



CONGENITAL HEART CENTER

Building The Future of Congenital Heart Care

Levine
 Children's
Hospital

Our world revolves around **children.**



Carolinas HealthCare System

www.levinechildrenshospital.org

www.carolinashealthcare.org/congenitalheart

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our mission

THE CONGENITAL HEART CENTER AT LEVINE CHILDREN'S HOSPITAL ASPIRES TO BE ONE OF THE NATION'S PREEMINENT PEDIATRIC CARDIOVASCULAR PROGRAMS, CHOSEN BY PATIENTS BASED ON OUR QUALITY OUTCOMES AND SUPERIOR PATIENT EXPERIENCE.

BUILDING THE FUTURE OF CONGENITAL HEART CARE, **TOGETHER.**



Dear Colleagues,

We are pleased to introduce The Congenital Heart Center at Levine Children's Hospital. Just over three years ago, we began constructing a new congenital heart program with the intention of building a resource for our community, our region and beyond. We've come a long way. In this book, we will share our program's highlights and illustrate our commitment to be a national leader in the delivery of high-quality care, outcomes and family-centered care.

Our program began with the fusion of two powerful healthcare providers: Sanger Heart & Vascular Institute - the region's leading integrated cardiovascular network, and Levine Children's Hospital - the most comprehensive children's hospital between Washington, D.C. and Atlanta, Georgia. In partnership with Carolinas HealthCare System - the second largest not-for-profit health system in the country, we began the journey of assembling a leading clinical team.

Our blueprint for success is simple: Recruit the finest physicians and clinicians. Foster collaboration between disciplines. Relentlessly pursue quality. Transform processes. Build relationships. Put patients and families first.

What we will highlight in this book are the results of an intensive period of hard work and collaboration. Celebrating three years of service and decades of preparation, it is time to share the outcomes of our collective efforts. With great pride, we will illustrate growing volumes, industry leading survival rates, high patient satisfaction and low infection rates. We will share the successes of our team and, most importantly, the triumphs of our patients.

As our program building continues, we are confident that the investments made today will yield a celebrated center for years to come. We look forward to continuously improving our program and our outcomes, and to partnering with you to better the lives of our patients.

We invite you to learn more about The Congenital Heart Center at Levine Children's Hospital.

Sincerely,

BENJAMIN B. PEELER, MD, FACS

CHIEF, PEDIATRIC AND ADULT
CONGENITAL CARDIAC SURGERY

JAMES RENÉ HERLONG, MD

MEDICAL DIRECTOR,
PEDIATRIC CARDIOLOGY

KSHITIJ P. MISTRY, MD, MS

MEDICAL DIRECTOR,
PEDIATRIC
CARDIOVASCULAR ICU





Carolinas HealthCare System, one of the nation's leading integrated healthcare organizations, provides a full spectrum of healthcare services throughout North and South Carolina. Our diverse network of more than 790 care locations includes academic medical centers, hospitals, physician practices, destination centers, surgical and rehabilitation centers. Recognized for healthcare leadership and innovation, Carolinas HealthCare System opened a dedicated children's hospital in 2007. Today, Levine Children's Hospital is the most comprehensive pediatric hospital between Washington, D.C. and Atlanta, Georgia.

Our sub-specialty programs attract physicians and patients from all over the world. Only five years into our history, Levine Children's Hospital is already ranked on *U.S. News & World Report's* Best Children's Hospitals list in six distinct pediatric specialties, including Pediatric Cardiology and Heart Surgery.

PROGRAM SERVICES AT-A-GLANCE:

- | | |
|--|---|
| - Fetal echocardiography and cardiology | - Pediatric and adult congenital cardiac surgery |
| - Pediatric cardiology, including initial evaluation, preventive medicine and follow-up care | - Heart transplant and ventricular assist device (VAD) |
| - Electrophysiological evaluation and treatment | - Extracorporeal membrane oxygenation (ECMO) |
| - Full-service non-invasive and invasive diagnostics | - Pediatric cardiovascular critical care unit and monitoring (PCVICU) |
| - Cardiac catheterization and intervention | - Adult congenital heart care |

the congenital heart center: a model of care

The Congenital Heart Center at Levine Children's Hospital is more than a place; it's a model of care. Collaboration is at the heart of our success, and the pursuit of excellence is what links our integrated team and propels us forward. From partnering with maternal fetal medicine to diagnose congenital heart disease in-utero, to treating an increasingly complex population of adults with congenital conditions, our multidisciplinary team unites to deliver the highest quality of care to patients from birth to adulthood.

