

Welcome

Welcome to the Children's Healthcare of Atlanta Center for Transplantation. We offer full pre- and post-transplant outpatient services for kidney, heart and liver transplant patients in one central location. A bright, cheerful butterfly-themed décor creates a welcoming, warm and comfortable environment for children and families. Our focus is on our patients. We want to create a friendly, family-centered experience for you and your child. In addition to our medical areas, the Center includes:

- A parent lounge
- A family library
- A playroom
- A parent business center
- A family consult room

The Center for Transplantation is located on the sixth floor of Children's at Egleston.

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. Together, our team can give you the support you need during your child's treatment. At each admission and clinic visit, you will experience a nurturing, caring environment.

If you have any questions, please feel free to call us. We look forward to helping your child have a healthy future.

About the Handbook for Patients and Families

This handbook is meant to help you learn more about kidney transplants. It can help you explore the best options for your child. It also contains information about resources that can help you.

This handbook should NOT replace instruction given to you by your child's healthcare team. It is not meant to be medical advice or a complete resource for all information on this subject. Your child's doctor is the best source of information about what is right for your child's treatment. If you have any questions about this handbook, please ask the Kidney Transplant team.

Important Phone Numbers

Children's Transplant Center at Egleston:	800-605-6175
<hr/>	
The Kidney Transplant Team:*	404-785-1405
<hr/>	
Nights/Weekends/Holidays:**	404-785-6000
<hr/>	
Billing and Finance	404-785-6478
<hr/>	
Kidney Transplant Social Worker:	404-785-6047
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Clinic Appointments:	404-785-1400
<hr/>	
Family Library:	404-785-1611
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For more information about the Children's Kidney Transplant Program, visit our web site at choa.org/transplant or call the Transplant Information Line at 800-605-6175.

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

PLEASE NOTE:

*All transplant questions should be addressed by the Kidney Transplant team.

**This is the phone number for the hospital operator. If your call is after hours, ask the operator to 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 performs the transplant surgery.

Nephrologist: A medical doctor that takes care of patients with kidney disease before and after a transplant.

Anesthesiologist: A medical doctor that monitors your child during surgery. Your child will be given a special medicine (anesthesia) that allows him to be in a deep sleep so he cannot see, hear or feel anything, not even pain.

Physician Assistant and Nurse Practitioner: Clinical staff that assist your child's doctor in surgery. 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 arrange your child's care and treatment before and after a transplant.

Intensive Care Unit (ICU) and Patient Floor Nurses: Nurses that care for your child while he is in the Intensive Care Unit (ICU) and on the patient floor.

Respiratory Care or Respiratory Therapists: Clinical staff that help your child with his breathing. They give breathing treatments and monitor how your child breathes.

Registered Dietitians/Nutritionists: Clinical staff that help your child with food and nutritional needs.

Transplant Pharmacist: A pharmacist who has special training with transplant medicines. This person arranges for your child's medicines, teaches you what you need to know about them and helps with research studies.

Psychologist: A medical professional 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 help you, your child and your family learn about why your child is in the hospital. They can answer your questions, show you medical supplies and teach you, your child, and his siblings about the hospital stay.

Social Workers: Healthcare professionals that help provide guidance, counseling and coping skills for you and your family. Social workers 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 exercises to make him stronger before and after transplant. Physical therapists can also teach you what you can do at home to help your child regain strength.

Chaplains: Chaplains help meet your family's spiritual needs. A chaplain can work with your pastor or religious leader to provide needed spiritual support. Hospital chaplains also conduct interfaith services in the hospital chapel at Egleston.

School Program Teachers: Hospital staff, who are certified teachers, that help your child keep up with his schoolwork so the transition between hospital, home and school will be easier. The schoolroom is located at Egleston.

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

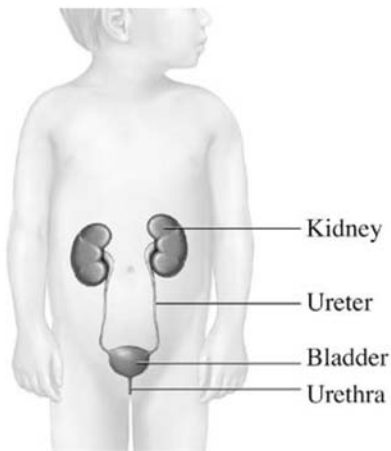
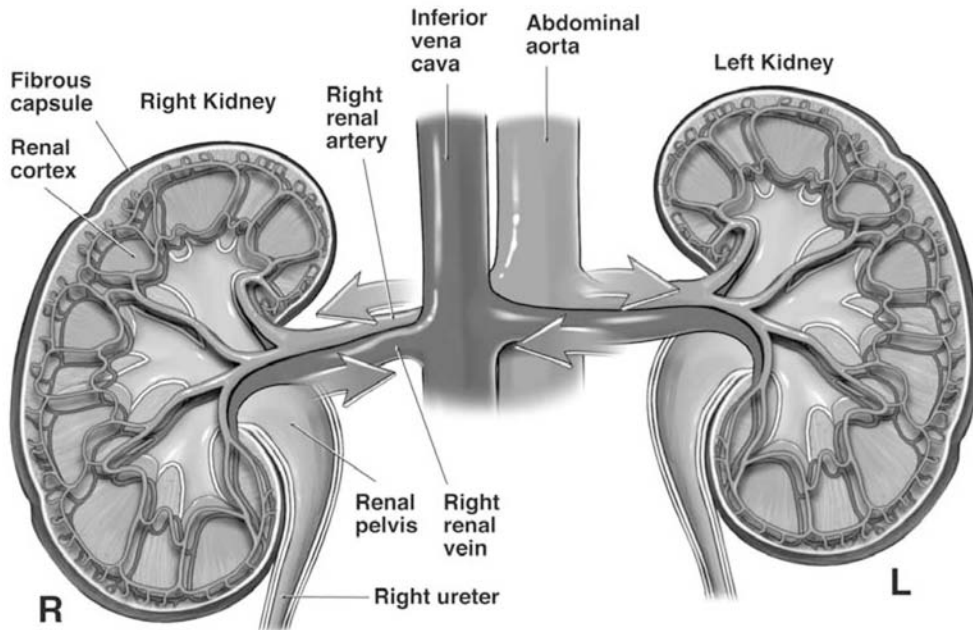
Why Your Child May Need a Kidney Transplant

What are the Kidneys?

The kidneys are:

- In the upper back—one on each side of the spine
- About the size of your fist and weigh about 4 to 6 ounces each—most people have two kidneys
- Shaped like a kidney bean and are reddish-brown in color

The Kidneys and Renal Blood Vessels



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What Do the Kidneys Do?

The kidneys are complex organs with many functions. You can live a normal, healthy life with just one kidney. You cannot live without one working kidney. Some of the main functions of the kidneys are listed in the chart below.

What do the kidneys do?	What does this do for the body?
Filter the body's blood of wastes	Removes excess sodium, potassium and urea (waste). They also reabsorb useful substances for the body.
Maintain fluid balance	Removes or reabsorbs water to maintain hydration (keep the right amount of fluids in the body).
Excrete acid	Filters out acids to help maintain the body's acid and base balance.
Produce the hormone erythropoietin	Erythropoietin helps the bone marrow make red blood cells. Lack of this hormone can cause anemia.
Help activate vitamin D	Activated vitamin D is needed to help with calcium balance and bone health. Lack of vitamin D causes a disease called rickets.

What Happens When Kidneys Fail?

When the kidneys fail (also called renal failure), these things can happen:

- Harmful wastes build up causing headaches, decreased appetite, nausea and vomiting
- Excess fluid collects, causing swelling in the legs and feet—this is known as edema
- Blood pressure often rises
- Your child can become anemic—*anemia* is a condition caused by too few red blood cells in the body, which causes your child to feel weak and tired
- Your child may have insomnia (not sleep well)
- Your child may not grow and develop normally

Common Causes of Kidney Failure

Medical Name	What this means	How this hurts the kidneys
<i>Dysplastic or cystic kidneys</i>	Multiple cysts grow in the kidneys. They are usually present at birth.	Cysts are fluid-filled sacs that prevent the kidneys from working well.
Urinary reflux or posterior urethral valves	Blockage in the urinary system (the kidneys, bladder and connecting tubes that make and store urine).	When urine flow is blocked, kidneys become infected and damaged.
<i>Glomerulonephritis</i>	A disease that can damage the part of the kidney that filters blood.	The kidneys are not able to filter out harmful substances from the blood. The body loses large amounts of protein through the urine.
<i>Nephrotic syndrome</i>	A disease that can damage the part of the kidneys that filters blood.	The kidneys are not able to filter out harmful substances from the blood. The body loses large amounts of protein through the urine.
<i>Nephropathy</i>	Kidney damage caused by continued high blood sugar levels from diabetes.	High blood sugar damages the filtering system of the kidneys. The body loses large amounts of protein through the urine.
<i>Lupus erythematosus or Goodpasture's syndrome</i>	These are <i>autoimmune diseases</i> . The immune system is the body's defense against harmful substances such as bacteria or viruses. Autoimmune diseases occur when the immune system destroys normal body tissues.	Autoimmune diseases cause inflammation of the filtering system and lining in the kidneys.
<i>Hemolytic uremic syndrome (HUS)</i>	Condition that affects the blood and blood vessels.	This causes kidney failure due to damage to very small blood vessels in the kidneys.
<i>Alport syndrome</i>	An inherited disease (passed from parent to child) that affects the <i>glomeruli</i> , 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, ask his 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 all of a sudden (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 is able to:

- Rid the body of harmful substances, extra salt and water
- Maintain a normal level of chemicals such as potassium, sodium and chloride
- Help control blood pressure

Dialysis is a long-term treatment for kidney failure. When your child's kidneys fail, dialysis is needed on a regular basis to help your child's kidneys function normally. There are two types of dialysis—*hemodialysis* and *peritoneal*.

