



Kidney & Liver

CHILDREN'S OF ALABAMA
PEDIATRIC TRANSPLANT CENTER

Dear Colleague,

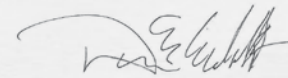
At Children's of Alabama, we have a rich history in the field of pediatric solid organ transplantation in conjunction with The University of Alabama at Birmingham (UAB). For decades children received pre and post transplant care at Children's, with the actual transplantation performed at UAB. We are now happy to announce the opening of the Pediatric Transplant Center at Children's of Alabama, located in the new Benjamin Russell Hospital for Children.

This fulfills a long-time vision to house the full complement of pediatric transplant and related services under one roof for the benefit of children in Alabama and the region. Our transplant team is multidisciplinary and includes transplant surgeons, hepatologists, nephrologists, gastroenterologists, anesthesiologists, physician assistants, transplant RN coordinators, and nurses. In addition, an entire team of support disciplines, including pharmacists, nutritionists, social workers, child life specialists, physical and occupational therapists, and chaplains, provide unparalleled care for our patients.

Children's is specifically focused on enhancing the patient-centered care that is essential to the well-being of these very sick children. We recognize the needs of each patient and family as unique and the transplant journey can be extremely stressful. By providing private patient rooms, dedicated operating suites and play therapy rooms we put the patient and family at the center of the care team and bring the finest in medicine, technology, and compassion to each child.

The consolidation of pediatric transplant services under one roof eliminates some of the stressors of hospitalization and treatment, by providing immediate access to their needs in a child-friendly environment. This also allows the physicians and transplant team to provide the best possible care to the children who come to us for this life-saving surgery and treatment.

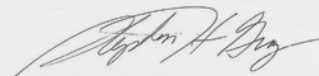
We hope you find this guide to the pediatric transplantation services at Children's of Alabama to be a useful resource as you make the best recommendations for your patients. It is our desire to provide excellent and comprehensive care to children in need of a transplant. We invite you to contact one of us or one of the transplant RN coordinators, at the numbers listed in this guide, should you have any questions or need additional information.



DEVIN E. ECKHOFF, MD
SURGEON - MEDICAL DIRECTOR
DIVISION OF TRANSPLANT



CARLTON J. YOUNG, MD
SURGEON - DIRECTOR
PEDIATRIC TRANSPLANT



STEPHEN H. GRAY, MD
SURGEON
DIVISION OF TRANSPLANT



"Children's of Alabama has one of the largest multidisciplinary transplant programs in the country."



Our Team Approach

The Pediatric Solid Organ Transplant Center at Children's of Alabama provides comprehensive care through a multidisciplinary team of medical clinicians who are dedicated to providing the very best in transplantation services. This team strives to understand the unique needs of each young transplant patient and utilizes an approach which addresses the medical, emotional, and social needs of each patient and their family. Additionally, the team works closely with the patient's referring physician to provide a continuum of care from medical home to referral and evaluation, to post-transplantation and follow-up care.

Transplant Flow



1

REFERRAL

Upon referral from a primary care physician, the Transplant Coordinator completes a demographic and clinical summary sheet and sends it to the Transplant team for review. The Transplant Coordinator collects the medical history, physical examination results, radiology studies, lab work, and requests other needed information from the primary care physician. The transplant surgeons review this information and formulate a customized plan of care. After the transplant office obtains insurance authorization, a transplant evaluation is scheduled with a multidisciplinary team.



2

EVALUATION

The transplant evaluation can be conducted on an outpatient or inpatient basis, and typically requires 1 to 2 days in Birmingham. The evaluation includes diagnostic testing, consultations by Cardiology, Nephrology, Hepatology or any subspecialty relevant to the care. The multidisciplinary team evaluates the patient and provides education throughout the evaluation. This team includes a pharmacist, a nutritionist, a child life therapist, a social worker, a psychologist, and the RN Transplant Coordinator. The patient is presented to the multidisciplinary team for consideration of transplant when all aspects of the evaluation are completed.