Our program extends past the walls of Levine Children's Hospital. The Congenital Heart Center includes 11 Sanger Heart & Vascular Institute pediatric cardiology practices in North and South Carolina. Our physician team is strategically distributed allowing us to provide the full continuum of congenital heart care to patients across the southeastern United States and beyond.

Our care model is built on a strong foundation of five key concepts:



QUALITY



ACCESS



INTEGRATION



BEST
PRACTICES



FAMILY-
CENTERED
CARE

But above all, The Congenital Heart Center at Levine Children's Hospital is committed to caring for our patients and families as if they were our own. We recognize that our responsibility is not only to heal hearts, but to support the emotional needs of our patients and their families alike. It is the enduring relationships we have built with our patients and their families that will sustain our program for years to come.

// HONORING OUR HISTORY

The roots of Sanger Heart & Vascular Institute's pediatric cardiology expertise, a key contributor to the opening of The Congenital Heart Center in 2009, reaches back more than 50 years. Francis Robicsek, MD, PhD, co-founder of Sanger Heart & Vascular Institute and renowned cardiothoracic surgeon, helped pioneer the first surgical treatments for congenital heart disease, some of which we still use today.

We expect that same spirit of innovation from our physicians today as we continue to build a program that will provide life-changing treatments for years to come.



1956

Paul Sanger, MD, recruits Francis Robicsek, MD, PhD, Chief of Cardiac Surgery at the University of Budapest to join him at Charlotte Memorial Hospital (now Carolinas Medical Center).

1959

Francis Robicsek, MD, PhD, performs western North Carolina's first cavo pulmonary anastomosis for corrected transposition and surgery on complex congenital malformations.



1990

Sanger Clinic surgeons perform Charlotte region's first neonatal cardiac transplant at Carolinas Medical Center.

1957

Francis Robicsek, MD, PhD, and Paul Sanger, MD, establish the first heart catheterization laboratory in western North Carolina at Charlotte Memorial Hospital (now Carolinas Medical Center).

Dr. Robicsek performs western North Carolina's first open heart operation for congenital heart disease.

1984

Sanger Clinic pediatric cardiologists perform first pediatric catheter based intervention in western North Carolina.



Sanger Heart & Vascular Institute

2005

Sanger Clinic joins Carolinas HealthCare System and becomes Sanger Heart & Vascular Institute.

2007

Carolinas HealthCare System opens Levine Children's Hospital.

2011

The Congenital Heart Center performs 302 congenital cardiac surgeries with a mortality rate of 2.4 percent as compared to the Society of Thoracic Surgeons (STS) national average of 3.3 percent. Neonatal mortality was 2.3 percent as compared to the STS national average of 9.3 percent.

2009

Levine Children's Hospital formally establishes the Congenital Heart Center under the direction of Benjamin B. Peeler, MD, FACS, Chief, Pediatric and Adult Congenital Cardiac Surgery; James René Herlong, MD, Medical Director, Pediatric Cardiology; and Kshitij P. Mistry, MD, MS, Medical Director, Pediatric Cardiovascular ICU.



2012

Levine Children's Hospital recognized as one of the 50 Best Children's Hospitals by *U.S. News & World Report* for Cardiology and Heart Surgery, along with five other specialties.