- Hemodialysis uses a man-made membrane called a dialyzer to remove wastes and return electrolytes to the body. These treatments can take up to four hours at a time and need to be done two to three times a week. Hemodialysis is usually done in a hospital or clinic setting.
- Peritoneal dialysis uses the body's own peritoneal membrane (a thin covering on the inside of the abdomen or belly) to filter the blood. Peritoneal dialysis may be done at home. The two forms of peritoneal dialysis are:
 - CCPD (Continuous Cycle Peritoneal Dialysis)—this uses a machine to perform dialysis, usually at night. A parent needs to assist with this type of dialysis, and it is most suitable for young children.
 - CAPD (Continuous Ambulatory Peritoneal Dialysis)—this type is usually done during the day. It can be done by the patient and may be better suited for an older child.

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 two types of kidney transplants: *deceased donor* and *living donor*.
- The new kidney takes over the work of two failed kidneys.
- Your child may need his own kidneys removed, depending on his medical condition.

1. Deceased Donor

A deceased donor is a person who has recently died and donated his kidneys.

- This is the most common type of kidney transplant.
- To receive a deceased donor kidney, your child is placed on the *United Network for Organ Sharing (UNOS)* list. UNOS matches deceased donors and patients waiting for a kidney.

2. Living Donor

A living donor is a person who volunteers to give your child one of his kidneys.

- Even when one kidney is removed, the donor can recover well. The remaining kidney works well enough for the donor to have a normal quality of life.
- A family member usually provides the best match, but many living donors are not related. Aunts, friends, firefighters and teachers have all volunteered as donors.

Steps for Your Child's Kidney Transplant

The Kidney Transplant team will discuss each step with you, your child and your family.

Step 1 Your child's doctor refers him to Children's. Your child's doctor must state your child's medical need for a transplant.

Step 2 Our financial counselors obtain financial approval for your child's pre-transplant evaluation and for the transplant.

Step 3 After completing financial approval, we will call you to schedule a pre-transplant evaluation date. A pre-transplant evaluation is a series of tests. These 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 Egleston. This is usually a one-day outpatient visit unless your child is in need of two organs.

Step 5 Based on the evaluation, the Kidney Transplant surgeon and team will decide if a transplant is the best option for your child. Once approved by the team, these next steps occur:

Deceased donor transplant

- If there is no suitable living donor and your child meets all of the standards from the pre-transplant evaluation, your child's name is placed on the UNOS list.
- This process can take one to two weeks. Once done, you will receive a pager.

Living donor transplant

- Notify the transplant coordinator as soon as possible if there is a living donor volunteer. This is best done before your child's eval so that the donor can have blood work done during the eval process too. During the eval, our staff can provide information about living donation.

- Have the person who wants to be a living donor (especially if he is not related to your child) calls the transplant coordinator. The Kidney Transplant team will not make the first contact with a donor.
- After financial approval is complete, the donor will be referred to Emory University Hospital. Emory's Living Donor Coordinator will contact the donor with a date for the eval.
- If the donor is not accepted due to medical or other reasons, your child will be placed on the UNOS list.
- If a second donor becomes available, the process starts over again at the beginning. Only one donor can be evaluated at a time.

Step 6 If the living donor is accepted, the donor's surgery is scheduled at Emory University Hospital. Your child's surgery will take place at t Egleston.

Step 7 Your child has his transplant surgery. He will stay in the hospital for about seven to 10 days.

Step 8 Your child will receive follow-up care at Egleston.

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 Egleston.
- The coordinator will schedule tests and meetings with the Kidney Transplant team during your visit. They will work closely with you during the entire process.
- Please plan to stay for the entire one or two days of evaluation.

How Does My Family 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. [See section: Finances and Insurance]
- Your child must have a pediatrician. Bring the doctor's name and phone number with you to the eval.
- Arrive on time. If you are late, we may need to reschedule your visit.
- Please leave young siblings at home. Your focus needs to be learning about the transplant. We do want your family to take part in follow-up clinic visits.
- Call your pediatrician to make sure that your child's immunization (shot) records are up-to-date. Bring your child's records along with his 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 My Child's Eval?

You will spend most of the day on the sixth floor at the Children's Center for Transplantation at Egleston. Your child will have some routine tests that may include:

1. A routine medical exam

- This includes your child's height and weight, family history of long-term diseases, and any surgery your child had in the past. Bring the following 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 and a medicine list
 - A list of questions you have about your child's transplant or eval

2. Blood tests that 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*

3. Other lab tests

- Other lab tests may be done as needed

4. Radiology and imaging tests

- Chest X-ray: This test checks your child's lungs.
- Ultrasound with Doppler exam: This test checks for blood flow through the major blood vessels. It is often done before and after a kidney transplant.

5. Heart function tests

- Echocardiogram: This test may be done if your child has a history of heart disease. It checks your child's heart.

6. Surgery

- Kidney *biopsy*: This test checks the kidney tissue itself. A needle is placed through the skin to take a sample of the kidney. The tissue sample goes to a lab for testing.

7. Other evaluations may include:

- Other doctors: Your child may see other doctors such as a urologist (a doctor who cares for disorders of the urinary system) or cardiologist (heart doctor) who help your child's doctor coordinate his care.
- A psychosocial eval: Your family will talk to a social worker and psychologist to make sure you all learn about the emotional aspects of a kidney transplant.
- Dietitian: You and your child will meet with the dietitian. The dietitian will help you choose the best foods for your child to eat.

Note: Your child may not require all of these tests. The transplant team will decide which tests your child needs.

Lab Tests

Below is a list of the most common blood tests that doctors use to find out how well the kidneys work. The Kidney Transplant team will check these lab tests during your child's pre-transplant eval and during and after his transplant.

Blood test	Change with kidney disease
<p>Albumin Albumin is a protein in the blood that is made by the liver. It transports certain substances in the blood and also helps maintain normal pressure inside the blood vessels. Kidney disease causes albumin to be lost in the urine.</p>	Low
<p>BUN (blood urea nitrogen) As kidneys break down protein, a substance called urea is formed. Urea is a waste product that is normally removed from the body in the urine. Poor kidney function will cause levels to rise.</p>	High
<p>Creatinine Creatinine is made as the body uses muscle and energy. It is removed from the body by the kidneys. Poor kidney function causes creatinine levels to rise.</p>	High
<p>Potassium Potassium is salt found in the cells in the body and in the blood. It is needed for nerve and muscle function. Excess potassium is excreted in the urine. Poor kidney function causes potassium levels to rise.</p>	High
<p>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.</p>	Low
<p>Hematocrit Hematocrit measures the number of red blood cells in the blood. A low hematocrit level can show anemia or blood loss.</p>	Low
<p>Glucose This is a test to measure the sugar level in the blood.</p>	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 placed on the UNOS waiting list to receive a deceased donor kidney.
2. UNOS works with an agency to obtain organs and keep a national list of people waiting for transplants. Your child will stay on the list until he receives a kidney.
3. UNOS gives your child a Pediatric End Stage Kidney Disease (PEKD) score. It is based on a formula that looks at his age, length of time on the list and percent antibody.
4. Your child is matched with a kidney based on the PEKD score and his blood type. Waiting for a deceased donor kidney can take time. If you have questions or concerns, please talk to the Kidney Transplant team.

NOTE: At the time of listing, your child or family receives a pager. Please check the battery each month. Ask our staff for instructions on how to use the pager.

How Does the UNOS Donor Matching Process Work?

1. A kidney is donated from a person who has just died.
2. The donor's medical information is put into the UNOS database.
3. UNOS notifies Children's that a kidney is available.
4. 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.
5. The transplant coordinator calls you when a kidney is available.
6. 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 factors include:

- Location of the kidney and the child
- 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 four most common blood types are O, A, B and AB

Blood Type Compatibility

If your child's blood type is:	The donor's (deceased or living) 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. Likewise, information about you and your family will not be given to the donor's family. You may write a letter to the donor's family. If you write a letter, a transplant coordinator will send it to LifeLink of Georgia. They will then forward it to the donor family.

Living Donor Kidney Transplant

In a living donor transplant, doctors take a kidney from a living person to replace your child's unhealthy (diseased) kidney.

There are several good reasons to have a living donor transplant:

- 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 lead to a quicker recovery

Who Can Be a Living Donor?

A living donor can be anyone—a parent, family member or friend. A donor has to meet certain health standards and have a donor evaluation. Based on these results, the Kidney Transplant surgeon and team will decide if a donor is a good match for your child. A donor must also:

- Be older than 18 years of age or age of majority (the age when a person has all of the rights and responsibilities of being an adult). In most states, the age is 18.
- Be in good health. Certain 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 able to be passed from one person to another) such as HIV, hepatitis or tuberculosis (TB)
 - Obesity (very overweight)
- Be willing to donate a kidney. The decision to donate must be made freely and without pressure from anyone.
- Be admitted to Emory University Hospital for the eval and surgery.
- Stay in the hospital for an average of seven to 10 days. The donor may not be able to work for up to two months.