3

PRE-TRANSPLANT

After the evaluation, the patient is discharged to his/her local medical provider. Children's of Alabama Transplant Coordinators will list the patient with the United Network for Organ Sharing (UNOS) and obtain authorization for the transplant procedure from the insurance company. The patient's listing status with UNOS is based on his/her current medical condition and lab tests. During the waiting period, the RN Transplant Coordinator will be in close communication with the referring physician to keep him/her informed about the patient's condition.



4

TRANSPLANT

When an organ becomes available, the Transplant Coordinator contacts the family and requests that they come to the hospital. The patient is admitted to the Transplant Unit and is prepared for surgery. During the surgery, the family will be updated about the patient's condition and the progress of the procedure. Immediately after surgery, the patient is admitted to the Intensive Care Unit (ICU). The length of time spent in the ICU varies based on each child's needs. Once the patient is stable, he/she will be transferred to the Transplant Unit.



5

POST-TRANSPLANT AND FOLLOW-UP CARE

The organ recipient and family will be educated on transplant maintenance and care including: medications, nutrition, scheduled lab work, clinic visits, activity level, returning to school, immunizations, and dental care, as well as individual specific instructions.

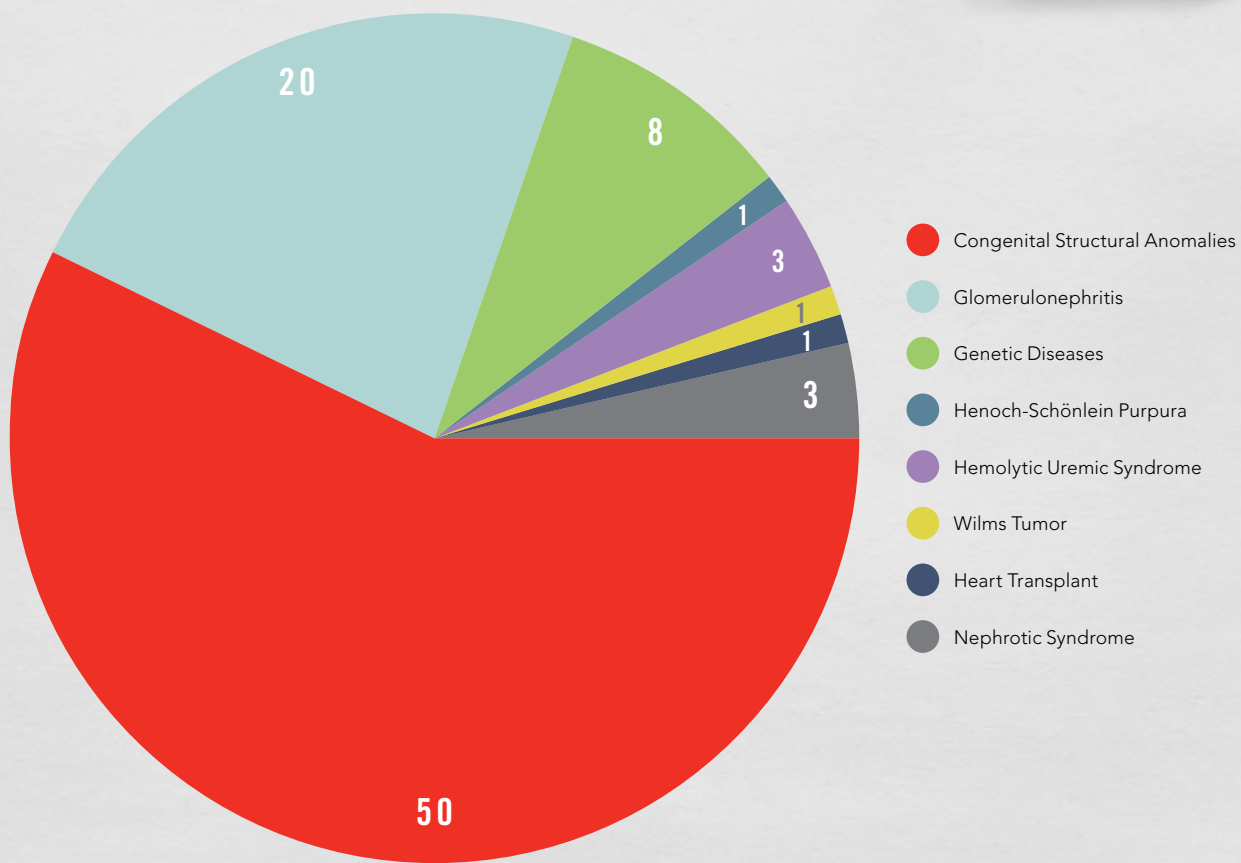
At a typical follow-up clinic visit, the doctor and the nurse will discuss the patient's current health, check the patient's weight and blood pressure, and perform a physical examination. Blood work will be ordered at each appointment to evaluate the organ's function, to observe for signs of rejection, and to monitor the effectiveness and level of the immunosuppressant medications.