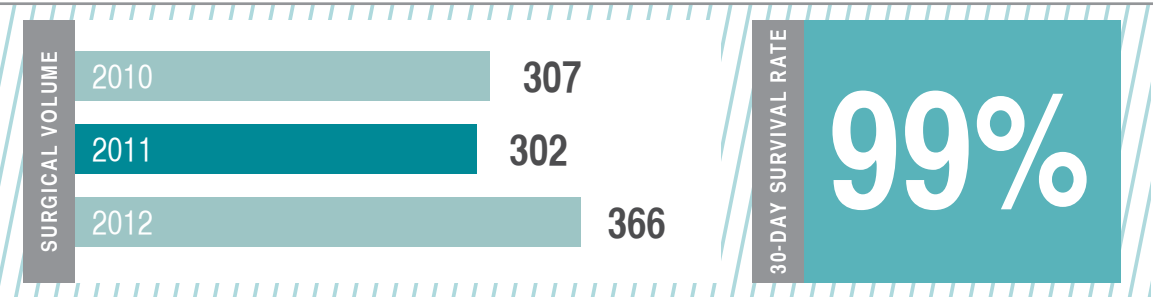


quality and outcomes

The Congenital Heart Center at Levine Children’s Hospital is setting the bar for quality in the southeastern United States and across the country. In a short time, our survival rates have earned recognition by the Society of Thoracic Surgery (STS) and *U.S. News & World Report*. Our commitment to pursuing clinical excellence is further demonstrated by our desire for transparent outcomes reporting.

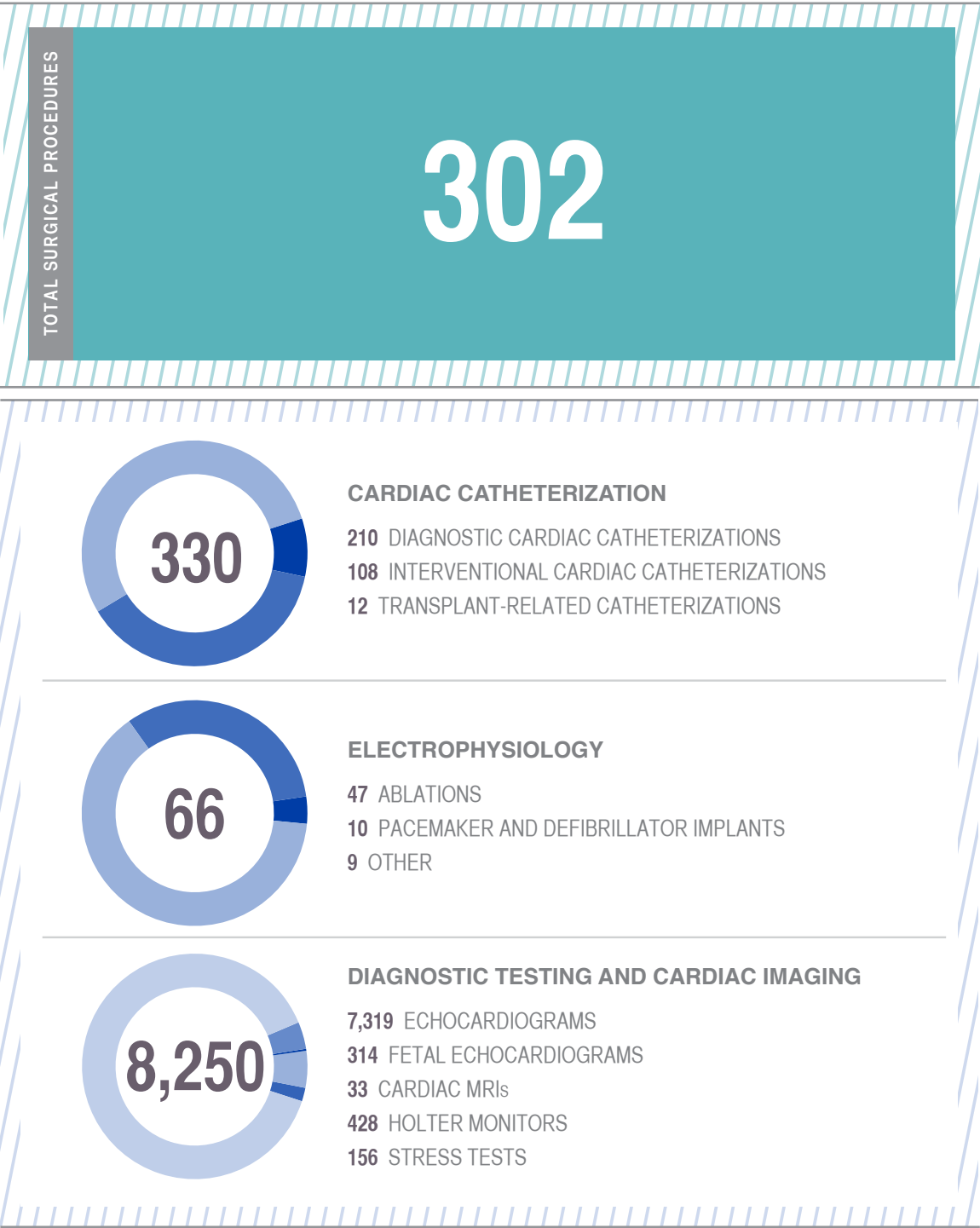
One of the most important reasons to continually evaluate our data is to identify areas for improvement, often comparing ourselves to other hospitals. Here, we share data related to program volume, procedure mortality rates and infection rates.