What are the Steps to Becoming a Living Donor?

Before anyone can be a living donor, he must have a series of tests to make sure he is the best match for your child.

Step 1 A person wishing to be a donor for your child's transplant calls the Children's transplant coordinator.

Step 2 The transplant financial counselor asks your insurance company for approval for the donor evaluation. The recipient's insurance may pay for this. If you do not have insurance, our financial counselors will work with you to set up a payment plan. [See section: Finance and Insurance]

Step 3 Your insurance company approves the donor eval. The transplant coordinator sets up the donor eval at Emory University Hospital. A living donor must have the same blood type as your child.

- Every person has one of four blood types: O, A, B or AB. Type O is the most common. Type B is the least common.
- If a potential living donor doesn't know their blood type, he can donate blood or call his local Red Cross and a blood type test can be done. If the potential donor has had surgery or a baby, the donor's doctor may have a record of the blood type.

- Step 4 If the donor's blood type is a good match with your child's, the evaluation can take place.
- Step 5 The donor will have a two-day, outpatient eval at Emory University Hospital. The donor's test results may take more than six weeks.
- Based on the donor's eval and tests results, the Kidney Transplant team decides if the donor is a good match.
 - If the donor is not a good match, the process will begin again with the insurance company (see Step 2).

What if I Want to Become a Living Donor?

A person must clearly express his interest to be a living donor.

- Set up an appointment with the transplant surgeon. Schedule a complete donor eval, which can be done as an outpatient.
- Your insurance company has to approve a donor eval. If the insurance company does not give Children's pre-certification or authorize these tests, you and your family may need to pay for the charges.
- Only one person at a time will be accepted for a donor eval. If that person is not accepted, the process will begin again starting with the insurance company (see Step 2).
- Exercise often. Activities such as walking, swimming or biking are strongly advised for donors. This will help the donor recover better after surgery.
- Follow a healthy diet and stop drinking alcohol or smoking. This allows your kidney to work better. You will also need to stop some medicines if you are taking them. Talk to your doctor and the Kidney Transplant team before you stop any medicine. Herbs, vitamins and nutritional supplements are medicines.

The Living Donor Evaluation

During the living donor evaluation, the donor may have some of these tests:

- Screening tests before the eval: All female donors must also have a Pap smear and mammogram. Men must have a prostate specific antigen (PSA test). These tests are not included in the eval.
- A routine medical exam: This includes the donor's height and weight, blood pressure, family history of heart, kidney or other chronic disease, history of smoking or obesity, alcohol or drug use, and whether the donor has had any prior surgery.
- Lab tests: These may include a complete blood count and tests for hepatitis, drugs, HIV and pregnancy. The transplant surgeon decides which lab tests the donor needs.
- Chest X-ray and electrocardiogram (EKG): These tests check the donor's lungs and heart.
- Kidney biopsy: This test checks the health of the kidney. A needle is placed through the skin to take a sample of kidney tissue. The tissue sample goes to a lab for testing.
- CT scan: This computerized image checks the size and shape of the donor's kidney and the amount of kidney tissue in each lobe.
- Angiogram: This test checks the size of the donor's blood vessels outside the kidney to see if there are any blockages. Dye is injected into the artery so the blood vessels show up on X-ray.
- A psychosocial evaluation: The donor will talk to a social worker and psychologist to make sure he understands the emotional aspects of living donation. The psychosocial exam also makes sure that the donor wants to donate his kidney free of any outside pressures from family or friends.

Based on his medical history, a donor may need more tests than those listed here. If there are no problems, the next step is to schedule the donor surgery. The entire process, beginning with the referral to the transplant coordinator to the scheduled living-donor transplant, can take up to six 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 any areas that you do not understand.

What are the reasons for a transplant?

What are the risks and alternatives of a transplant?

How long is the transplant process from beginning to end?

What is the process for a living donation?

Questions that haven't been answered yet:

Preparing for Your Child's Transplant

While You Wait

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

Stay in touch and be ready at all times

- Make sure the transplant coordinator can reach you at all times. Provide school, work, family and vacation phone numbers. This ensures that the transplant team can contact you right away.
- Tell us if your phone number or address changes. If we can't make contact, the kidney will be given to another patient waiting for a transplant.
- The transplant team may give you a pager. Check your pager each day to make sure it works. Keep it with you at all times.
- 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 the day of the transplant. The transplant coordinator will tell you when your child must arrive at Egleston.

- Make sure your car or truck is working well and is ready for your trip at any time.
- Have a plan to take care of siblings during the transplant.

Make sure your child is ready

- Report all infections. The transplant will be canceled if your child is sick.
- If your child becomes ill, get treatment right away. This helps ensure he will be ready for the transplant when a donor kidney is ready.
- Make sure the transplant team is aware of any changes in your child's health.

Help your child get in good physical shape for the transplant.

- Have him eat healthy foods as allowed by his diet guidelines. Keep him as active as possible.
- Spend time with your child. Talk with him about his transplant. Let him express feelings, fears or concerns. Let him ask questions and be truthful with your answers. The transplant team will be happy to help you if concerns or questions arise.
- Keep your child in school and involved in activities, if possible. Try to keep your child's routines normal and balanced.

Pager

The social worker can arrange for you to have a pager. As soon as your child is listed for a transplant, the team must be able to reach you at all times. Carry a pager or cell phone at all times so you can be reached as soon as a donor kidney is available. This is your responsibility!

Be sure to call us back as quickly as possible.

When the Call Comes

The transplant coordinator will call or page you when UNOS finds a donor kidney. When the call comes, your child must get to Egleston as quickly and safely as possible. As soon as you are called, your child should stop eating and drinking so that his stomach will be empty.

When you receive the call, bring:

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

Make sure your child takes all of his medicine as prescribed to prevent problems. It is okay to swallow small sips of water with his 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, if needed. If your insurance company does not cover the flight, you must pay for it.

Transplant Surgery

If Your Child Has a Deceased Donor Transplant

- Step 1 When a donor kidney is ready, the transplant coordinator will call you at home. If no one is home, you will be paged or called on your cell phone. Be sure to call us back as quickly as possible. We will tell you when to come to the hospital.
- Step 2 Your transplant coordinator will tell you where to report. You will go either to admissions or to the Emergency Department to check-in.
- Step 3 Your child will be admitted and staff will direct you to your child's room. He will be prepared for surgery.
- Step 4 The Kidney Transplant team will do a medical review of your child in the next few hours that might include:
- A complete history and physical exam
 - A review of your child's current medicines—please have a complete list of all medicines your child is taking
 - A review of any health problems that your child has had lately such as a sore throat, cold, peritonitis (infection of the fluid in the abdomen), ear infection, rashes, cold sores or contact with people who have infections
 - A chest X-ray

Note: If your child is sick or if an emergency situation arises, your child's surgery may be canceled.

- Step 5 The *anesthesiologist* will come to your child's room to discuss his allergies and types of anesthesia. An anesthesiologist is a medical doctor who monitors your child during surgery. Anesthesia is medicine that allows your child to be in a deep sleep so he cannot see, hear or feel anything, not even pain.
- Step 6 The transplant surgeon will come and talk to you about your child's surgery. You will be asked to sign a consent for surgery after the transplant surgeon has explained the operation and its possible risks.
- Step 7 The transplant surgery will take place.
- The surgery may take from four to 12 hours.
 - During surgery, there is a 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 to you after your child's surgery.
- If you need to leave the hospital, please tell your coordinator. Be sure to leave a number where you can be reached.

Step 8 Immediately after your child's surgery, he will go to the Pediatric Intensive Care Unit (PICU).

Step 9 When his doctor feels he is ready, your child will go to a patient floor at Children's at Egleston.

If Your Child Has a Living Donor Transplant

Step 1 The transplant surgery is scheduled. Your child may be admitted to Egleston the afternoon before surgery. Please be aware that if your child is sick or if an emergency situation arises, your child's surgery may be canceled.

Step 2 The anesthesiologist will come to your child's room to discuss his allergies and types of anesthesia. An anesthesiologist is a medical doctor who takes care of your child's body functions during surgery. Anesthesia is medicine that allows your child to be in a deep sleep so he cannot see, hear or feel anything, not even pain.

Step 3 The transplant surgeon will talk to you about your child's surgery. You will be asked to sign a consent for surgery after the transplant surgeon has explained the operation and its possible risks.

Step 4 The transplant surgery will take place.

- The surgery may take from four to 12 hours.
- During surgery, there is a 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 to you after your child's surgery.
- If you need to leave the hospital, please tell your coordinator. Be sure to leave a number where you can be reached.

Step 5 Immediately after your child's surgery, he will go to the Pediatric Intensive Care Unit (PICU).

Step 6 When his doctor feels he is ready, your child will go to a patient floor at Egleston.

The Donor's Surgery

Step 1 Once the donor eval is complete, the donor's surgery is scheduled at Emory University Hospital.

Step 2 The Emory Transplant Coordinator will give the donor information about pre-registration and when to stop eating and drinking the day before surgery.

Step 3 The donor will be admitted to Emory University Hospital.

Step 4 The surgery will take place the following morning and may take from three to eight hours.

Step 5 After surgery, the donor will recover at Emory University Hospital.

After the Transplant

In the Hospital

The PICU

After surgery, your child will go to the Pediatric Intensive Care Unit (PICU).

