the anesthesia for a few days.
- Your child will have a Foley catheter to drain urine from their bladder. The catheter stays in for a few days to check how much urine the kidney makes.
- Your child will have an I.V. or tubes put into small veins that allow us to give fluids and medicines.
- Your child may stay in the PICU for 2 to 3 days.
- The kidney transplant team and PICU team take care of your child after surgery.

TSU

After the PICU, your child will be taken to the transplant stepdown unit (TSU).

- The nurses and staff will help your child recover and prepare to go home.
- The transplant team will do family-centered rounds each morning.
  - Please be awake and present for rounds. Ask your child's nurse before you leave the unit.
  - This is a time for you to ask the team questions and set goals for discharge.
- Most children go home 7 to 14 days after surgery.
- The transplant coordinator and nurses will teach you how to care for your child at home.

Visitor guidelines

- Wash your hands well for at least 20 seconds each time you enter and leave your child's room.
- Do not allow sick family or friends to visit you or your child in the hospital.
- Only 2 visitors are allowed in the PICU at a time.
- It is best to always stay with your child. A family member or friend who is at least 18 years old is allowed if the parent cannot stay.
- Parents can stay with your child overnight. There are sleep rooms available for parents who cannot stay at bedside.
- Visitors younger than 10 years old must be with an adult.

Take care of yourself and your family

We want you to be available for your child during their hospital stay. We also know you will be tired from stress and poor sleep. This means you should take regular breaks, eat well and get plenty of rest. You will be able to take better care of your child and make decisions. Please let us know if there is anything that we can do to help you.

Going home

Taking your child home with a new kidney can be very stressful. The transplant coordinator and team will help you get ready for discharge. They will teach you how to take care of your child at home.

Complications

Some children have complications during their transplant recovery. Infection and rejection are 2 of the most common complications after a kidney transplant. Your child's transplant team will talk with you about the early signs of complications.

Rejection

Rejection is a natural response to your child's immune system. The immune system is the body's defense against an unknown material like viruses, bacteria or cancer. Your child's body treats the new kidney as an unknown material. Their body tries to attack the new kidney. Your child will take medicines to lower the immune system to help prevent rejection.

Immunosuppressants

Your child will take medicines called immunosuppressants to help prevent rejection.

- These medicines can lower the risk of severe rejection. Severe rejection can damage the kidney.
- They also decrease the actions of your child's immune system. This puts your child at risk for infections.
- Give these medicines on time and as ordered by the doctor.
- Your child will take this medicine for the rest of their life.

Some of the medicines may affect how your child looks and feels. Call the transplant coordinator if your child has any of these side effects:

- Puffiness and red face
- Weight gain
- Acne
- Bad dreams
- Wounds that may take longer to heal
- Diabetes (high blood glucose)
- Insomnia (trouble sleeping)
- Headache
- High blood pressure
- Tremors or shakes

NOTE: All of these medicines cause a higher risk of infections.

Name of medicine	**Reason for taking**	**When to take**	**Side effects**
Tacrolimus (Prograf)	Suppresses immune system, helps prevent organ rejection	Every 12 hours	Mouth sores, diarrhea, diabetes, post-transplant lymphoproliferative disease (PTLD)
Cyclosporine	Suppresses immune system, helps prevents organ rejection	Every 12 hours	Nausea, hair growth, gum growth
Prednisone	Helps prevents inflammation	1 time a day	Full face, nausea, weight gain, poor sleep, high blood glucose
Mycophenolate Mofetil (Cellcept)	Suppresses immune system, helps prevents organ rejection	Every 12 hours	Nausea, diarrhea, weakness, tremors
Sirolimus (Rapamune)	Suppresses immune system, helps prevent organ rejection	1 time a day	Nausea, diarrhea, acne, sleeping problems, wound healing problems, increased triglycerides, mouth sores, bone aching, pneumonia
Azathioprine (Imuran)	Suppresses immune system, helps prevents organ rejection	Every 12 hours	Nausea, loss of appetite, diarrhea, mouth sores

Your child may take more than 1 of these medicines. They should be given on time each day. Give them as ordered by your child's doctor.

- Blood levels of the medicines are checked 1 or 2 times each week. Levels are checked 12 hours after the nighttime dose, but before the morning dose is given.
- We can help you find the best medicine schedule for you and your child.

Your child should not take these medicines while they are taking immunosuppressants before talking with your transplant team:

- Anti-inflammatory medicines like ibuprofen and similar medicines like Advil, Motrin or Pediaprofen.
- Erythromycin, an antibiotic.
- Antifungal medicines.
- Anticonvulsants medicines (seizure medicine).

Always talk with your child's transplant team before giving them new medicines. Call the transplant coordinator if you have any questions about your child's medicines. If your child is not able to take their medicines or is vomiting their medicines, please contact your transplant team.

Kidney biopsy

Rejection can still happen if your child takes their medicines. The only way to check for rejection is with a blood test or biopsy. Your child's doctor may decide to do a biopsy. This test checks the kidney tissue.

- A needle is used to take a tiny sample of the kidney.
- The sample is checked under a microscope to look for rejection.

Infection

Your child has a higher risk of infection because of the immunosuppressant medicines. The risk of infection is highest in the first 3 to 6 months after transplant. You can help prevent infection by:

- Washing your hands often and teaching your child to wash their hands after:
  - Going to the bathroom.
  - Giving and taking medicines.
  - Handling uncooked food.
  - Touching trash or anything that may have germs.
  - Blowing their nose, coughing or sneezing.
  - Wiping their nose.
  - Caring for someone who is sick.
  - Playing with or touching pets.
  - Leaving a public place like a store or playground.
- Washing your hands and teaching your child to wash their hands before:
  - Eating and drinking.
  - Giving and taking medicine.
- Avoiding people with colds, measles, mumps, chickenpox or flu.
- Keeping your child’s skin clean and cleaning cuts and scrapes with soap and water.
- Getting the flu vaccine every year.

Infection warning signs

Call the kidney team **<u>right away</u>** if your child has any of these symptoms:

- Fever of 101.5° F or higher
- Pain near the new kidney
- Extreme tiredness

- Redness, swelling, warmth, tenderness or yellowish drainage at the surgery site
- Pain when urinating

Other possible infection warning signs include:

- Cold or flu symptoms.
- Nausea, vomiting or diarrhea that lasts more than 24 hours.
- Headache with congestion or runny nose or a change in the color of the drainage.
- Continued cough with or without mucus.
- Rash.
- Snoring or breathing through the mouth when asleep.

In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.

Viral infections

Epstein-Barr virus (EBV), cytomegalovirus (CMV) and BK virus (BKV) are common viral infections that affect many people. These viruses are everywhere. They can be serious for your child because their immune system is weak.

- Your child may not have symptoms if they get EBV or CMV. Or they may have fatigue, muscle aches or fever. Young children may have stomach pain, cramping and diarrhea. Call the doctor if your child has any of these symptoms.
- Your child may need to be admitted to the hospital if their symptoms are severe. Your child's doctor will talk with you about treatment. This may include antiviral medicine or changes to your child's medicines.
- Your child's transplant team will test for EBV and CMV each month for the first 12 months after transplant.
- Your child may not have symptoms with BKV. Our team tests for it regularly as this virus can damage the kidney over time. If your child tests positive for BKV, the transplant team may make changes to your child's immunosuppression to help resolve BKV.

Clinic visits

Clinic visits and blood tests are very important to your child's care. Infection and rejection can happen even when your child feels good. We will check for problems that you may not see as symptoms or complaints. Transplant clinic is on the 5th floor of the South tower at Arthur M. Blank Hospital.