Throughout the transplant process, the referring physician will be regularly updated on the patient's progress by the Transplant Physician or the Transplant Coordinator. When the patient is discharged, the Transplant Coordinator will send the referring physician a packet of information outlining a treatment regimen, including medical records, current medications, and the recommended laboratory schedule. Transplant surgeons will continue to keep the referring physician aware of any changes to immunosuppressant medications and annual evaluations.





Renal Diagnoses for Transplant Patients



Kidney



Graph: Data from 2008-2013. N = 87.

----- SINCE 1968, OVER -----

500

----- pediatric kidney transplants have been successfully
performed, with outcomes above the national average. -----

THE RENAL CARE TEAM AND THE DIVISION OF TRANSPLANTATION SURGERY AT UAB have provided comprehensive care for transplant patients since 1968. During that time, over 500 pediatric transplants have been successfully performed, with outcomes above the national average. In March of 2013, the pediatric transplant services transitioned to Children's of Alabama's state-of-the-art Benjamin Russell Hospital for Children. Our newly approved Transplant Center continues to partner with UAB to provide excellent care. Our team consists of highly skilled UAB surgeons, pediatric nephrologists, dedicated nurses, transplant coordinators, social workers, nutritionists, child life professionals, pharmacists, and other specialists. Our experienced team performs the evaluation phase in our Transplant Outpatient Clinic and facilitates all aspects of care throughout the transplant process.

Pediatric Nephrology

The Pediatric Nephrology team at Children's of Alabama includes specialized nurses, nutritionists, social workers, family counselors, and physician faculty, who evaluate and treat children with kidney disease from infancy to adolescence. We care for those with urinary tract infections, hypertension, hematuria, proteinuria, glomerulonephritis, nephrotic syndrome, vasculitis, systemic lupus erythematosus, and chronic kidney disease — including those who require chronic dialysis or transplantation.

The Renal Care Center is one of the largest comprehensive pediatric dialysis units in the United States offering acute and chronic dialysis therapies. The specialized staff offers peritoneal dialysis, hemodialysis, continuous renal replacement therapies, kidney biopsies, and plasmapheresis for infants, children, and adolescents. In order to maximize health and quality of life, the Renal Care Center at Children's of Alabama is one of three pediatric programs in the country that provides training for qualifying pediatric patients to perform hemodialysis at home using an NXSTAGE Portable Dialysis Machine.