- Your child will be sleepy from the anesthesia (a medicine that puts your child to sleep during surgery) for up to several days.
- Your child will have I.V.s (tubes that deliver medicine through his veins) and a Foley catheter (a small, flexible tube that drains urine from the bladder) to measure his urine. The catheter will stay in place for several days to check his urine output.
- Your child may stay in the PICU for two to three days.
- The Kidney Transplant team and the PICU staff will take care of your child after surgery.

The Patient Floor

After a few days, your child will be taken to a patient care area.

- The nurses and staff will help your child recover and prepare him to go home.
- Your child can usually go home about seven to 14 days after surgery.
- The transplant coordinator and nursing staff will teach you how to care for your child at home.

Guidelines for Visiting Egleston (PICU and 6 East Patient Floor)

- Wash your hands each time you enter and leave your child's room.
- Tell your child's nurse if any visitors are sick. The nurse will give them protective clothing to keep your child healthy and prevent infections.
- Due to limited space, only two visitors at a time are allowed in the PICU.
- Please stay in your child's room when doctors do daily rounds. Rounds are times when doctors, nurses and the transplant team talk about the care of your child. Your child's nurse will tell you when the doctor will make rounds.
- It is best to stay with your child at all times. A family member or friend who is at least 18 years old is allowed if the parent cannot stay.
- One parent can stay with your child overnight. Your social worker can help you with accommodations.
- Child visitors less than 10 years old must be with an adult.

Taking Care of You and Your Family

The Kidney Transplant team knows that you have a great need to be near your child during his hospital stay. We also know that it is easy to become tired from worry or lack of restful sleep. This means you should take regular breaks, eat well and get plenty of rest. You will be in a better position to make care decisions for your child. Please let us know if there is anything that we can do to help you.

Getting Ready to Go Home

Taking your child home with a new kidney can be very stressful. The transplant coordinator and team will prepare you for discharge. They will give you information to help care for your child at home.

Complications

Some children who receive a kidney transplant have complications. Infection and *rejection* are two of the most common complications after a kidney transplant. Your child's transplant team will help you learn about the early signs of complications. They can also discuss your child's care and advise further treatment when needed.

Rejection

Rejection is a natural response of your child's *immune system*. The immune system is the body's defense against an "unknown" material such as viruses, bacteria and some types of cancers. Your child's body treats a transplanted organ as an "unknown," so it tries to reject the new kidney.

Immunosuppressants

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

- These medicines can reduce the risk of severe rejection that damages the kidney.
- They also decrease the actions of your child's immune system. This places him at greater risk for infections.
- Give these medicines on time and as ordered by the doctor.
- Your child will take this medicine for the rest of his life.

Some of the medicines may affect how he looks and feels. Side effects may include:

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

If your child has any of these symptoms, call the transplant coordinator.

Immunosuppressant Drugs

NOTE: All of these medicines cause an increased risk of infections.

Drug	Reason for Taking	When to take	Side Effects
Tacrolimus (Prograf)	Suppresses immune system, prevents organ rejection	Every 12 hours	Mouth sores, diarrhea, diabetes, Post-Transplant Lymphoproliferative Disease (PTLD)
Cyclosporine	Suppresses immune system, prevents organ rejection	Every 12 hours	Nausea, hair growth, gum growth
Prednisone	Prevents inflammation	Once a day	"Moon face," nausea, weight gain, insomnia, high blood sugar
Mychophenolate Mofeteil (Cellcept)	Suppresses immune system, prevents organ rejection	Every 12 hours	Nausea, diarrhea, weakness, tremors
Sirolimus (Rapamune)	Suppresses immune system, prevents organ rejection	Once a day	Nausea, diarrhea, acne, sleeping problems, wound healing problems, increased triglycerides, mouth ulcers, bone aching, pneumonia
Azothiaprine	Suppresses immune system, prevents organ rejection	Every 12 hours	Nausea, loss of appetite, diarrhea, mouth sores

Your child may take any combination of these medicines. They should be given on time each day as ordered by your child's doctor.

- Blood levels of the medicines are drawn once a week. Levels are drawn 12 hours after the last dose is taken, but before the next dose is due.
- We can change your child's medicine schedule to fit your needs.

Avoid these medicines while your child is taking immunosuppressants:

- Anti-inflammatory medicines such as Advil® and ibuprofen
- Erythromycin
- Antifungal medicines
- Anticonvulsants medicines (seizure medicine)

Always speak with your child's nephrologist before giving him any new medicines. If you have any questions about your child's medicines, call the transplant coordinator.

Kidney Biopsy

Rejection can still occur even though your child is taking medicines. The only way to detect rejection is with a lab test or biopsy. Your child's doctor may decide to do a biopsy. This test checks the kidney tissue itself:

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

Infection

Your child is more likely to get an infection when taking immunosuppressants. The risk of infection is greatest in the first three to six months after transplant. Some ways to help prevent infection include:

- Hand washing—wash your hands often and teach your child to wash his hands after:
 - Going to the bathroom
 - Giving and taking medicines
 - Handling uncooked food
 - Touching garbage or anything that might have germs
 - Blowing his nose, coughing or sneezing
 - Wiping his nose
 - Caring for someone who is sick
 - Playing with or touching pets
 - Leaving a public place

Also teach him to wash his hands before:

- Eating and drinking
- Giving and taking medicine
- Avoiding people with colds, measles, mumps, chicken pox or the flu; use common sense—for example, your child may attend church and go to the mall
- Cleaning your child's cuts and scrapes with soap and water
- Covering cuts with antibiotic ointment and a clean, dry bandage

Infection Warning Signs

- Fever over 101.5° F
- Pain over the new kidney
- Extreme tiredness
- Wound redness, swelling, excess warmth or tenderness, or yellowish drainage
- Pain when urinating (passing water)

If your child has any of these symptoms, call the transplant coordinator right away.

Other possible infection warning signs:

- Cold or flu symptoms
- Nausea, vomiting or diarrhea that lasts more than 24 hours
- Headache with increased sinus drainage or a change in the color of the drainage
- Recurring cough, with or without mucus
- Rash
- Snoring or breathing through the mouth while sleeping

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) and *Cytomegalovirus (CMV)* are common viral infections that affect many people. These viruses are everywhere. Since your child's immune system is weak, they can be serious for your child.

- If your child picks up EBV or CMV, he may show no signs. Or he may show signs of tiredness, muscle aches or fever. Young children may complain of stomach pain, cramping and diarrhea. Call your doctor if your child shows any of these signs.
- If your child shows signs of EBV or CMV, he may need hospital care. Your doctor will talk with you about treatment. This may include anti-viral medicine or stopping your child's immunosuppressants for a while.
- A test for EBV and CMV is done monthly for the first 12 months after transplant to monitor for these viruses. The test has to be shipped overnight to a specialty lab for processing.

Clinic Visits

Follow-up clinic visits and lab tests are vital to your child's care when he is well and ill. Even when your child is well, infection and rejection can occur. There are not always signs or complaints to show a problem. Every child is different. Talk to your child's doctor so you can learn about the treatment plan and any problems that may arise. Blood work is the most certain tool a doctor can use.

The transplant team will follow your child closely after his transplant. During the first few months, you will see your transplant doctor and the transplant team each week. As your child's health improves, your visits will decrease.

- Transplant Clinic is every Thursday on the sixth floor at Egleston. To schedule appointments, please call 404-785-1400.
- Please call the clinic as early as possible to schedule routine visits.
- A review of your child's medicines will be done with each visit. Bring all bottles of medicine your child takes to each visit.

Your transplant coordinator will set up your first visit at the Children's Transplant Clinic. Each visit may include:

- Seeing the transplant doctor, 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 work

This is also a great time for you to ask questions.

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:

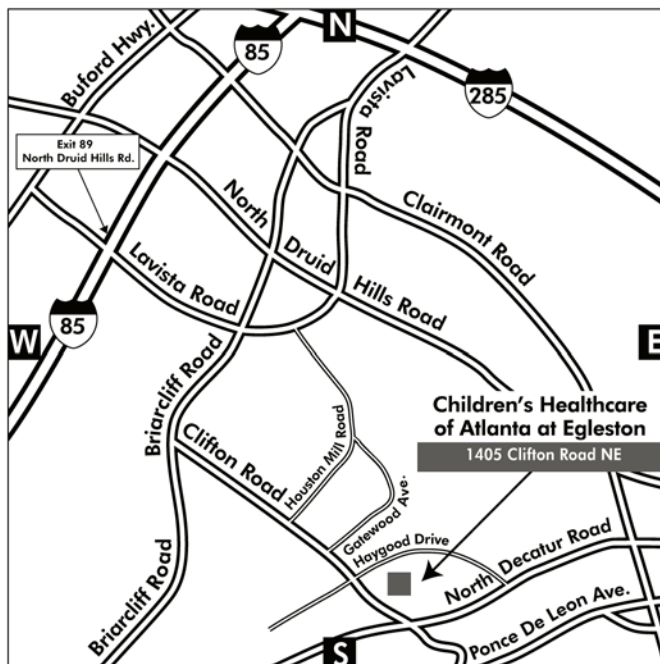
- Guidance and support
- Education
- Resources

Teens will learn how to take responsibility of 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 six months post-transplant. Call **404-785-6175** for more information.

Routine Lab Work

- 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 lab tests done as your doctor orders.
- Call the transplant office if you forget to have lab tests done or need to have them drawn at a time other than scheduled.