- The Kidney Transplant Clinic is open Monday through Friday for labs. We will see your child for clinic on specific days. The transplant clinic does not have appointments every day of the week.
- You and your child will see your transplant provider and the transplant team 1 time a week during the first few months. Your visits will decrease as your child recovers from the transplant.

- Each transplant clinic visit may include:
  - Visit from the doctor or advanced practice provider (APP), coordinator and transplant team.
  - A check of your child's vital signs (blood pressure, heart rate and breathing), energy level, appetite, weight and activities.
- A physical exam.
- Blood tests.
- Other tests such as:
  - 24 hour blood pressure monitoring
  - Echocardiogram
  - Transplant ultrasound
- To schedule clinic and lab visits:
  - Call 404-785-1400.
  - Please call the clinic as early as possible to schedule routine visits. Clinic times fill up quickly.
- The care team will review your child's medicines at each visit. Please bring all medicine bottles to each visit.

Adolescent Clinic

The years between being a teenager and becoming an adult can present difficult and unique challenges, especially after a transplant. The Children's Adolescent Kidney Transplant Clinic helps make the transition to adulthood as smooth as possible by providing teens with:

- Guidance and support
- Education
- Resources

Teens will learn how to take responsibility for their own healthcare and the importance of taking their medicine, having regular checkups and eating healthy. Our clinic is for teens between the ages of 14 and 21 who are 6 months post-transplant. Call 404-785-6175 for more information.

Routine lab work (blood tests)

Lab work is one way to make sure your child is on the right amount of medicine.

- After discharge, your child will need lab work often. As time goes by, the lab schedule will vary based on how your child is doing.
- Have all blood tests done as your doctor orders.
- Call the transplant clinic if you forget to have blood tests done or need to have them drawn at a time other than scheduled.

Notes

Caring for Your Child

Vital signs

Many children have high blood pressure after their transplant. Anti-rejection medicine may increase blood pressure. It is important to take blood pressure medicines as ordered by the transplant doctor.

The transplant team may ask you to keep a daily record of your child's blood pressure, weight and temperature. Call the kidney transplant team if the reading is not normal for your child. They may ask for your child's blood pressure. Bring the blood pressure record with you when you visit the transplant clinic.

Immunizations (vaccines)

When possible, your child should receive all needed vaccines before the transplant. Talk with your child's doctor about the vaccines your child needs. In general, your child should receive these vaccines before a transplant:

- Diphtheria, pertussis and typhoid (DPT)
- Polio
- Measles, mumps and rubella (MMR)
- Influenza type B (inactivated)
- Haemophilus flu type B
- Chickenpox
- Hepatitis B

Your child should not get any vaccines until the transplant team says it is OK.

- It is important to avoid live vaccines.
- Let the transplant team know when vaccines are given.
- Please call the transplant team if you or your child's pediatrician have any questions about what vaccines to give to your child.
- Your child should get their flu shot 1 month after the transplant.
    - All people living with your child should get the flu shot. No one in the house should get the flu mist nasal spray vaccine.
- Your child can start to get other vaccines 3 months after the transplant. Talk with the transplant team about this schedule.
- The COVID-19 vaccine is recommended for your child after transplant.

If your child is exposed to chickenpox or shingles, call the transplant doctor or coordinator **right away**. Your child may need intravenous (I.V.) medicine.

Pediatrician

Make an appointment with your child’s pediatrician or family doctor after the transplant. The pediatrician should check your child and update their chart with new medicines.

- It is important to continue care with your child’s pediatrician for wellness exams.
- The pediatrician can treat your child for things like ear infections, colds or rashes.
- Always ask the transplant team before starting new medicines ordered by the pediatrician.

Car seats

All states have laws requiring that babies and toddlers are buckled in a car safety seat that is correct for their age and weight. Have them ride in the back seat. Use your seat belt to set a good example.

Medical alert identification

You may want to buy your child a medical identification (I.D.) bracelet or necklace. This is for healthcare workers that may take care of your child during a medical emergency like a car accident. It tells them your child had a kidney transplant. Ask the transplant team about these products.

Nutrition

Most children are on special diets before their transplant. Your child's diet may limit sodium, potassium, protein or phosphorus. These restrictions may change over time. We will review changes with you if they are needed.

Eating healthy food helps your child's body grow and heal. The body needs protein, carbohydrates, fats, vitamins and minerals. The dietitian will check your child's diet and weight. They will teach your family about the right foods or formulas for your child's special needs. The dietitian will also check your child's diet and growth rate after transplant.

After the transplant:

- Your child should avoid any uncooked or raw foods such as clams, oysters or sushi.
- Help your child eat a balanced diet that includes fruits and vegetables. Follow the no added salt rule.
- Avoid chips, sodas, excess fruit juice and other snack foods. They are empty calories and do not provide good nutrition.

- Our goal is for your child to reach their ideal body weight for their age and height. We will check your child's weight during clinic visits to make sure they are growing well.
- You should not force feed your child. This may cause your child to dislike or avoid food.
- Your child's taste for food may change. They may like new foods.

Are there foods and drinks my child cannot have?

Some foods and drinks can interact with transplant medicines. They can make the levels of medicines in the blood too high. Never let your child eat or drink:

- Grapefruit or grapefruit juice.
- Pomegranate or pomegranate juice.
- Any fruit related to grapefruit, such as pomelo.
- Any mixed fruit juices with grapefruit or pomegranate.
- Unpasteurized milk products or untreated water.
    - They can cause infections that may be more harmful to your child because their immune system is decreased.

Exercise

Your child's activity will increase as they feel better. They can do any activities they feel up to doing.

When can my child play sports again?

Exercise and physical activities are part of a healthy lifestyle for all children. We suggest regular physical activity and exercise in all transplant patients. It will help keep your child strong and healthy.

Some tips about activities after a transplant include:

- Regular exercise helps your child develop an active lifestyle. It also supports long term health benefits.
- There is a chance that your child could hurt their kidney with any activity. It is important to think about the risk to the kidney.
- Your child should wear a kidney protector if there is a chance that the kidney could be injured.
- Your child should not swim in pools, open water or fresh water until 3 months after transplant.
- Please talk with your transplant team before your child starts a new sport or activity. Your child should not do high impact sports that could cause direct injury to the kidney.

Sunscreen

We are exposed to the sun all year, not just during the summer. The best way to help prevent skin damage is to limit time in the sun.

Your child needs to wear sunscreen due to the side effects from their medicines. Use sunscreen with an SPF of 15 or higher. Use it even if your child will only be in the sun for a short time.

To help prevent sunburn, your child should:

- Wear clothing that protects their skin, such as a hat, long pants and long sleeves.
- Put sunscreen on exposed skin 30 minutes before going outside. Follow the instructions on the sunscreen bottle. This often means you need to put it on every 2 hours and after playing in the water.
- Use sunscreen for children of all ethnic backgrounds, regardless of skin color.

Dental care

Medicines, such as cyclosporine or amlodipine, can cause overgrowth of gum tissue. Keep your child's teeth, mouth and gums clean. This helps lower the chance of an infection.

- Your child should brush and floss their teeth 2 times a day.
- Use a soft toothbrush. Gently brush up and down. This may help keep their gums from overgrowth.
- Your child should wait 6 months after transplant to go to the dentist.
- Your child should see a dentist every 6 months. They may need antibiotics before dental surgery or if they have a history of heart disease.

Ear and body piercings and tattoos

Your child should not get any ear or body piercings or tattoos until they talk with the transplant doctor. This is not something the treatment team would advise for the first year after transplant.