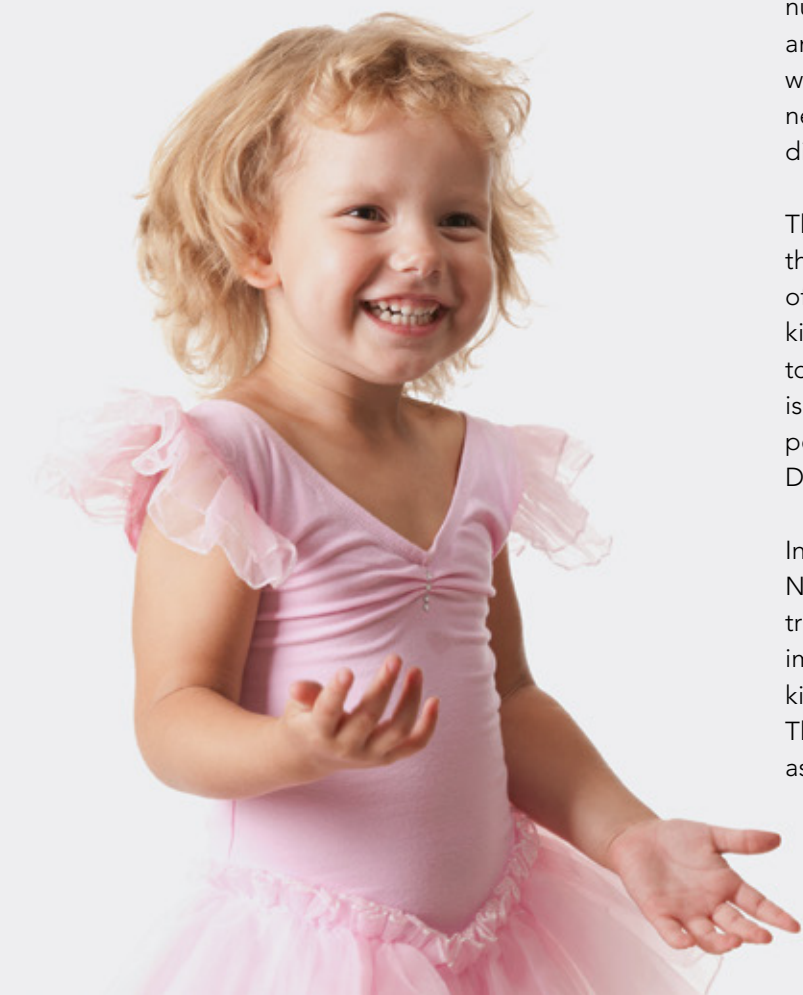
In conjunction with Pediatric Transplantation Surgery, the Division of Pediatric Nephrology at Children's of Alabama is one of the largest pediatric kidney transplant programs in the country. Multi-center studies determine the optimal immunosuppression therapy to maximize long-term outcomes for children with kidney transplantation. The research and clinical interests of the division are broad. The division participates in multi-center studies on drug discovery/pharmacokinetics, assessment, progression, and treatment of chronic kidney disease in children.

Pediatric Gastroenterology

The Division of Pediatric Gastroenterology and Nutrition at Children's of Alabama provides comprehensive, multidisciplinary evaluation and management of all pediatric gastrointestinal, liver, and nutritional problems. These may include such common conditions as gastroesophageal reflux, abdominal pain, and constipation, to complex problems like inflammatory bowel disease, liver transplants, metabolic diseases, and nutritional disorders. State-of-the-art GI laboratory and endoscopy facilities are used to perform a number of diagnostic and therapeutic procedures including:

- Upper and lower endoscopy with biopsies
- Polypectomies
- Variceal Sclerotherapy and Banding
- Foreign body removal from upper GI tract
- PEG Placement
- Dilatations
- Percutaneous liver biopsies
- PH probe
- Hydrogen Breath Testing
- Anorectal Motility Testing

Multidisciplinary patient centered care is the focus of the Division. Close interaction with Pediatric Surgery, Radiology, Pathology, Anesthesiology, and Nutrition services provide ample opportunity for optimizing patient care. Special interests of the Division Members include GERD, abdominal pain, motility disorders, liver disease, lipid disorders, functional GI disorders, childhood obesity, and inflammatory bowel disease. An ACGME accredited subspecialty training program offers subspecialty residents a wide range of clinical experience.



It didn't seem right that Jashawn's skin was pale and his eyes were teary and weak.

JASHAWN
HOWARD



RASHUNDRA HOWARD KNEW SOMETHING WASN'T RIGHT with her baby. Even though he was her first child, it didn't seem right that Jashawn's skin was pale and his eyes were teary and weak. She took him to the doctor, and from there he was airlifted from his hometown in Phenix City to Children's of Alabama. That's when doctors ran tests and discovered his kidneys had failed.

"I was in shock," Rashundra says. "It was just scary."

Jashawn had to go on dialysis to keep him alive. Three days a week, Jashawn underwent dialysis first at the hospital and then at home. But eventually he would need a new kidney. In the meantime, he needed to gain weight. He couldn't get on the transplant list until he was at least 10 kilograms, or about 22 pounds. It didn't take long. By January 2011, he was put on the transplant list. In March of 2012, Rashundra got the call that a kidney had become available for Jashawn.