THREE-YEAR OVERALL SURGICAL VOLUME 2010 - 2012



†STS Benchmark is 2008-2011 mortality rate average

2011 PROGRAM VOLUMES

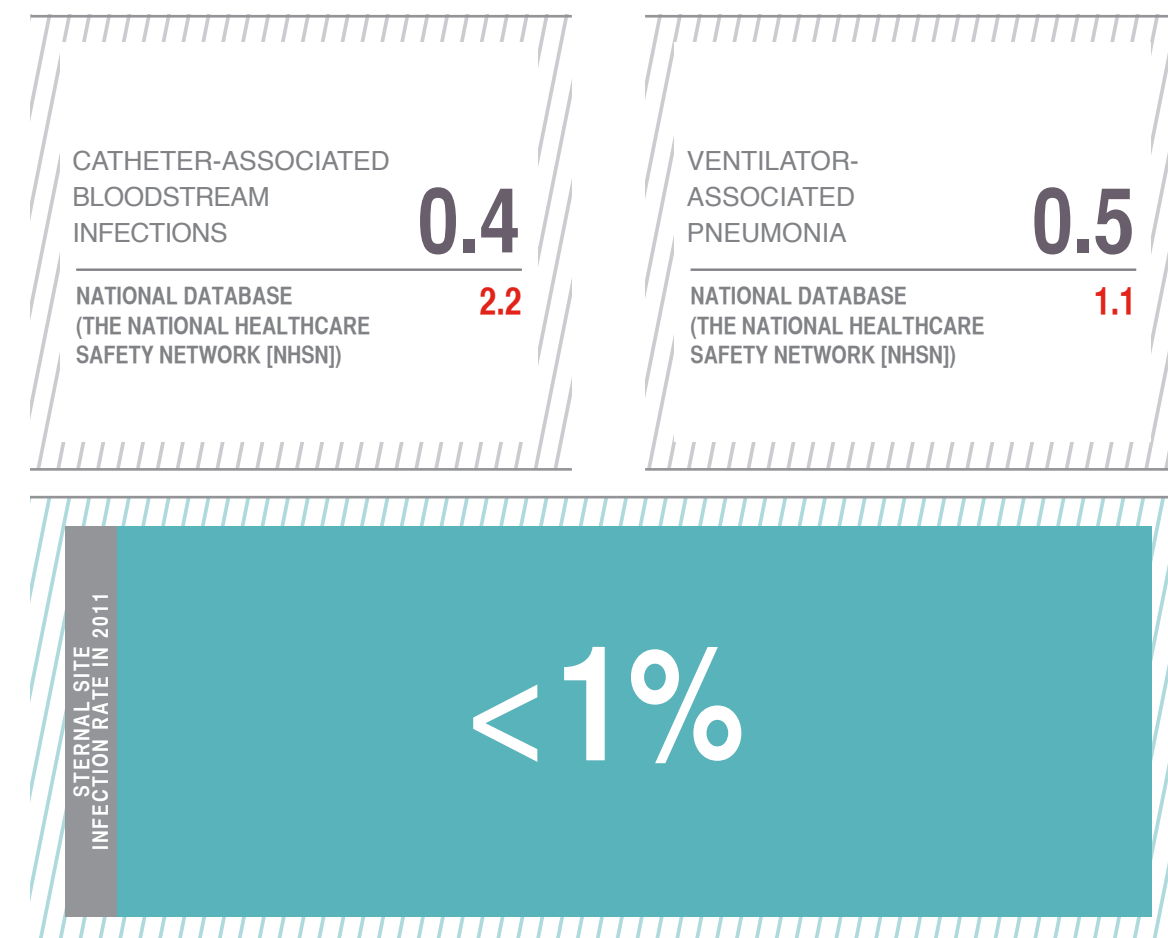


// 2010-2012 INDIVIDUAL PROCEDURE RESULTS



// 2011 INFECTION RATES PER 1,000 DAYS

In an effort to continually improve our performance, we review important metrics – such as patient survival, avoidable complications, and hospital efficiency – on a monthly basis. Included on this dashboard are hospital-acquired conditions, such as preventable infections, adherence to evidence-based guidelines, and quality performance measures endorsed by the Society of Thoracic Surgery (STS) and National Quality Forum (NQF).



IN A SHORT TIME, OUR SURVIVAL RATES HAVE **EARNED RECOGNITION** BY THE SOCIETY OF THORACIC SURGERY (STS) AND *U.S. NEWS & WORLD REPORT*.


†STS Benchmark is 2008-2011 mortality rate average

IN 2011, THE CONGENITAL HEART CENTER EXPERIENCED MORE THAN 8,900 PEDIATRIC CARDIOLOGY VISITS.

overview of services

// PEDIATRIC CARDIOLOGY

MEDICAL DIRECTOR:



JAMES RENÉ HERLONG, MD
Medical Director, Pediatric Cardiology and Echocardiography

Sanger Heart & Vascular Institute’s pediatric cardiology practice has more than a half century of history caring for children. Today, under the The Congenital Heart Center umbrella, it remains the region’s largest pediatric cardiology service with 11 outpatient locations offering initial evaluation, diagnosis and follow-up care for patients from birth to adulthood. The care team includes 10 board-certified pediatric cardiologists strategically placed throughout the region to provide access, care management and treatment to communities near and far. Our comprehensive services include evaluation and treatment for conditions such as:

CONDITIONS TREATED:

- Congenital cardiac defects
- Previously repaired or palliated cardiac defects
- Prolonged QT Syndrome
- Familial hyperlipidemia
- Heart murmurs
- Chest pain

- Congestive heart failure
- Arrhythmias
- Syncope
- Angina
- Cardiac structural abnormalities
- Malformations of the chest
- Palpitations



// ADVANCED DIAGNOSTICS AND CARDIAC IMAGING

We have invested in the industry’s leading diagnostic, cardiac imaging and echocardiography technologies to guide our physicians through the most fundamental step in the continuum of congenital heart disease care: diagnosis. Our echocardiography labs are certified by the Intersocietal Commission for the Accreditation of Echocardiography Laboratories (ICAEL). Staffed by pediatric cardiologists and an expansive team of echocardiography technicians, we conduct more than 8,200 studies per year.

SERVICES INCLUDE:

- Magnetic resonance imaging (MRI)
- Computed tomography (CT)
- Cardiac catheterization
- Electrophysiology
- Remote monitoring in the NICU, PICU, and PCVICU

- Stress and exercise testing
- 24-hour ambulatory and event monitoring, Holter monitoring

// FETAL CARDIOLOGY



K. ANITHA JAYAKUMAR, MD, MBBS, MRCP (U.K.)
Medical Director, Fetal Cardiology

Using state-of-the-art technology, our pediatric cardiologists can diagnose congenital heart disease as early as 12 weeks of gestation. Advanced in-utero evaluation and cardiac prenatal diagnosis allows our physicians to effectively collaborate with obstetricians and other specialists before birth to determine optimal care for the mother and baby. This approach helps rationally and emotionally prepare for each step in the continuum of the baby’s heart care.