School and daycare

Talk with your child's transplant doctor about when your child will be ready to return to school, preschool or daycare. Most often children return to school 6 to 8 weeks after transplant. The team can help you with any information the school needs. The goal is for all transplant children to go to school. This helps your child maintain their developmental milestones.

Children's has a hospital school program to help your child get their school work done. The hospital school teacher, transplant coordinator or social worker can help you with plans for your child's return to school. This may include letters, guidelines and options to help explain why your child may:

- Need to return to school part-time.
- Not be able to get certain vaccines.
- Have limits on contact activities.
- Need school options for home when they are sick or unable to attend school full-time.

Travel tips

You and your family may want to travel or take a vacation as your child starts to feel better. Please call your transplant team before travelling.

- Take your child's medicines with you in your purse or carry-on bags if you are flying. This is helpful in case your checked luggage gets lost in flight.
- Bring extra medicine in case of travel delays.
- Carry an up-to-date list of all of your child's medicine in case of an emergency.
- Your child should wear a medic alert bracelet and carry an identification (ID) card. Include the phone number of the transplant team.
- Talk with the transplant coordinator before your child goes to an amusement park. Some rides, such as roller coasters, are not advised for transplant patients.

After hours and urgent calls

In case of an urgent concern or emergency, call 911 or go to the nearest emergency department <u>right away</u>.

For urgent needs after hours (weekdays 5 p.m. to 7 a.m., weekends and holidays):

1. Call 404-785-KIDS (5437).
2. Press ”0” and ask for the kidney transplant nurse practitioner on call.

Call **<u>right away</u>** if your child:

- Has a fever of 101.5°F or higher.
- Has pain over the new kidney.
- Has redness, swelling, warmth, tenderness, or yellow drainage at the surgery wound.
- Has pain when urinating.
- Has decreased, bad smelling or dark urine.
- Has nausea, vomiting or diarrhea for more than 24 hours.

- Is unable to stay hydrated.
- Is not able to take or medicines or is vomiting them.
- Has a new rash.
- Has stomach pain.
- Is exposed to chickenpox or shingles.
- Has weight gain or swelling.
- Has cold hands or feet.
- Is admitted to another hospital.
  - If a doctor at another hospital wants to talk with our team, they can call 404-785-DOCS (3627) and ask to talk with the nephrology provider on call.

Medicines

Your child will take many medicines after their transplant. These medicines are very important. They will help prevent rejection of the new kidney. The medicines help keep your child healthy after transplant. Give your child all of their medicines as your doctor orders. Your child's doctor may change or stop some of the medicines when your child does not need them.

Skipped or missed doses

- Call the transplant coordinator
  - If your child vomits within 30 minutes after you give them their medicine.
  - If your child gets the wrong dose of medicine accidentally.
  - If you are unable to get the medicine.
- Skipping or missing doses increases the chance of kidney transplant rejection.
- This can cause the transplanted kidney to stop working well.
- Do not double the next dose the next time your child take it.
- Call your transplant team for help on what to do.

Medicines your child may take

Name of medicine	**What does the medicine do?**
Immunosuppressants: Tacrolimus, cyclosporine, prednisone, mycophenolate mofetil, azathioprine, sirolimus	Helps prevent rejection

Medicines your child may take

Name of medicine	What does the medicine do?
Blood pressure medicines (antihypertensives): Amlodipine, nifedipine	Helps lower blood pressure
Antivirals: Acyclovir, valganciclovir	Helps prevent or treat viruses
Antibiotics: Sulfamethoxazole/trimethoprim	Helps prevent or treat infections from bacteria
Antipyretics: Acetaminophen	Helps lower fevers

Medicine tips

- Ask your child's doctor or pharmacist for the best time to take each medicine.
- Ask your child's doctor or pharmacist if the medicines can be crushed or opened.
- Some medicine can be crushed and put in a small amount of food or drink. Use a small amount in case your child does not want to finish the mixture.
- Some medicine can be crushed and put in a gel cap for older children who can swallow a capsule.
- Ask the transplant coordinator before you give your child any medicine for coughs or colds. You can also find information about over the counter medicines in the handbook you will receive after your child’s transplant.
- Call the transplant coordinator if your child’s pediatrician or another doctor starts any medicine. The transplant team keeps a complete record of all your child's medicine and illnesses.
- Ask other healthcare teams to call your child’s transplant team if you take your child to a local doctor, urgent care or emergency department. This helps the local healthcare team provide the best care for your child’s situation.
- Do not give your child any herbal medicine, teas or nutritional supplements without checking with the transplant team first.
- Please call the transplant clinic if you have any questions about medicines or treatments.

Refills

- Call your pharmacy to refill your prescriptions 1 to 2 weeks before it runs out. This gives the pharmacy time to order medicine if needed.
- Check the bottle for the correct dose and strength each time you pick up medicine. The number of tablets or volume of medicine may change if the prescription is filled with a different strength tablet or a more concentrated liquid. Call the care team if you have questions about how much medicine your child should take.

- Your child needs blood tests checked often after the transplant. Their medicine may be changed based on blood test results. The transplant coordinator will contact you to change your child’s dose.
- Some medicines need approval from insurance before they are refilled. This is called a prior authorization. This process can take several days.

Helping your child cope

A transplant changes the life of your child and family. Many parents ask:

- What does my child know or understand about their transplant?
- How will my child feel about treatment?
- How can I support my child?

Your child's personality, age, support system and treatment will affect how they cope with their transplant. It is normal for behaviors to change when there is stress. Your child may become more dependent on adults and act younger than their age. Your child may not know how to handle their feelings.

You know your child best. Work with the care team to find new ways to help your child cope. Child life specialists can also help.

Guidelines to support your child

Babies (birth to 12 months)

Your child expects you to meet their needs. They do not understand kidney transplants. A baby will:

- Rely on you for food, comfort, play and care.
- Learn about their world through senses such as smells, colors and tastes.
- Develop trust in familiar people and things.
- Respond to new people and environments.

Common issues and fears	**How you can support your baby**
Separation from their parents	• Be with your baby as much as possible. • Leave something of yours when you go such as a picture or shirt. • Rock or hold your baby. Keep familiar blankets and toys in the room.
Fear of strangers	• Have the same people take care of your child. • Limit the number of people and voices in the room.
Development	• Allow your baby to explore toys with their hands and mouth. This is normal development. Be sure toys are clean and do not have small pieces they could choke on. • Use gentle touch and massage to comfort them. • Play games with your baby like you would at home.
Sense of safety	• Keep your baby's crib as a safe place. Ask if staff can use the treatment room for painful procedures. • Make sure your baby is awake before a painful procedure. • Continue or develop familiar feeding, bedtime and bathing routines.

Guidelines to support your child

Toddlers (12 months to 3 years)

Children begin to do more on their own as toddlers.

- Your child may say no and want to do things on their own.
- Let them do things that are safe for them to do.
- Their actions may reflect their feelings.
- Help them understand how their body works.
- Explain the transplant in their words.
- Toddlers think they make things happen. This creates the wrong idea about how they got sick.

Common issues and fears	**How you can support your toddler**
Separation from their parents and fear of strangers	• Be with your toddler as much as possible. • Have the same people care for your child. • Leave security things such as a blanket or stuffed animal. • Tell your child where you are going and when you will be back. • Leave something of yours when you go such as a picture or shirt.
Loss of control	• Allow your child to make choices when it is appropriate. • Give your child a job to do. • Allow them to play and choose the game or activity.
Loss of normal routine	• Keep normal eating, sleeping and bathing routines as much as possible • Let them play with their favorite toys.
Behavior changes	• Give them safe ways to express anger and other feelings such as painting or building blocks. • Tell your child it is OK to feel mad or sad. • Spend time with them and support them. • Set limits with your child and give discipline when needed. Boundaries and limits help them feel safe. • Praise them whenever possible.
Fear of treatment	• Tell your child that they did not do anything wrong. • Keep security things nearby such as a blanket, pacifier or stuffed animal. • Use simple words, pictures or books to tell them what is going to happen. • Tell them what will happen just before the treatment or procedure.