Children's Healthcare of Atlanta at Egleston



Caring For Your Child

Helpful Tips

Vital Signs

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

- When you get home, you may be asked to keep a daily record of your child's blood pressure, weight and temperature. Call the coordinator if the reading is not normal for your child. If there is a problem, the coordinator may ask for your child's recent vital blood pressure signs. 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
 - Chicken pox
 - Hepatitis B
- After the transplant, your child cannot receive any vaccines for three months. In addition, he cannot receive any live vaccines at any time because his immune system is weak. He could get the disease the vaccine is trying to prevent. Live vaccines include the measles, mumps and rubella (MMR), smallpox and chicken pox.
- Infants, children and family members who have weakened immune systems should receive the inactivated polio vaccine (IPV).
- You, your child and family members older than 6 months old should receive a flu shot each year.
- If your child is exposed to chicken pox or shingles, call the transplant doctor or coordinator right away. He might need intravenous (I.V.) medicine. If your child has not had chicken pox or a chicken pox vaccine and is exposed, he will need a varicella zoster immunoglobulin (VZIG) shot within 72 hours of exposure.

Pediatrician

After the transplant, make an appointment with your local pediatrician or family doctor. This gives your local doctor a chance to check your child and update his chart with new medicines.

- Have your local doctor keep your child's vaccine list up-to-date and give him a flu shot each year.
- This doctor can also treat your child for any routine problems such as ear infections, colds or rashes.

Car Seats

All states have laws that require babies and toddlers to be properly restrained 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. In case of a car accident or other emergency, health workers will know he has had a kidney transplant. Find out how to order it at www.medicalert.org or ask your child's doctor or nurse.

Nutrition

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 nutritional status. She 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.

Before a kidney transplant, most children are on special diets. Your child's diet may be restricted in sodium, potassium, protein or phosphorus. These restrictions may change over time. We will review changes with you if they are needed.

After the transplant:

- Have your child avoid any uncooked or raw foods such as clams, oysters or sushi.
- Help your child eat a balanced diet that includes fruits and vegetables. Stay with a "no added salt" rule.
- Avoid chips, sodas, excess fruit juice and other snack foods. They are empty calories and do not provide good nutrition.
- Have your child eat more healthful foods by eating them yourself and setting a good example.
- Your child's weight will be checked during clinic visits to make sure he is growing well. Our goal is for your child to reach his ideal body weight for his age and height.
- Avoid force-feeding any food. This may cause your child to dislike food, even after treatment.
- Your child may dislike foods he once enjoyed. He may begin to like new foods. Be sure to support your child during this time of change.
- If your baby is bottle-fed, give him formula or milk in his bottles. Do not give your baby soda and juice in the bottle.

Exercise

As your child feels better, his activity level will increase. He can do any activities he feels up to, except contact sports such as football, wrestling and dodgeball. Please feel free to call the transplant office or ask us questions during clinic visits about your child's activity or energy level.

Sunscreen

Sun exposure happens all year, not just during the summer. The best way to prevent skin damage is to limit the time spent in the sun. Because of side effects with your child's medicine, he must use sunscreen. Choose one with an SPF of 15 or higher. Use it often, even if your child will only be in the sun a short time. To prevent sunburn, your child should:

- Wear clothing that protects his skin, such as a hat, long pants and long sleeves
- Put sunscreen on exposed skin 30 minutes before going outdoors and put it on again as the package directs—this usually means you need to put it on every two hours and after playing in the water
- Use sunscreen for children of all ethnic backgrounds, regardless of skin color

Dental

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

- Make sure your child brushes and flosses his teeth twice a day.
- Use a soft toothbrush and gently brush up and down. This may help keep his gums from overgrowing.
- Your child should also see a dentist regularly. He may need prophylaxis (preventative antibiotics) before dental surgery or if he has a history of heart disease.

Ear/Body Piercing and Tattoos

Your child should not get any ear or body piercing or tattoos until you talk to the transplant doctor. This is not a needed medical treatment, and we cannot advise this procedure.

School and Daycare

Talk to your transplant doctor about when your child will be ready to return to school, preschool or daycare. He can also advise you of any special plans that may be needed. The goal for all transplant children is to attend school full-time. This helps your child keep up with learning, socializing and physical activities.

Children's also offers a Hospital School program to help with studies when your child is in the hospital. Your transplant coordinator, social worker or hospital school program coordinator 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 receive certain vaccines that are needed to enroll in school
- Have limits on contact sports
- Need home-care school options for when he is ill or unable to attend school full-time

Travel Tips

As your child feels better and returns to a regular schedule, you may want to travel or take a vacation. Please call your transplant coordinator before travel.

- If you fly, take your child's medicines with you in your purse or carry-on bags. 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.
- Have your child wear a medic alert bracelet and carry an identification (I.D.) card.
- Include the phone number of the transplant team.
- Talk with the transplant coordinator before your child goes to an amusement park. There are certain rides, such as roller coasters, that are not advised for transplant patients.

When to Call the Transplant Coordinator

Please call the transplant office or the on-call transplant coordinator any time you have questions or concerns about your child's health. Call the transplant coordinator right away if your child has:

- Redness, swelling, drainage or pain at the incision site or other sites
- Any redness, drainage, swelling or damage to the drain, if your child has one
- Any fever over 101.5°
- Diarrhea or vomiting that lasts more than two to three hours
- Weight gain or swelling
- Headaches or dizziness
- Exposure to chicken pox or shingles
- Any rashes
- Stomach pain
- Any decrease or darkening of urine
- Poor appetite or fluid intake
- Cold hands, fingers or toes

Also call if your child:

- Is not able to take his medicine
- Is sleepy and doesn't want to wake up (lethargy)

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

Medicines

After a kidney transplant, your child will take many medicines. These medicines are very important. They will help keep your child from rejecting his new kidney and keep him in the best possible health. As time passes, your child's doctor may decide that some of the medicines may be decreased or stopped. Until your doctor makes any changes, give your child all of his medicines on a regular schedule.

- Do not give your child medicine twice if he vomits. Call the transplant coordinator if this happens.
- Do not skip doses, even if they are several hours late.
- Do not double doses. If your child is accidentally given the wrong dose of medicine, call the transplant coordinator to see if you need to take any action to prevent a bad reaction.
- Call the transplant financial counselor if there are any financial concerns in getting your child's medicines.

Examples of Medicine Your Child May Take:

Name of medicine	How you can support your baby in the hospital:
Immunosuppressants Tacrolimus, cyclosporine, prednisone, mychophenolate mofeteil, azothiaprin, sirolimus	Help prevent rejection
Blood pressure medicines (antihypertensives) Amlodipine, nifedipine	Control blood pressure and help keep it from getting too high
Antivirals Acyclovir, valganciclovir	Help the body fight viruses such as chicken pox
Antibiotics Sulfamethoxazole/trimethoprim	Fight infections
Antipyretics Acetaminophen and aspirin	Reduce fever

Helpful Hints

Time to give medicines:

- Ask your child's doctor or pharmacist for the best time to take each medicine.
- Call the transplant coordinator or your doctor if your child vomits the medicine less than 30 minutes after it was taken.

Ways to give medicines:

- Check with your child's pharmacist or doctor to find out if your child is taking any time released medicine. Some time-released medicine cannot be crushed or opened.
- Some medicine can be crushed and put in a small amount of food (applesauce, ice cream, juice or flavored syrup). Use a small amount because your child may not want to finish all the food.
- Some medicine can be crushed and put in a gel cap for older children who can swallow a capsule.

Other medicines:

Some over-the-counter medicine can change the effects of prescription medicines. Be sure to keep track of all medicines given to your child.

- Ask the transplant coordinator before you give your child any medicine for coughs or colds.
- Call the transplant coordinator if a pediatrician or other doctor starts any medicine. The transplant team needs to keep a complete record of all of your child's medicine and illnesses.
- Ask staff to call the transplant coordinator if you take your child to a local doctor or emergency center. This will help your child's doctor deliver the best care by having a complete picture of his health.
- Do not give your child any herbal medicine, teas, nutritional supplements or any other natural or herbal treatments without checking with your transplant doctor or transplant coordinator.

If you have any questions about any medicines or treatments, please call the transplant office.

Medicine Refills

- Call your pharmacy a few days ahead to refill your prescriptions. This ensures the pharmacy has enough medicine in stock for your child.
 - Check the bottle for the correct dose and strength each time your child's medicine is refilled. The dose may change if the prescription is filled with a different strength tablet or a more concentrated liquid.
 - Your child needs his blood work checked often, right after the transplant. His medicine may need to be changed based on blood work results. The transplant coordinator may contact you to change your child's dose.
 - A refill from the pharmacy may not be the same as your child's current dose. If you have questions about the dose of any medicine, call the transplant office or have your pharmacist contact the office.
 - Some medicine needs to be approved before it can be refilled. This process may take several days.

Helping Your Child Cope

A transplant changes the life of your child and family. You may ask:

- What does my child know or understand about his 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 he copes with having a transplant. When children are faced with stress, their normal behaviors may change. They may become more dependent on adults and act younger than their age. Your child may not know how to handle his feelings.

You know how your child handles stress. Work with your healthcare team to find new ways to help your child cope. Child life specialists can also help.

Guidelines to Support Your Child

Infants (birth to 12 months)

Your child expects you to meet his needs. He does not understand a kidney transplant.