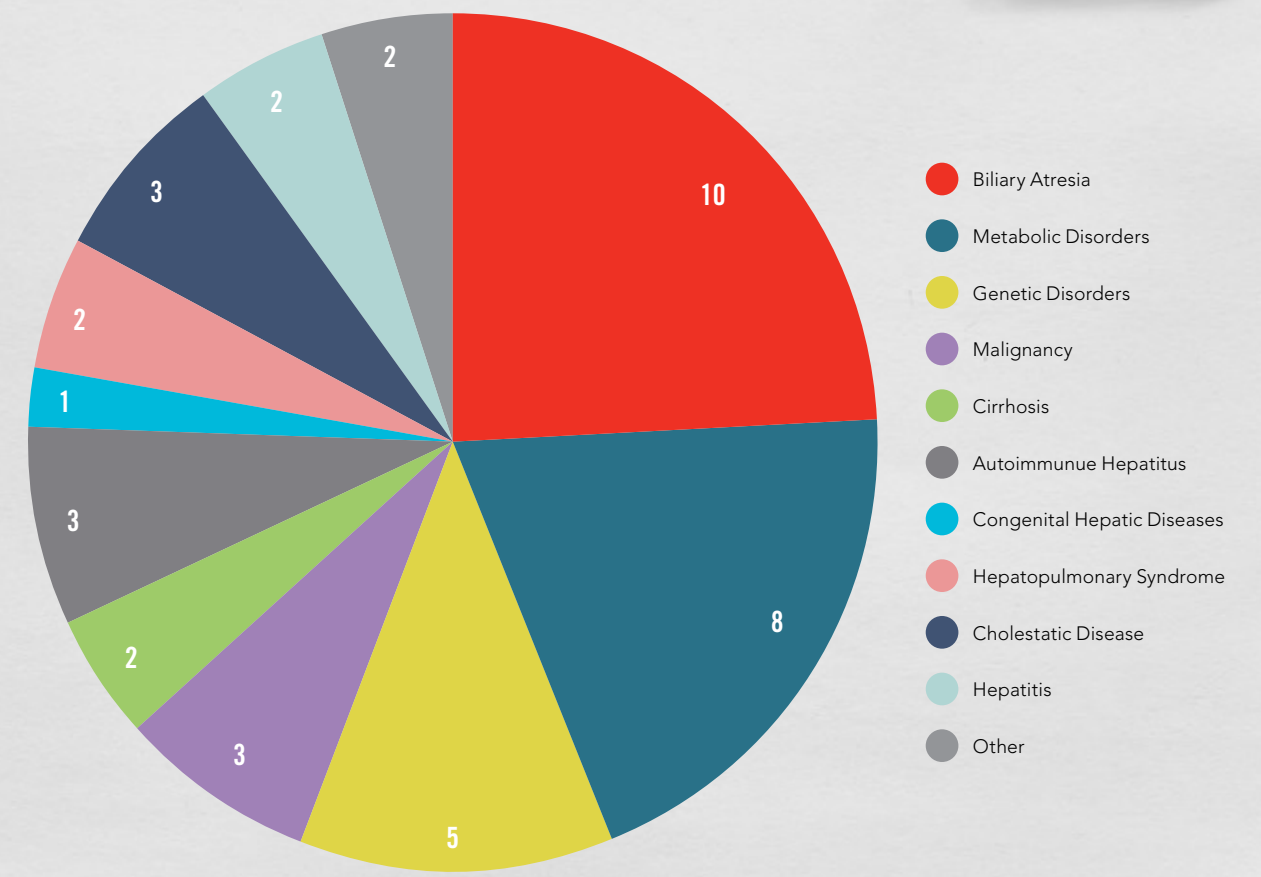
"They called us that morning and said pack your bags because they had a kidney," Rashundra recalls. It was a long, tough day, but almost immediately after surgery, Jashawn looked better, she says.

For people with kidney disease, a transplant can be a lifesaver, but the drugs used to help the body accept a new kidney can wreak havoc with the body's insulin production. For some patients, like little Jashawn, it can cause diabetes in previously non-diabetic transplant recipients. Jashawn had to start taking medication for diabetes, but since surgery nearly six months ago, he is improving and beginning to wean off those medications.