Guidelines to support your child

Preschoolers (3 years to 5 years)

Preschoolers like to do things for themselves. They may:

- Have more words to say what they think and feel.
- Use play to express themselves.
- Think the hospital is punishment for something they did wrong.
- Get confused by adult words and make up reasons for what happens.

Common issues and fears	**How you can support your preschooler**
Fear of treatment	• Use simple words, pictures or books to tell them what will happen. • Tell your child what will happen before treatment. • Let your child play with doctor kits and safe medical supplies.
Loss of control	• Allow your child to make choices when it is appropriate. • Give them a job to do.
Loss of normal routine or behavior changes	• Praise your child for doing things for themselves. • Give them time to adjust to change. • Use play to help them share their feelings.

Guidelines to support your child

School age children (6 years to 12 years)

School age children like to do things themselves.

- Your child enjoys school because it helps them learn new things.
- Friends are very important.
- School age children understand cause and effect. Your child has a better sense of time.
- Your child may have more words to describe their body, thoughts and feelings.
- Your child understands how their body works. They may not understand medical words.

Common issues and fears	**How you can support your school age child**
Loss of control	• Allow them to make choices when appropriate. • Give your child a job to do. • Let them practice new things. • Let them go to school or do schoolwork. • Provide games and activities.
Being away from friends and school	• Schedule friends to visit at the hospital. • Write letters to friends and family with your child.
Fear of harm to body and fear of unknown	• Use simple words, pictures or books to tell your child what will happen. • Tell them what will happen a few days before a treatment or procedure. • Let your child play with safe medical supplies.

Guidelines to support your child

Teens (13 years to 18 years)

Teens see themselves as individuals and want to be independent.

- Friends and peers are important.
- Your teen wants to be like their friends and cares about what others think of them.
- Illness and treatment cause teens to be different.
- Teens can see things from many points of view.

Common issues and fears	**How you can support your teen**
Loss of control or independence	• Allow your teen to make choices when appropriate. • Let them be active in school and social activities. • Involve them in the treatment plans and discussions. • Have them do their own self-care as much as possible.
Body image or self-esteem	• Give your teen chances to talk about physical and emotional changes. • Talk with them about their feelings. • Talk with them about things they are doing well. • Allow your teen to do things that make them feel good about themselves.
Loss of privacy	• Respect their need to do things by themselves. • Knock before entering their room. • Offer them alone time.
Separation from friends	• Provide time with friends. • Allow friends to visit and call.
Concern for the future	• Answer their questions openly and honestly. • Help your teen plan for the future. • Allow your teen to do their normal activities.
Behavior changes	• Give your teen safe ways to express feelings, especially anger. • Tell your teen that their feelings are normal.

Talking with your child about a transplant

Many parents want to protect their child by not telling them things that could be scary. Your child is more afraid when they do not know what is happening. Talking with your child can:

- Build trust in you and hospital staff.
- Help them know what to expect.
- Correct false ideas about transplants.
- Help them cooperate during treatment.
- Help give them a sense of control.
- Help them learn how to get through hard situations.

It may be hard to tell your child about the transplant. Children know when something is wrong. They may feel lonely and separated from family and friends.

- Think about your child's age when choosing words to explain the transplant. Your child life specialist can help you find ways to explain tests and treatments.
- Children learn from doing, seeing and hearing things many times. You may need to explain the transplant again.

How to talk with your child about a transplant

The items below may help you talk with your child and answer their questions. Be sure to tell the truth when answering questions.

- A transplant is no one's fault. Many children believe a transplant is caused by something they thought, said or did . Explain what your child thinks, says and does will not cause their transplant. It is no one's fault.
- A transplant is not contagious. Your child did not catch the need for a transplant from someone else.
- Surgery is when a doctor takes out all or part of the kidney and replaces it with a donor kidney. Your child will be given special medicine (anesthesia) that puts them in a deep sleep so they cannot see, hear or feel anything, not even pain.
- Tell your child how healthy bodies work. Avoid using words like bad and good; instead use sick and healthy.
- Talk with your child about their feelings. Let them know that any feeling is normal. Children feel angry, guilty, sad, lonely, scared and sometimes, even happy. Be honest with your child about your feelings.

Disciplining your child

From the time you find out that your child needs a transplant, your family's routine and the way your family reacts to each other may change.

- Your child may become the center of attention and receive gifts. Although they may feel sick, gifts and attention are fun. It is easy for them to feel special and want special treatment to last.
- Once your child feels better, discipline problems may happen. This happens because special attention stops as normal routines begin again.

Your child's illness can also slow discipline. Pain and side effects of treatment can put any child in a bad mood. Your child may act more helpless when they feel sick. This can make it hard to know what to expect from your child. Medicines may also cause them to feel bad.

You may feel helpless when you see your child suffer. You may want to help your child by giving special rewards. These feelings are normal. Children need adults to provide rules and limits. Structure helps children feel safe.

If you do not expect your child to follow the same rules that are in place for your other children, you can:
- Set clear limits that your child can understand.
- Know that the limits may need to change when your child does not feel well.
- Praise them and reward good behavior.

Notes

Caring for the Whole Family

Coping with your feelings

Your family life will be different before, during and after your child's transplant. There will be many new stresses. Every family is different, but many families have said that they feel fear, anger, guilt and depression. Share these feelings. Your child's transplant team is here to listen to and help you and your family.

Fear

The time of diagnosis is often the hardest. The fear of the unknown may be overwhelming. This may be the first time your child has been in the hospital. This can be stressful for you and your child. You may also have fears about treatment, costs or how to help your child cope with a transplant. Talk about these fears and get them out in the open.

Anger

You may feel very angry. Feeling angry is normal. Find a way to express your anger. Take a walk or talk with someone.

Guilt

Parents may feel guilty that they did not know their child was sick. Others wonder if they caused their child's kidney failure. Family members may feel guilty that they are healthy. Young children often have "magical thinking" and may feel that they caused the illness. Let your family know they did not cause your child's kidney failure.

Depression or grief

Depression is used to describe a range of emotions and behaviors. Feeling sad is a normal reaction. You may have changes in family routines. You may feel alone. These changes can cause feelings of depression:

- Crying
- Eating more or less
- Lack of interest
- Poor sleep or sleeping too much
- Low energy
- Tightness in the chest
- Headaches

All these feelings are normal. You are not alone. Most families can work through these feelings with the support of family, friends and your child's transplant team. They can regain coping skills needed to meet care demands.

Ideas to help you cope with your child's illness:

- Find private time to talk with your partner, or a close friend or family member. Try to talk about things other than your sick child.
- Do not talk about your child in front of them unless they are included.
- Find ways to reduce stress. You know what works best for you. You may try exercise, reading, massage or shopping.
- Take turns with your partner or another support person who can stay with your child at the hospital or go to clinic visits. This helps everyone be involved with your child’s care. It also helps parents feel closer if they are both involved in their child’s care.
- Ask your child’s transplant team for help and support.
- Talk with other parents of children with transplants.
- Talk with a spiritual leader.
- Go to a support group.

Sometimes feelings are overwhelming. This can be especially true when there are other stresses like:

- Death of a loved one.
- Loss of a job.
- Marriage problems.
- Divorce.
- Mental health problems.
- Substance abuse.