An infant will:

- Rely on you for food, comfort, play and care
- Learn about his 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 in the hospital:
Separation from familiar people	<ul style="list-style-type: none">• 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	<ul style="list-style-type: none">• Have the same people care for your child inside and outside the hospital as much as possible• Limit the number of people and voices in the room
Development	<ul style="list-style-type: none">• Allow your child to explore toys with his hands and mouth—be sure toys are clean and do not have small pieces that could make him choke• Use gentle touch and massage to comfort him• Play games with your baby like you would at home
Sense of safety	<ul style="list-style-type: none">• Keep your baby's crib as a safe place—ask if staff can use the treatment room for painful procedures (this may not be possible every time)• Wake your infant before a painful procedure• Continue or develop familiar feeding, bedtime and bathing routines

Toddlers (12 months to 3 years)

Toddlers begin to do more on their own.

- Your child may say, “me do” or “no.”
- Let him do things on his own. He may show feelings by his actions.
- Help him understand how his body works.
- Explain the transplant in his terms. Toddlers think they make things happen. This creates a false idea about how your child got sick.

Common issues and fears:	How you can support your toddler:
Fear of separation or fear of strangers	<ul style="list-style-type: none">• Be with your child as much as possible• Have the same people care for your child when possible• Provide security objects such as a blanket or stuffed animal• When leaving, tell him where you are going and when you will be back• Leave something personal when you go, such as a picture or shirt
Loss of control	<ul style="list-style-type: none">• Allow your child to make choices, but do not offer a choice when there is not one• Give your toddler a job to do• Allow him to play and be in control of the game or activity
Loss of normal routine	<ul style="list-style-type: none">• Maintain normal eating, sleeping and bathing routines as much as possible• Let him play with favorite and familiar toys
Behavior changes	<ul style="list-style-type: none">• Give him 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 him and offer reassurance• Set limits with your child and give discipline when needed—he needs limits to feel safe• Praise him whenever possible
Fear of treatment	<ul style="list-style-type: none">• Ensure your child that he did nothing wrong• Keep security objects nearby such as a blanket, pacifier or stuffed animal• Use simple words, pictures or books to tell what will happen• Tell him what will happen just before the treatment

Preschoolers (3 years to 5 years)

Preschoolers take pride in being able to do things for themselves.

- Preschoolers learn more words to say what they think and feel. Your child might use play to express himself.
- Your child may think the hospital is punishment for something he did wrong.
- He may 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	<ul style="list-style-type: none">• Use simple words, pictures or books to tell 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	<ul style="list-style-type: none">• Allow your preschooler to make choices, but do not offer a choice when there is not one• Give him a job to do
Loss of normal routine or behavior changes	<ul style="list-style-type: none">• Praise your child for doing things for himself• Give him time to adjust to change• Use play to help him show feelings

School Age (6 years to 12 years)

School-age children take pride in doing things themselves.

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

Common issues and fears:	How you can support your preschooler:
Loss of control	<ul style="list-style-type: none">• Allow him to make choices, but do not offer a choice when there is not one• Give your child a job to do• Let him practice new things• Let him go to school or do schoolwork• Provide games and activities
Being away from friends and school	<ul style="list-style-type: none">• Let friends visit• Have him write letters to friends and family
Fear of harm to body or fear of unknown	<ul style="list-style-type: none">• Use simple words, pictures or books to tell your child what will happen• Tell him what will happen a few days before treatment• Let your child play with safe medical supplies

Teenagers (13 years to 18 years)

Teens see themselves as individuals and want to be independent.

- Friends and peers are important.
- Your child wants to be like his friends and is concerned with how others view him.
- Illness and treatment cause teens to be different.
- Teens are able to see things from many points of view.

Common issues and fears:	How you can support your teen:
Loss of control or independence	<ul style="list-style-type: none">• Allow your teen to make choices• Let him be active in school and social activities• Involve him in the treatment plan• Include him when talking to the medical team• Have him do his own self-care as much as possible
Body image or self-esteem	<ul style="list-style-type: none">• Give your teen chances to talk about physical and emotional changes• Talk with him about his feelings• Point out things he does well• Allow your teen to do things that make him feel good about himself
Loss of privacy	<ul style="list-style-type: none">• Respect his need to do things by himself• Knock before entering his room• Offer him private time
Separation from peers	<ul style="list-style-type: none">• Provide time with peers• Allow friends to visit and call
Concern for the future	<ul style="list-style-type: none">• Answer questions openly and honestly• Help your teen plan for the future• Have your teen keep doing normal activities
Behavior changes	<ul style="list-style-type: none">• Give your teen safe ways to express feelings, especially anger• Ensure your child that his feelings are normal

Talking to 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 he does not know what is happening. Benefits of talking to your child about his transplant include:

- He can build trust in you and hospital staff
- He will know what to expect
- Honest information corrects false ideas about transplants
- It can help him cooperate during treatment
- It can help give him a sense of control
- He can learn how to get through hard situations

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

- Think about your child's age when choosing words to explain his 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 to Your Child about a Transplant

The items below may help you talk with your child and answer his questions about the transplant. Answer his questions honestly.

- A transplant is no one's fault. Many children believe a transplant is caused by something they did, said or thought. Explain that what your child thinks, says and does will not cause his 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 him in a deep sleep so he does not feel, hear or see anything, not even pain.
- Tell your child how healthy bodies work. Avoid using "bad" and "good." Instead use "sick" and "healthy."
- Talk to your child about his feelings. Let him know that any feeling is normal. Many times children feel angry, guilty, sad, lonely, scared and sometimes even happy. Be honest with your child about your feelings.

Disciplining Your Child

- A transplant can disrupt your family routine.
- Your child is the center of attention and may receive gifts. Although he may feel sick, gifts and attention are fun. It is easy for him to feel special and want special treatment to last.

Discipline can be a problem when special attention stops.

- Your child's illness can make discipline hard. Pain and side effects of treatment can make any child short-tempered. He may act more helpless when he feels sick. Medicines may also cause your child to feel ill-tempered.
- You may feel helpless when you see your child suffer. You want to help him by giving special rewards. These feelings are normal. Keep the same rules he had before his transplant.

Keep these ideas in mind to provide limits:

- Set clear limits your child can understand.
- Realize limits may need to change as your child receives treatment.
- Praise him and give rewards for good behavior.

Caring for the Whole Family

Coping With Your Feelings

Since your child was diagnosed, your lives have changed. A transplant brings changes to your home life, including new stresses. Every family is unique. Your family may feel fear, anger, depression and guilt. By sharing these feelings, you may find it easier to cope with change. Your child's healthcare team is here to listen to your concerns and help you in any way that they can.

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 to 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 a normal reaction. Find a way to express your anger. Take a walk or talk with someone.

Guilt

Parents may feel guilty because they did not know their child was sick. Families have said they wonder if they caused their child's kidney failure. Other family members may feel guilty that they are healthy. Young children often believe they 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, which may cause changes in family routine and feelings of being alone. Change can cause grief and depression.

Common symptoms are:

- Crying spells
- Decreased energy
- Decreased or increased eating
- Tightness in the chest
- Lack of interest
- Headaches

All these feelings are common human emotions. You are not alone. With the support of family, friends and your child's healthcare team, most families are able to work through these emotions. They are able to regain coping skills needed to meet care demands.

Suggestions to help cope with your child's illness:

- Find a private time to talk with your spouse or a close friend. Try not to talk only about your sick child.
- Avoid talking about your child in his presence, unless he is included.
- Find ways to reduce stress. You know what works best for you. Ideas include exercising or reading.
- Take turns with your spouse or another person who can stay with your child in the hospital or go to clinic visits. This helps everyone be involved with your child's treatment. It also reduces the gap that may grow between parents when one is more involved in treatment than the other.
- Ask a member of your child's healthcare team for help and support.
- Talk with other parents of children with transplants.
- Talk with your spiritual leader.
- Attend a support group.

Sometimes emotions become so overwhelming that it can be hard to regain balance. This is very true when there were stresses before diagnosis. If there have been other family strains or losses, mental health problems or substance abuse, counseling and medicine may be needed. Discuss your feelings with the healthcare team to get the help that you need.

Impact of a Transplant on a Marriage

An illness can upset a family's life. You may become emotionally and physically tired. Parents often continue to work while trying to keep a normal home routine. Many couples feel the strain on their marriage. They feel angry and upset and do not have time for each other. Suggestions that can help include:

- Assess your coping styles. It is important to know and accept how your spouse deals with stress. Each person shows feelings in different ways. Some people withdraw, others cry or get angry, some try to learn as much as possible.
- Talk to each other. The key to a good relationship is talking. The need to discuss feelings, fears and information is even more important in times of stress. Silence can make you feel distant from your partner. Sharing feelings and facts can help. This will help you make decisions.
- Change roles when needed. The stress of an illness can change the roles of family members:
 - The mother who once took care of the home may now be too busy.
 - Another family member may need to help out in the home.
 - The father may have made decisions in the past. Now the mother is with the sick child and may be the one who helps make decisions with the healthcare team.

Changes in roles can cause stress in a marriage or a family. Some short-term role changes may be needed to help the ill child. Other changes may be long-term if they help the family work together.