Today, Jashawn is an active toddler. He'll soon turn 3 and has adopted a vibrant personality. "He's doing well," Rashundra says. "And we are all very happy."



Liver Diagnoses in Transplant Patients



Liver



Graph: Data from 2008-2013. N = 39.

----- SINCE 1993, -----

150

----- liver transplants have been performed in
collaboration with UAB transplant services. -----

THE PEDIATRIC LIVER TRANSPLANT TEAM has collaborated with UAB transplant services since 1993 and has performed 150 liver transplants year to date, exceeding the national average for both one-year and three-year graft and patient survival rates. The pediatric transplant services transitioned in March 2013 to Children's of Alabama's Benjamin Russell facility. Our patients are cared for by a skilled, multidisciplinary team including UAB surgeons, pediatric gastroenterologists, hepatology services, liver transplant coordinators, and other specialists in our newly approved Transplant Program. The evaluation phase is completed in the outpatient transplant clinic by the entire team including a social worker, nutritionist, child life professional, pharmacist, and other specialists. Our team coordinates all aspects of care during the evaluation phase, transplantation, and post-procedure care to ensure positive outcomes.

The first sign that anything was wrong with the little girl came during a doctor's visit.

RAINE
KEIR



SONYA WHITE COULD NEVER HAVE GUESSED the role she would play in the life of her great niece Raine Keir. Looking back, she says it's been a "scary ride, but this is a ride I'd do again tomorrow."

Sonya and her husband have spent a lot of time caring for Raine since her birth on April 29, 2008. When she was 3½ months old, the Whites became her primary guardians. "We changed our whole lives around to care for her," Sonya recalls.

The first sign that anything was wrong with the little girl came during a doctor's visit, when Sonya mentioned Raine's odd coloring. The doctor ordered tests and found her bilirubin to be unusually high. High levels of bilirubin can lead to serious health complications and may indicate a more serious problem with the liver or pancreas. Raine was scheduled to have more tests the following week, but before she could make that appointment Raine became violently ill.

Sonya rushed her to the emergency room, where doctors performed more tests. "I remember they came out and I'll never forget it. They said Raine would have to have a liver transplant," Sonya says. They were sent to Children's of Alabama where, Sonya says, "Everything fell together."

Doctors explained that Raine had developed hepatitis before she was born, but went undiagnosed even after birth. Her condition escalated into a liver disease known as biliary atresia, and then she developed cirrhosis of the liver. Her condition was dire. She was placed on the transplant list, and Sonya was told it could take up to two years for Raine to get a liver.

However, it took just a few weeks for a liver match to be found. On Christmas Eve 2008, just before her 8-month birthday, Raine underwent transplant surgery.

Today, Raine is an energetic 4½-year-old. Her health has dramatically improved. She still has regular checkups at Children's of Alabama and considers it her home away from home. "I cannot express how grateful I am to everyone at Children's," Sonya says. "They are family to us."

The Referral Process

SOLID ORGAN TRANSPLANT Children's of Alabama utilizes a team approach of comprehensive care that includes the referring physician. The patient referral process is designed to be straightforward and simple for the referring office and the patient.

STEP ONE

A demographic and clinical summary sheet is completed and sent to the Transplant Team with copies of the following patient records:

- Recent medical history and physical or clinical summary
- Laboratory data and clinic notes
- Hospitalization records
- Renal biopsy, radiology, renal ultrasound, and VCUG
- Blood type
- OP notes
- Discharge summaries
- Immunization records
- TB skin test
- Dental records/checkup

STEP TWO

The information is reviewed by the surgical team and insurance authorization is obtained.

STEP THREE

After authorization is obtained, a transplant evaluation is scheduled.



PLEASE SEND REFERRAL INFORMATION TO:

Pediatric Solid Organ Transplant
Attn: Transplant RN Coordinator
Children's of Alabama
1600 7th Avenue South
Birmingham, AL 35233

Phone: 205-638-6631
Fax: 205-638-2319



Children's
of Alabama®

UAB MEDICINE

PEDIATRIC TRANSPLANT PROGRAM

ChildrensAL.org/transplant

205-638-9100