You may need mental health counseling or medicine. Share your feelings with the transplant team so you can get the help you need.

Impact on marriage or relationship

An illness can turn a family’s life upside down. You may feel emotionally and physically tired. Often, parents keep working and try to keep a normal home routine. Many parents feel the strain on their marriage or relationship. They feel angry and upset about what has happened to their child. They often say that they do not have time for their partners.

Ideas that may help prevent marriage or relationship problems

- **Knowing coping styles:** It is important to know how your partner deals with stress. Each person shows feelings in different ways. Some people pull away, cry or get angry. Some people try to learn as much as possible. Be aware of how your partner deals with their feelings.
- **Talking with each other:** The key to a good relationship is talking. It is important to talk about feelings, fears and information during times of stress. Silence can make you feel distant from your partner. Sharing feelings and facts can help you know what your partner is thinking. Sharing and talking may help with making decisions.
- **Changing roles when needed:** The stress of an illness can change the roles of family members. One parent who took care of the home may now be too busy. The other parent may have made most decisions in the past. If one parent is with the sick child more than the other, they may now make many decisions. Changing roles can cause stress in a relationship. Some ways parents can work together include:
    - Show your partner kindness and understanding. Do not blame or criticize.
    - Make your sick child a priority. Both parents need to learn about the diagnosis and treatment.
    - Continue to share in caring for and loving your other children.
    - Share your feelings of anger, sadness and hope with each other.
    - Accept the help of family, friends and neighbors.
    - Be loyal to each other if family members criticize or blame one of you for decisions that are made.

Divorced parents

Divorce is hard on most families. Problems may get worse when a child is sick. Sometimes children may try to use their illness to bring together divorced parents. Other times, they may try to play 1 parent against the other to gain some feeling of control. Try not to let the stress of divorce affect your child’s care. Though the marriage has ended, the job of parenting continues. Good communication can help you both provide the best care for your child.

Tips to help avoid problems

- Talk with the transplant team if your child is having behavior problems.
- Provide copies of divorce decrees, custody agreements and visitation rights for your child's medical record.
- Meet together with your child's transplant team to help avoid confusion about the plan of care.
- Ask for 2 copies of all teaching materials so both parents have the same information.

Siblings

Brothers and sisters have many feelings. They may have some of the same needs as their sick brother or sister. They may feel upset, scared and unsure of the future. They may worry about death. Children of any age will see a change in their family life.

Siblings may:

- Feel sad and worried about their sick brother or sister. They may cry easily.
- Feel angry or jealous. Their parents may spend all of their time with or talking about the sick child. Friends and family send gifts and money.
- Have trouble sleeping, physical complaints or problems in school.
- Feel they are being left out of what is going on and the latest updates.

Some tips to help siblings include:

- Try to spend time alone with your other children, doing things that they like.
- Let them know that you love them and they are special.
- Talk with them about the transplant in a way they can understand. Help them understand their brother or sister's illness and treatment. Let them know that the illness is not contagious and they did not cause their brother or sister to get sick. Ask your child life specialist for helpful tips.
- Take them to the hospital. Help them feel involved in the care of their sibling. This may help decrease fears and help them feel closer to their brother or sister.
- Ask a loving friend or family member to stay in your home. Try to avoid sending your children somewhere else to stay.
- Ask your children to help with chores at home. Including your other children makes them feel needed and helps you too.
- Talk with their teachers. Teachers can support your children and let you know if there are any problems at school.
- Ask for help from the transplant team. Talk with a child life specialist, social worker or child psychologist if needed.

Grandparents

Grandparents have many responses when they hear their grandchild has kidney disease. They may feel:

- Shock and disbelief.
- Guilt for living a long life.
- Blame. They may think they passed kidney disease through the family.
- Sadness for their grandchild and also their son or daughter.

Include grandparents in meetings with the care team. This can help them understand the treatment plan.

Grandparents can be a great help to you. If they are in good health, they can:

- Relieve you in the hospital or help at home.
- Give your other children attention, comfort and love.
- Help update others so you do not have to spend as much time on the phone.

Programs and events

The Children's Kidney Transplant team knows it is important to treat your child’s whole body and not just their kidneys. We will also focus on your child’s quality of life. There are programs that support social and emotional needs of your child.

Teen Program

- This is for teens, ages 14 to 20 years old.
- There are activities that provide time for teens to interact with peers in a fun and relaxing environment.

Parent Support Groups

- These groups give parents time to gain support from each other and members of the transplant team.
- They include teaching materials and guest speakers.

Camp Independence

- This week-long summer camp is for children and teens, ages 8 to 18 years old, who have been diagnosed with kidney disease, are on dialysis, or have an organ transplant. It is at Camp Twin Lakes in Rutledge, Georgia.
- Campers do team-building activities, build friendships and make memories.

Family Camp

- This is a weekend getaway at Camp Twin Lakes in Rutledge, Georgia. It is scheduled in the fall.
- Families join discussion groups. Families are grouped with families that have the same organ transplant.
- Activities are family-friendly and include: canoeing, swimming, square dancing, music, entertainment, mountain biking, fishing, archery, wall climbing, and arts and crafts.

Call the transplant program coordinator at 404-785-6735 for more information about any of these programs and events.

Notes

Resources

Financial resources

The cost of a transplant is stressful for most families. The Children's Kidney Transplant Team is here to help you. A financial counselor can help you learn about your insurance benefits and payment options. A transplant financial counselor can also:

- Contact your insurance company and find out about your child's benefits.
- Get approval for the eval and transplant.
- Meet with you to review your insurance benefits.
- Answer benefits questions.
- Help assess your financial needs.
- Talk with you about a long-term financial plan for your child's healthcare needs.
- Help get your child into a case management program if your insurance company has this service.
- Help you learn about government programs.
- Teach you about hospital and doctor billing practices.

Financial counselors at Children's can also help you with:

- Financial aid packets for the Charitable Hospitable Fund. Aid is based on federal poverty guidelines and other financial guidelines.
- Questions about Medicare, Medicaid and Georgia's Peach Care Program.
- Which government assistance your child can get. The counselor can help you fill out forms and paperwork.
  - There may be a lot of paperwork to complete. Please fill out all of the forms as soon as possible.
  - This process may take weeks or months to complete.

Please tell the clinic if your insurance changes. Medical bills can be confusing. Please tell the financial counselor if you have any financial trouble with your child's medical costs.

Insurance companies

It is important that you know about your insurance policy. Helpful hints:

- Ask someone in your company's human resources department to explain your benefits.
- If your doctor or hospital is not in-network, contact your insurance company. You should ask about your co-insurance rates and out-of-pocket costs.

- Your insurance company may ask you to give them a letter of medical necessity so your child can be treated at Children's. Please call the hospital financial counselor to help you get this from your transplant surgeon.
- Bring a copy of your insurance benefits with your deductible and co-payment amounts each time you visit the hospital.
- Tell the transplant clinic **right away** if there are changes in your address, phone number or insurance.

Helpful hints in the billing process

You will receive bills from several places. Hospital bills are called technical or facility fees. Doctor bills are called professional fees.

- Call the phone numbers listed on your billing statement if you have a question about a bill.
- Keep a folder for hospital bills and insurance forms. This will help you to track payments, denials and requests for more information.
- You may need to call your insurance company to ask questions about the transplant. Ask to talk with someone who can answer transplant benefits questions.
- Below is a list of offices that will send you bills:
    - Children's Healthcare of Atlanta for all services received at any Children's hospital or clinic location.
    - Children's Physician Group for any doctor services.
    - Other staff or doctors who care for your child.
- Read bills closely. You may get statements that are still pending payment. These statements are for your records and are not bills. Put them in your bills folder.