Suggestions for Divorced Parents

While divorce is hard on most families, problems can get worse when your child is ill. Your child may use his illness to bring divorced parents closer. In other cases, he may play parents against each other to feel in control. Do not let divorce affect your child's care. You are still a parent and good communication is key. Tips to help avoid problems:

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

Impact of Transplant on Siblings

Siblings (brothers and sisters) also have feelings about your child's kidney disease. They may feel upset, scared and unsure of what will happen. Children of any age will sense a change in their family life. Other children may feel resentment or anger. Mom and dad are spending time with the sick child. Siblings may have problems of their own, such as depression, trouble sleeping, physical complaints or school problems.

How to help siblings:

- It is normal to spend more time with your sick child. Set aside time to spend with other children.
- Tell them you love them and they are special.
- Talk about the transplant so they understand. Help them understand the illness and how it affects their brother or sister. Tell them kidney disease is not contagious and they are not to blame.
- Take them to the hospital. Help them feel involved in the care of your sick child. This may help decrease fears and help them feel close to their brother or sister.
- Ask a friend or relative to stay in your home, rather than send your children elsewhere.
- Ask your children to help with chores. This makes them feel needed.
- Talk with their teachers. Teachers can support your children and let you know about any problems at school.
- Ask for help from a member of the healthcare team such as a child life specialist, social worker or child psychologist.

Impact of Transplant on Grandparents

Grandparents have many responses when they hear their grandchild has kidney disease. They may feel shock and disbelief or feel guilty for living a long life. They may also feel blame, thinking they passed kidney disease through the family. Grandparents may also feel sadness, not just for their grandchild, but also for their son or daughter. Include grandparents in meetings with the healthcare team. This can help them understand the treatment plan.

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

- Relieve you in the hospital or help at home
- Give your other children attention, comfort and love
- Serve as a contact person, giving others information, so you don't have to spend as much time on the phone

Programs and Events

The Children's Kidney Transplant team knows that there is more to treating your child than just taking care of his health. We know it's about treating the whole child. This means enhancing your child's quality of life while in our care. We also know that your child's life is centered on his family. That is why we offer Second Chance programs that involve the entire family. Some of the programs are listed here:

Teen Program

- Teens ages 14 to 20
- Teens participate in activities, which provide a great opportunity for teens to interact with peers in a fun and relaxing environment.

Parent Support Groups

- Support groups are scheduled to give parents an opportunity to gain support from each other and members of the transplant staff.
- Educational materials and guest speakers are provided.

Spring Evening with the Atlanta Braves

- Transplant recipients, families and staff are invited to a picnic and parade around the bases at Turner Field prior to the first pitch.
- Families have the opportunity to meet and have their photograph taken with Atlanta Braves players before enjoying the game.

Camp Independence

- Children and teens ages 8 to 18 who have been diagnosed with kidney disease, are on dialysis, or have received an organ transplant
- A week-long summer camp held at Camp Twin Lakes in Rutledge, GA
- Campers participate in team-building activities, build friendships and make memories that last a lifetime.

Family Camp

- A fall weekend getaway held at Camp Twin Lakes in Rutledge, GA
- Families participate in open, organ-specific discussion groups.
- Activities are centered on family-friendly themes and include: canoeing, swimming, square dancing, learning to play instruments, watching African dancers, mountain biking, fishing, archery, wall climbing, and arts and crafts.

Winter Event

- A festive party in early December at varying locations in metro Atlanta
- Picture-taking with Santa Claus and his elves
- Activities include: cooking decorating, face painting, T-shirt decoration and many other holiday-themed activities

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

Resources

Financial Resources

At times, the cost of a transplant may seem overwhelming. 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 evaluation and transplant
- Meet with you through the transplant evaluation to review your insurance benefits
- Answer benefits questions
- Help assess your financial needs
- Talk about making 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 for which you qualify
- 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 regarding Medicare, Medicaid, Georgia's PeachCare program and hospital and doctor payment plans.
- Which government assistance your child can receive. The counselor can help you fill out forms and paperwork. There may be a lot of paperwork to complete. Fill out all the forms as soon as possible. The sooner the papers are sent, the sooner you can receive benefits. This process may take weeks or months to complete.

Please let the office know if your insurance coverage has changed. Medical bills can be confusing. Please let the financial counselor know if you are having any financial trouble regarding 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," please contact your insurance company to discuss 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 contact the hospital financial counselor to help you get this information from your transplant surgeon.
- Bring a copy of your insurance benefits with your deductible and co-payment amounts each time you visit the hospital.
- Be sure to tell the transplant office right away of any changes in your address, phone number or insurance coverage.

Helpful Hints in the Billing Process

You will receive bills from several places: hospital bills, known as technical or facility fees, and doctor bills, known as professional fees.

- If you have a question about a bill, please call the phone numbers listed on your billing statement.
- Make a file for hospital bills and insurance forms. This will help you to track payment, denials and requests for more information.
- You may need to call your insurance company to ask questions about the transplant. Ask to speak to someone that can answer transplant-benefits questions.
- Below is a list of common offices that will send you bills:
 - Children’s Healthcare of Atlanta for all services received at any Children’s hospital or satellite location
 - Emory Children’s Center for any doctor-related services
 - Emory Clinic for any radiology, pathology and anesthesiology services
 - Other staff or doctors who care for your child
- Read bills closely. You may receive statements that are still pending payment. These statements are for your records and are not bills. Please respond to all inquiries from your caregiver’s billing offices or your insurance company.

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 occur three months prior to the month your child becomes eligible for Medicaid.

Medicaid may be able to pay for:

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

Children’s has an onsite Medicaid office located on the first floor of Children’s at Egleston and Children’s at Scottish Rite. A DeKalb County or Fulton County case manager is on staff at each office.

Medicare

Medicare is a health insurance program for:

- People 65 years of age and older
- Some people with disabilities less than 65 years of age

Medicare has two parts:

- Part A (hospital insurance) helps pay for:
 - Inpatient hospital care
 - Some skilled nursing facility care
 - Hospice care
 - Some home healthcare

Most people get Part A as soon as they turn 65. 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 doesn’t cover like some home healthcare

Part B helps pay for these covered services and supplies when they are medically necessary. You pay the Medicare Part B premium monthly. Premium rates can change yearly. In some cases, this amount may be higher if you did not choose Part B when you first became eligible at age 65. The cost of Part B may go up 10 percent for each 12-month period that you could have had Part B but did not sign up for it. You will have to pay this extra 10 percent for as long as you remain eligible for Medicare.

Resources at Children’s

Family Center

The Children’s Betty and Davis Fitzgerald Family Center is located at Egleston on the Second Floor (Butterfly elevators) of Tower Two. It includes:

Sleep Rooms

- All sleep rooms accommodate two people and can have either two twin beds or two sleep chairs; or one twin bed and one sleep chair.
- Only the parent or legal guardian of children in the intensive care unit (ICU) can use sleep rooms.
- Only two family members may sleep in a room at one time. Children 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 9 a.m. and 2 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.
- You cannot have a sleep room once your child has been discharged from the ICU.
- Sleep rooms are assigned each day based on a lottery system.
- Contact the front desk in the center or a service ambassador for more information.

Showers and Restrooms

- Private showers and restrooms are available for parents and guardians.
- 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 to your family.
- Laundry can be done between 7 a.m. and 10:30 p.m.

Exercise Room

- Includes a treadmill and stationary bike
- Open 8 a.m. to 10 p.m.

Family Kitchen/Lounge

- Vending machines
- Ice machine
- Family refrigerator

Family Library

The Family Library is open from 10 a.m. to 6 p.m., Monday through Friday, and noon to 6 p.m., Saturday and Sunday, and includes:

- 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 computers for adults, two for children and two for adolescents and young adults
- Access to the Internet for e-mail and medical information searches
- Library staff to assist you

Business Center

- Open 8 a.m. to 10 p.m., seven days a week
- Four computers with Internet access and printing available from 10 a.m. to 6 p.m.

Pediatric Intensive Care Unit (PICU)

- A family center is available for families with children in the PICU on the Fourth Floor of Tower One. It contains parent sleep areas and other amenities. Visitors should use the lobby or publicwaiting areas.
- A play area is available for children. A space for patient activities is located on each floor. Children must always be with an adult.
- Family members younger than age 18 must have an adult with them when using the center.

Contact a service ambassador or your child's nurse for more information.

The following resources are provided to you for informational purposes only. Children's is not associated with any of these organizations and does not make any representations regarding their services. Children's does not recommend or endorse any particular products, services or organizations, or make any determination that such products, services or organizations are appropriate for you or your child. Children's assumes no liability or responsibility for acts or omissions of these organizations

Area Lodging

The social work office keeps a list of area hotels that offer reduced rates to families. The transplant social worker can make reservations for you. The social work office is located on the fourth floor of Egleston.

Atlanta Hospitality House

1815 Ponce de Leon Avenue NE
Atlanta, GA 30307
Phone: 404-377-6333

A referral from a social worker or chaplain is required for the first visit.

Mason Guest House

1555 Shoup Court, Decatur, GA 30033
Phone: 404-712-5110

The Mason House offers low-cost lodging for transplant candidates, recipients and their families from Atlanta's four 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

Children's at Egleston
795 Gatewood Road, Atlanta, GA 30329
Phone: 404-315-1133

The Ronald McDonald house provides temporary lodging for families of hospitalized children who live outside of Atlanta. An adult family member or guardian must be present with children at all times. 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 usually done before a transplant.