Medicaid

Medicaid is a state medical assistance program that covers most costs for hospital stays, clinic visits and medicines. There are some procedures or exams not covered by Medicaid, and some must be pre-approved. Some Medicaid programs are based on family income and others are based on medical needs. You may be able to get coverage for medical services that happen 3 months before Medicaid is approved.

Medicaid may also pay for:

- Doctor and hospital bills.
- Up to 5 prescriptions each month.
- Physical, occupational and speech therapy.
- Adaptive equipment.

Children's has a financial counseling office on the 1st floor at Arthur M. Blank Hospital. You can also visit medicaid.georgia.gov for more information about Medicaid.

Medicare

Medicare is a health insurance program:

- Typically for people 65 years and older.
- For some people younger than 65 years of age with disabilities, such as end stage renal disease or kidney transplant, who may receive Medicare benefits.

Medicare has 2 parts: part A and part B.

Part A (hospital insurance) helps pay for:

- Inpatient hospital care.
- Some skilled nursing facility care.
- Some home health care.
- Hospice care.

Most people get Part A as soon as they turn 65 or have a qualifying disability. They do not have to pay a monthly fee for Part A because they or a spouse paid Medicare taxes while they were working.

Part B (medical insurance) helps pay for:

- Doctor's services.
- Outpatient hospital care.
- Other medical services that Part A does not cover like some home health care. Part B helps pay for these covered services and supplies when they are medically necessary.

You pay the Medicare Part B premium each month. Premium rates can change each year.

You can visit these websites for more information on Medicare benefits for children with end stage renal disease or kidney transplant:

- medicare.gov/coverage/organ-transplants
- medicare.gov/basics/children-and-end-stage-renal-disease

Resources at Children's

Sleep rooms

- All sleep rooms accommodate 2 people.
- Only the parent or legal guardian can use sleep rooms. Any exceptions must be approved by social work.

- Only 2 family members may sleep in a room at one time. Children younger than 18 years of age are not allowed in sleep rooms.
- Sleep rooms should be used only for sleeping. Meetings and visitors are not allowed.
- Cleaning takes place each day between 11 a.m. and 4 p.m. Bed linens and towels are provided.
- Families must be out of sleep rooms by 9 a.m. You must remove all of your personal items.
- To request a sleep room, you may scan the QR code available on your hospital patient room TV or visit the sleep room check in desk on the 2nd floor near the coffee shop.

Showers and restrooms

- Every hospital patient room has a private shower and restroom. Showers and restrooms are also available near the sleep rooms for anyone assigned use of a room.
- Toiletries, such as soap, razors and shaving cream, are donated. If you need toiletries, talk with a service ambassador, the transplant social worker or your child's nurse.

Washers and dryers

- Washers and dryers are available on every patient floor in the family lounge.
- Laundry can be done 24 hours a day.

Exercise

- Children's has outdoor walking trails and gardens.

Family lounge

- Vending machines
- Ice machine
- Family refrigerator

Family library

- Open every day from 10 a.m. to 4 p.m.
- The family library has:
  - Consumer health collection.
  - Recreational books and movies for all ages.
  - One hour digital camera checkout.
  - Laptop checkout for long-term patients (laptops are locked in the patient's room).
  - Four (4) computers for adults, two (2) for children and two (2) for teens and young adults.

    - Access to the Internet for e-mail and medical information searches.
- There are also library staff to assist you.

Business center

- Open every day from 8 a.m. to 10 p.m.
- The business center has computers and printers with Internet access.

Patient activities room

- Open 24 hours a day. **A caregiver older than 18 years of age must stay with children at all times.**
- A space for patient activities is available on every patient floor. Our activity rooms have toys, games and crafts for all ages. These areas are meant to be “safe” spaces where no medical procedures happen.
- If your child is on isolation precautions or unable to leave their room, talk with your nurse or child life specialist about activities they can bring to the room.

Contact a Family Experience Liaison or your child's nurse for more information.

Area lodging

The social work office keeps a list of hotels that offer reduced rates to families. The transplant social worker can assist you in making reservations. The social work office is on the 5th floor of the South tower at Arthur M. Blank Hospital.

Mason Guest House

1555 Shoup Court
Decatur, Georgia 30033
404-712-5110
emoryhealthcare.org/services/transplant/mason-house

The Mason House offers low-cost lodging for transplant candidates, recipients and their families from Atlanta's 4 transplant hospitals. Please call 24 hours in advance to check availability. For families who qualify, assistance with cost of lodging is available through the Georgia Transplant Foundation.

Ronald McDonald House

795 Gatewood Road
Atlanta, Georgia 30329
404-315-1133
armhc.org

Ronald McDonald House at Arthur M. Blank Hospital will open in 2025.

The Ronald McDonald House provides temporary lodging for families of hospitalized children who live outside of Atlanta. An adult family member or guardian must always be present with children. New guests must have a referral from a hospital social worker.

Other transplant resources

There are many family resources that can help with costs. Each one has its own rules. Make sure to pick one that suits your needs. For example:

- Some require families to count money raised as income. That is not the case with all of them.
- Some match funds raised at a rate set by the organization.
- The most success with fundraising is most often done before a transplant.

Some of the more common resources are listed below.

Children's Organ Transplant Association (COTA)

2501 COTA Drive
Bloomington, Indiana 47403
800-366-2682
cota.org

National nonprofit agency that helps organize community resources in fundraising on behalf of patients who need or have had organ transplants.

Georgia Transplant Foundation Inc.

6600 Peachtree Dunwoody Road, 600 Embassy Row, Suite 250
Atlanta, Georgia 30328
770-457-3796 or 866-428-9411
gatransplant.org

Private, nonprofit organization that financially assists Georgia residents who are transplant candidates or recipients.

National Kidney Foundation

Nonprofit organization that provides education, support and advocacy for people with kidney disease and their families.

kidney.org

United Network for Organ Sharing (UNOS)

P.O. Box 2484
Richmond, Virginia 23218
888-894-6361
unos.org

The United Network for Organ Sharing (UNOS) is the national agency that oversees organ transplant.

Websites

Kidney related sites

- National Kidney Foundation: kidney.org
- National Institute of Diabetes and Digestive and Kidney Diseases: niddk.nih.gov
- American Urological Association: urologyhealth.org
- National Transplant Assistance Fund: transplantfund.org
- Lifelink: lifelinkfoundation.org

Local Georgia resources

- Children's Healthcare of Atlanta: choa.org
- Atlanta Chamber of Commerce: metroatlantachamber.com
- MapQuest: mapquest.com
- Georgia Department of Human Services: dhr.georgia.gov
- Peach Care for Kids: dch.georgia.gov/peachcare-kids
- Medicare: medicare.gov
- Medicaid: medicaid.gov

Please be advised that the resources included in this handbook are solely for informational purposes and do not constitute a clinical referral, endorsement or recommendation.

Notes

Glossary

Absorption: The amount and time it takes for a medicine to get into the bloodstream.

Alport syndrome: A disease passed in families that affects the glomeruli (filtering units in the kidney).

Anemia: Not enough red blood cells in the body.

Anesthesiologist: A doctor who gives anesthesia medicines to put your child to sleep.

Antibiotic: Medicine used to fight infections from bacteria.

Antibody: A protein the body makes to fight things in the body, like germs.

Antigen: Something in the body that cause the immune system to make antibodies. Antibodies try to destroy the antigen. A transplanted organ is an antigen and the body makes antibodies to the organ.

Anesthetic: Medicine that reduces pain. Some of these are used to put people into a deep sleep for procedures or surgery.

Arteriogram: X-ray of the arteries or tubes that carry blood throughout the body. A dye is used to help the arteries show up on the X-ray.

Autoimmune disease: Condition where a person's immune system attacks the body like it is an antigen.

B cell: Type of white blood cell that helps the immune system make antibodies.

Bacteria: Germs that can cause infections.

Bioavailability: The amount of a medicine that the body can use. This tells doctors how much of the medicine gets to the organ.

Biopsy: A piece of organ removed from the body and tested for changes or disease.

BK virus: A virus that can cause kidney damage and rejection in a transplanted kidney.

Blood urea nitrogen (BUN): A blood test that measures the amount of urea in the blood. Urea is formed when protein breaks down in the body. It is carried in the blood to the kidneys and removed through the urine. BUN is high when the kidneys do not work well.

Creatinine: A waste made when the body uses muscle and energy. It is removed from the body by the kidneys. Creatinine levels are high when the kidneys do not work well.

Crossmatch blood test: A blood test done to check and match your child's blood for antibodies with a potential donor.

Cytomegalovirus (CMV): A common virus that affects most adults.

Deceased donor transplant: A kidney transplant that comes from a person who recently died.

Dialysis: Treatment for kidney failure that uses a machine to filter body fluid and waste. It does the work the kidneys cannot do.

Diuretic: A medicine that helps the kidneys make and remove more urine.

Dysplastic or cystic kidneys: Cysts that grow in the kidneys. Children are often born with them.

Edema: Extra fluid in body tissues.

Electrolyte: Minerals in your blood and other body fluids, such as sodium, potassium and chlorine.

Enzyme: Proteins the body makes to change a substance from one form to another.

Epstein-Barr virus (EBV): Common virus that affects most adults.

Glomeruli: Tiny blood vessels in the kidneys that filter waste from the blood.

Glomerulonephritis: A disease that damages the part of the kidney that filters blood.

Goodpasture's syndrome: An autoimmune disease that affects the lungs and kidneys.

Hematocrit: The amount of red blood cells in the blood. It can be caused by anemia or blood loss.

Hemodialysis: Type of dialysis that uses a man-made filter to remove wastes and return electrolytes to the body.

Hemoglobin: The part of the red blood cell that carries oxygen. Hemoglobin carries oxygen through the body.

Hemolytic uremic syndrome (HUS): Condition that damages the kidney's blood and blood vessels.

HLA system: Antigens on the white blood cells (leukocytes) and tissues.

Hypertension: High blood pressure.

Immune response: Reaction from the immune system to a foreign material like a transplanted organ.

Immune system: The system that protects the body from harmful substances like germs and cancer cells.

Immunity: The body's ability to fight a disease or harmful substance.

Immunosuppressants: Medicines that help prevent rejection of a transplanted organ.

I.V. or intravenous: A way to give medicines or fluids into a vein.

I.V. catheter: A small hollow tube put into a vein. It is used to give medicines or fluids. It is put in with a needle and then the needle is removed.

Kidney: An organ that is on both sides of the spine, just above the waist. They remove waste and maintain fluid balance in the body. They make urine.

Lifelink Foundation: A nonprofit organization that helps receive organs and tissues for transplants.

Living donor transplant: A healthy kidney from a living person that is given to someone that needs a new kidney.

Lupus erythematosus: A disease that can damage the kidney and other organs. The cause of the disease is unknown.

Malignant tumor: A tumor made of cancer cells that can spread and destroy tissues.

Match: The ability for an organ from one person to be given to another person. The better the match the greater the chance for success with a transplant.

Nephrologist: A kidney doctor that takes care of your child before and after transplant.

Nephropathy: Kidney problem caused when the filtering system of the kidney is damaged.

Nephrotic syndrome: A condition that causes damage to the filtering units in the kidneys. They cannot filter fluids and waste blood from them.

Neutrophil: A type of white blood cell that fights bacteria.

Noncompliance: When patients and families do not follow doctors' instructions. This often means a child does not take their medicine or come to clinic visits.

Orally: By mouth or to be swallowed.

Organ procurement organization (OPO): This is the organization that matches donors and recipients. It picks up, preserves and transports the organs. OPO is part of the United Network for Organ Sharing (UNOS).

Peak levels: When a medicine level is highest in the blood.

Pediatric intensive care unit (PICU): The unit in the hospital that cares for children who need very close medical support.

Percent antibodies: The amount of antibodies in the blood. Antibodies are matched between the donor and recipient for an organ match.

Peritoneal dialysis: A type of dialysis that uses a natural filter to remove waste and return electrolytes to the body.

Potassium: A mineral in the body. It helps the nerves and muscles work. Extra potassium leaves the body in the urine. Potassium levels are high when the kidneys do not work well.

Prednisone: A steroid medicine that most transplant patients take to help prevent rejection.

Prophylactic medicine: Medicines that helps prevent disease.

Rejection: An immune response that fights the transplanted organ. The transplant can fail if rejection is not treated.

Renal: It means kidney.

Renal function tests: Tests that check your child's kidney function.

Renal ultrasound: Test that takes pictures of organs in the abdomen (belly).

Re-transplantation: A second transplant. Some patients need another transplant if their transplant fails.

Sclerosis: When tissue in the body gets hard. It can be caused by inflammation or disease.

Sensitized: When the body already has an immune response against an antigen. It happens when the body has made antibodies to something it has been exposed to before.

Shingles: A herpes virus infection (herpes zoster) that causes a rash and pain along nerves in the body.

Sodium: A mineral needed for the body to work. It is the main salt in blood.

Status: The level of medical need for patients waiting for a kidney transplant.

Survival rates: The number of patients or transplanted organs that are alive or working after transplant. Survival rates are often given at 1, 3 and 5 years.

T cells: A type of white blood cell that is part of the immune system. T cells help the body fight disease and germs. They can also react against cells in a transplanted organ.

Tissue typing: Blood tests to check for human leukocyte antigens (HLA). It is also called genetic matching. Tissue typing is done for donors and recipients before a transplant.

Trough levels: When the medicine level is lowest in the blood.

United Network for Organ Sharing (UNOS): An organization that teaches people in the community about organ donation. It supports donors and recipients. It help recipients through education, technology and policy development.

Virus: A very small germ that causes infection.

Waiting list: The list of people who are waiting for an organ. Patients are added to the national UNOS waiting list after evaluation. Lists are based on area of the country and organ type. The UNOS computer makes a list of possible recipients based tissue typing, organ size and medical need.

White blood cells: Cells in the blood that fight infection. They are part of the immune system.

Health-related information changes frequently, and therefore information contained in this handbook may be outdated, incomplete or incorrect. This handbook may contain printed material that has been updated by Children's Healthcare of Atlanta. Please talk with a member of your child's healthcare team if you need an up-to-date copy.

Children's Healthcare of Atlanta has not reviewed all of the sites listed as resources and does not make any representations regarding their content or accuracy. Children's Healthcare of Atlanta does not recommend or endorse any particular products, services or the content or use of any third-party websites, or make any determination that such products, services or websites are necessary or appropriate for you or for the use in rendering care to patients. Children's Healthcare of Atlanta is not responsible for the content of any of the above-referenced sites or any sites linked to these sites. Use of the links provided on this or other sites is at your sole risk.

Call 911 or go to the nearest emergency department right away in case of an urgent concern or emergency.

Children's Healthcare of Atlanta Nondiscrimination Statement

Discrimination is against the law. Children's complies with applicable federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability or sex. Children's does not exclude people or treat them differently because of race, color, national origin, age, disability or sex.