Some of the more common resources include:

Children's Organ Transplant Association (COTA)

2501 COTA Drive
Bloomington, IN 47403
Phone: 800-366-2682
Web site: www.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, GA 30328

770-457-3796 or 866-428-9411

www.gatransplant.org

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

National Organization for Rare Disorders (NORD)

P.O. Box 1968, Danbury, CT 06813

800-999-6673

www.rarediseases.org

Manages drug cost share program for individuals who cannot afford cyclosporine.

National Foundation for Transplants

1102 Brookfield, Suite 200, Memphis, TN 38119

800-489-3863 or 901-684-1697

www.transplants.org

Limited emergency grants available for medicines.

Pharmaceutical Manufacturers Association

1100 Fifteenth Street NW, Washington, D.C. 20005

Publishes the "Directory of Prescription Drug Indigent Programs."

You can get a copy by writing to the company.

The Sunshine Foundation

1041 Mill Creek Drive, Feasterville, PA 19053

215-396-4770

www.sunshinefoundation.org

National, nonprofit organization that grants wishes for seriously ill children ages 3 to 21. Contact the organization for more information.

United Network for Organ Sharing (UNOS)

P.O. Box 2484, Richmond, VA 23218

888-894-6361

www.unos.org

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

Web Sites

The following is a list of informative Web sites about pediatric kidney transplants. Children's has not reviewed all of the sites listed as resources and makes no claim regarding their content or accuracy. Children's does not recommend or endorse any particular products, services or the content or use of any third party Web sites, or make any determination that such products, services or Web sites are necessary or appropriate for you or for the use in rendering care to patients. Children's is not responsible for the content of any of the sites. Use of these links is at your sole risk.

Kidney-Related Sites:

National Kidney Foundation

www.kidney.org

National Institute of Diabetes and Digestive and Kidney Diseases

www.niddk.nih.gov

American Urological Association

www.urologyhealth.org

Immunizations Contraindication

www.cdc.gov/nip/recs/contraindications.pdf

National Immunization Program

www.cdc.gov/nip/default.htm

National Transplant Assistance Fund

www.transplantfund.org

Partnership for Organ Donation

www.transweb.org/partnership

LifeLink

www.lifelinkfound.org

Sandrine's Gift of Life

www.sandrinesgift.com

Local Georgia Resources:

Children's Healthcare of Atlanta

www.choa.org

Atlanta Chamber of Commerce

www.metroatlantachamber.com

Atlanta Hotel Guide

<http://atlanta.hotelguide.net/>

MapQuest

www.mapquest.com

Georgia Department of Human Resources

www.dhr.georgia.gov

Georgia PeachCare

www.peachcare.org

Medicare

www.medicare.gov

Centers for Medicare and Medicaid Services

www.cms.hhs.gov/medicaid

Glossary

Absorption The degree and speed at which a drug enters the bloodstream.

Alport Syndrome An inherited disease that affects the glomeruli (filtering units in the kidney).

Anemia A condition caused by too few red blood cells in the body.

Anesthesia A medicine that puts your child to sleep during surgery.

Anesthesiologist The doctor who administers anesthesia.

Antibiotic A medicine used to fight infections.

Antibody A protein made by the body to fight foreign matter, such as germs.

Antigen A type of foreign matter in the body, such as a transplant, that triggers an action by the immune system. This action leads to the production of antibodies. Antibodies then try to destroy the antigen (transplanted organ).

Anesthetic A medicine that reduces pain in a local area, such as novocaine for pulling teeth. Some types can also be used to put people into a deep sleep and are used for surgery.

Arteriogram An X-ray of the arteries. A dye is used to help the arteries “show up” on the X-ray.

Autoimmune Disease A condition where a person’s immune system attacks its own tissues as if they were unknown substances.

B Cell A type of white blood cell that helps the immune system with antibody production.

Bacteria Germs that can cause disease.

Bioavailability A measure of how much of a drug dose is absorbed into the bloodstream. This helps doctors know how much of the drug gets to the part of the body it is intended for.

Biopsy A piece of tissue 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 lab test that measures the level of urea in the blood. Urea is formed when protein breaks down in the body. It is carried by blood to the kidneys and removed through the urine. Poor kidney function causes BUN to rise.

Creatinine Made as the body uses muscle and energy. It is made and removed from the body by the kidneys. When the kidneys do not work well, creatinine levels will be high.

Cross-Match Blood Test A test done before a living donor transplant that checks and matches your child for antibodies to a potential donor.

Cytomegalovirus (CMV) A common viral infections that affect most adults.

Deceased Donor Transplant A diseased kidney is replaced with a healthy kidney from a person who recently died.

Dialysis A treatment for kidney failure that uses a machine to filter body fluid and waste and helps perform the work of healthy kidneys.

Diuretic A drug that helps the kidneys make and excrete more urine.

Dysplastic or Cystic Kidneys Multiple cysts that grow in the kidneys and are usually present at birth.

Edema Excess fluid in body tissues.

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

Enzyme A protein made in the body that can change a substance from one form to another.

Epstein Barr Virus (EBV) A common viral infection that affects most adults.

Glomeruli Tiny blood vessels within the kidneys that filter waste from the blood.

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

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

Hematocrit Measures the number of red blood cells in the blood. A low hematocrit can occur with anemia or blood loss.

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

Hemoglobin The substance that carries oxygen in red blood cells. Hemoglobin plays an important role in carrying oxygen through the body. It also shows if iron in the blood is low, which is called anemia.

Hemolytic Uremic Syndrome (HUS) A condition that affects the kidney's blood and blood vessels.

HLA System Antigens that are present on human white blood cells (leukocytes) and tissues.

Hypertension High blood pressure.

Immune Response A reaction of the immune system to a foreign material.

Immune System The system that protects the body from harmful substances, such as germs and cancer cells.

Immunity Being able to resist a disease or harmful substance.

Immunosuppressants Medicines given to help prevent rejection of a transplanted organ.

I.V. or Intravenous In the vein. It is a way to give medicines or fluids directly into a vein.

I.V. Catheter A small needle with a hollow tube put into a vein. It is used to give medicines or fluids.

Kidney One of the two kidney-bean-shaped organs on both sides of the spine, just above the waist. They rid the body of waste and maintain fluid balance by producing urine.

LifeLink Foundation A nonprofit organization that recovers organs and tissues for transplants.

Living Donor Transplant A diseased kidney is replaced with a healthy kidney from a living person.

Lupus Erythematosis A chronic inflammatory disease that can affect the kidney and other organs. The cause of the disease is unknown.

Malignant Tumor A tumor made up of cancerous cells that have the ability to spread and to invade and destroy tissue.

Match The compatibility between the person who receives an organ and the donor. In general, the better the "match," the greater the chance for success with a transplant.

Nephrologist A kidney doctor who cares for your child before and after transplant.

Nephropathy A 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 from the blood.

Neutrophil A type of white blood cell.

Noncompliance Failure to follow the instructions of one's healthcare providers, such as not taking medicine as prescribed or not showing up for clinic visits.

Orally By mouth.

Organ Procurement Organization (OPO) Serves as the organ link between the donor and recipient. It retrieves, preserves and transports the organ for transplant. They are part of the United Network for Organ Sharing (UNOS).

Peak Levels A time when medicine levels in your child's blood are highest.

Pediatric Intensive Care Unit (PICU) The intensive care unit at Children's at Egleston is dedicated to the care of pediatric patients.

Percent Antibodies The amount of antibodies present in the blood. Antibodies are produced as a result of pregnancy, blood transfusions and transplants. 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 wastes and return electrolytes to the body.

Potassium A mineral found in the body. It is needed for proper nerve and muscle function. Excess potassium leaves the body through urine. When the kidneys do not work well, potassium levels will be high.

Prednisone A steroid medicine taken by most transplant recipients to help prevent rejection.

Prophylactic Medicine A medicine that helps prevent disease.

Rejection An immune response against grafted tissue, such as a transplanted organ. If it is not successfully treated, the transplant can fail.

Renal Refers to the kidney.

Renal Function Tests Tests to check your child's urine to find out about his kidney function.

Renal Ultrasound (also called a sonogram) A test that provides pictures of organs in the abdomen (belly).

Re-transplantation A second transplant. Due to organ rejection or transplant failure, some patients need another transplant. If this happens, they return to the waiting list for another organ.

Sclerosis A hardening of tissues that results from several causes, such as inflammation or disease.

Sensitized Being immunized, or able to have an immune response against an antigen. It often occurs from a previous exposure to that antigen.

Shingles A herpes virus infection (herpes zoster) that can affect a nerve, causing a rash and pain along the nerve track in the body.

Sodium A mineral needed for body function. It is the main salt in blood and is also a part of table salt (sodium chloride).

Status The degree of medical urgency for patients waiting for a kidney transplant.

Survival Rates How many patients or transplanted organs are alive or functioning after transplant. Survival rates are often given at one, three and five 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 A blood test to check for human leukocyte antigens (HLA). It is also called "genetic matching." Tissue typing is done for all donors and recipients before a transplant.

Trough Levels The time when medicine levels in your child's blood are lowest.

United Network For Organ Sharing (UNOS) An organization that helps advance organ availability and transplantation by uniting and supporting its communities. It helps patients through education, technology and policy development.

Virus A very small type of germ that causes infection.

Waiting List After evaluation, patients are added to the national UNOS waiting list by the transplant center. Lists are made based on area of the country and organ type. Each time a donor organ becomes available, the UNOS computer makes a list of potential recipients based on factors such as tissue typing, organ size and medical urgency. Through this process, a "new" list is made each time an organ becomes available.

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