Children's Healthcare of Atlanta:

Provides people with disabilities reasonable modifications and free appropriate auxiliary aids and services to communicate effectively with us, such as:

- Qualified sign language interpreters.
- Written information in other formats (large print, audio, accessible electronic formats).

Provides free language assistance services to people whose primary language is not English, including:

- Qualified interpreters.
- Information written in other languages.

If you need any of these services, contact Children's Civil Rights Coordinator at **404-785-4545**.

If you believe that Children's has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability or sex, you can file a grievance with:

Children's Civil Rights Coordinator
1575 Northeast Expressway NE
Atlanta, GA 30329
404-785-4545
section1557coordinator@choa.org

If you need help filing a grievance, Children's Civil Rights Coordinator is available to help you.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services Office for Civil Rights electronically through the Office for Civil Rights complaint portal, available at **ocrportal.hhs.gov/ocr/portal/lobby.jsf**, or by mail or phone at:

U.S. Department of Health and Human Services
200 Independence Ave. SW
Room 509F, HHH Building
Washington, DC 20201
800-368-1019
800-537-7697 (TDD)

Complaint forms are available at:
http://www.hhs.gov/ocr/office/file/index.html

This notice is available at **choa.org**.

Created in 2024

Language Assistance Services and Auxiliary Aid Services

English

ATTENTION: If you speak English, free language assistance services are available to you. Appropriate auxiliary aids and services to provide information in accessible formats are also available free of charge. Call 404-785-4545 or speak to your provider.

Spanish

ATENCIÓN: Si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. También están disponibles de forma gratuita ayuda y servicios auxiliares apropiados para proporcionar información en formatos accesibles. Llame al 404-785-4545 o hable con su proveedor.

Vietnamese

LƯU Ý: Nếu quý vị nói tiếng Việt, chúng tôi cung cấp miễn phí các dịch vụ hỗ trợ ngôn ngữ. Các dịch vụ và phương tiện hỗ trợ phù hợp để cung cấp thông tin theo các định dạng dễ sử dụng cũng được cung cấp miễn phí. Vui lòng gọi theo số 404-785-4545 hoặc trao đổi với người cung cấp dịch vụ của quý vị.

Korean

주의: 한국어를 사용하시는 경우 무료 언어 지원 서비스를 이용하실 수 있습니다. 이용 가능한 방식으로 정보를 제공하는 적절한 보조 기구 및 서비스도 무료로 제공됩니다. 404-785-4545 번으로 전화하거나 서비스 제공업체에 문의하십시오.

Chinese

注意：如果您说[中文]，我们将免费为您提供语言协助服务。我们还免费提供适当的辅助工具和服务，以无障碍格式提供信息。请致电 404-785-4545 或咨询您的服务提供商。

Gujarati

ધ્યાન આપો: જો તમે ગુજરાતી બોલતા હો તો મફત ભાષાકીય સહાયતા સેવાઓ તમારા માટે ઉપલબ્ધ છે. સુલભ ફૉર્મેટમાં માહિતી પૂરી પાડવા માટે યોગ્ય સહાયક સાધનો અને સેવાઓ પણ વિના મૂલ્યે ઉપલબ્ધ છે. 404-785-4545 પર કૉલ કરો અથવા તમારા પ્રદાતા સાથે વાત કરો.

Language Assistance Services and Auxiliary Aid Services

French

ATTENTION : Si vous parlez français, des services d'assistance linguistique gratuits sont à votre disposition. Des aides et des services auxiliaires appropriés pour fournir des informations dans des formats accessibles sont également disponibles gratuitement. Appelez le 404-785-4545 ou parlez à votre fournisseur de services.

Amharic

ማሳሰቢያ፡- አማርኛ የሚናገሩ ከሆነ፣ የቋንቋ ድጋፍ አገልግሎት በነፃ ይቀርብልዎታል። መረጃን በተደራሽ ቅርጸት ለማቅረብ ተገቢ የሆኑ ተጨማሪ እገዛዎች እና አገልግሎቶች እንዲሁ በነፃ ይገኛሉ። በስልክ ቁጥር 404-785-4545 ይደውሉ ወይም አገልግሎት አቅራቢዎን ያናግሩ።

Hindi

ध्यान दें: यदि आप हिंदी बोलते हैं, तो आपके लिए निःशुल्क भाषा सहायता सेवाएँ उपलब्ध हैं। सुलभ प्रारूपों में जानकारी प्रदान करने के लिए उपयुक्त सहायक साधन और सेवाएँ भी निःशुल्क उपलब्ध हैं। 404-785-4545 पर कॉल करें या अपने प्रदाता से बात करें।

Haitian

ATANSYON: Si'w pale Kreyòl, sèvis assistans lang ou disponib pou ou gratis. Èd ak sèvis oksilyè apwopriye pou bay enfòmasyon nan fòma aksesib yo disponib gratis tou. Rele nan 404-785-4545 oswa pale avèk founisè ou.

Russian

ВНИМАНИЕ: Если вы говорите на русском, вам предоставляются бесплатные услуги языковой поддержки. Также бесплатно предоставляются соответствующие вспомогательные средства и услуги по предоставлению информации в доступных форматах. Позвоните по телефону 404-785-4545 или обратитесь к своему поставщику услуг.

Arabic

تنبيه: إذا كنت تتحدث اللغة العربية، فستتوفر لك خدمات المساعدة اللغوية المجانية. كما تتوفر وسائل مساعدة وخدمات مناسبة لتوفير المعلومات بتنسيقات يمكن الوصول إليها مجانًا. اتصل على الرقم 404-785-4545 أو تحدث إلى مقدم الخدمة.

Language Assistance Services and Auxiliary Aid Services

Brazilian Portuguese

ATENÇÃO: Se você fala português do Brasil, serviços gratuitos de assistência linguística estão disponíveis para você. Auxílios e serviços auxiliares, apropriados para fornecer informações em formatos acessíveis, também estão disponíveis gratuitamente. Ligue para 404-785-4545 ou fale com o seu provedor.

Telugu

గమనించండి: మీరు తెలుగు మాట్లాడితే, మీకు ఉచిత భాషా సహాయ సేవలు అందుబాటులో ఉంటాయి. యాక్సెస్ చేయగల ఫార్మాట్‌లలో సమాచారాన్ని అందించడానికి తగిన సహాయక చర్యలు మరియు సేవలు కూడా ఉచితంగా అందుబాటులో ఉంటాయి. 404-785-4545 కి కాల్ చేయండి లేదా మీ ప్రొవైడర్‌తో మాట్లాడండి.

German

ACHTUNG: Sie haben Anspruch auf kostenlose Sprachdienste, wenn Sie Englisch sprechen können. Kostenlose Dienstleistungen und Hilfsmittel, die geeignet sind, Informationen in zugänglicher Form zu vermitteln, werden ebenfalls angeboten. Sprechen Sie mit Ihrem Anbieter oder rufen Sie die Nummer 404-785-4545 an.

Tamil

கவனிக்க: நீங்கள் ஆங்கிலம் பேசுபவராக இருப்பின், இலவச மொழி உதவி சேவைகள் உங்களுக்கு வழங்கப்படும். எளிதில் அணுகக்கூடிய வகையில் தகவல்களை வழங்குவதற்கான பொருத்தமான துணை உதவிகளும் சேவைகளும் இலவசமாகக் கிடைக்கின்றன. இந்த சேவையை பெற 404-785-4545 என்ற எண்ணிற்கு அழைக்கவும் அல்லது உங்கள் வழங்குநரிடம் கலந்துரையாடவும்.