We partner with maternal fetal medicine (MFM) specialists and medical geneticists to evaluate patients with risk factors or circumstances that may result in cardiac defects, including:

EVALUATE PATIENTS WITH:

- Abnormal fetal ultrasound
- Family history of congenital heart disease
- Advanced maternal age
- Fetal exposure to select prescription medications or drugs
- Maternal chronic disease like lupus, diabetes or arthritis

- Complicated twin pregnancy
- Abnormal skin fold thickness in the fetal neck
- Assisted conception such as in vitro fertilization (IVF)

NON-INVASIVE FETAL IMAGING

Fetal heart disease is confirmed by a fetal echocardiogram. We offer this non-invasive test in our advanced diagnostic and imaging centers. Conditions we diagnose include but are not limited to:

- Aortic valve stenosis
 - Atrioventricular septal defects
 - Coarctation of the aorta
 - Ebsteins anomaly
 - Hypoplastic left heart syndrome (HLHS)
- Pulmonary arterial hypertension
 - Single ventricle defects
 - Tetralogy of Fallot
 - Transposition of the great arteries
 - Truncus arteriosus

CONTINUING FETAL CARE

Upon diagnosis, our fetal cardiology team coordinates a continuum of care which includes periodic evaluation, education, labor and delivery, and neonatal care. Even before the baby is born, families will have opportunities to meet and discuss all aspects of the baby’s care after birth with a multidisciplinary team of obstetricians, neonatologists, geneticists, pediatric cardiologists and pediatric cardiac surgeons.





// ELECTROPHYSIOLOGY

MEDICAL DIRECTOR:



RICHARD T. SMITH MD, FACC, FAPP
Medical Director, Pediatric Cardiac Electrophysiology and Cardiac Pacing

Our electrophysiology program offers the full scope of evaluation and treatment for arrhythmias in both children and adults with congenital heart disease. Levine Children’s Hospital houses an electrophysiology laboratory for device implants, lead extractions and procedures. Lead extractions are performed in a state-of-the-art hybrid lab in conjunction with an adult electrophysiologist. Our sub-specialty physicians are niche trained in abnormal heart rhythm management and the team offers ongoing care for patients with cardiac rhythm devices. Electrophysiological diagnostics and treatments offered include:

SERVICES INCLUDE:

- Invasive electrophysiology studies
- Non-invasive electrophysiology studies
- Cardiac ablation for arrhythmias
 - Radiofrequency ablation
 - Cryoablation

- 3-D computerized cardiac mapping
- Implantation of pacemakers and ICD devices
- Placement of implantable loop recorders
- Lead extraction



// CARDIAC CATHETERIZATION AND INTERVENTION



JOSEPH A. PAOLILLO, JR., MD, FACC, FAAP, FSCAI
Medical Director, Pediatric Cardiac Catheterization

Pairing expertise with compassionate care, our cardiac catheterization program focuses on delivering a superior patient experience to minimize the stress of invasive procedures on patients and their families. We perform more than 250 non-electrophysiology catheterizations per year, a testament to the expertise of our clinician team. Many of our procedures serve as alternative interventional treatments to open surgical repairs. Other procedures provide our cardiology and cardiothoracic surgery team with more information to help identify the best medical and surgical management strategies.

Levine Children’s Hospital is equipped with a catheterization lab dedicated solely to pediatric patients. Services range from standard interventions to the most cutting-edge methods for transcatheter repairs, including:

- SERVICES INCLUDE:
- Diagnostic cardiac catheterization
 - Catheter-based closure for ASD, PFO, PDA and select VSDs
 - Valvuloplasty
 - Angioplasty
 - Coil or device closure of abnormal vessels
 - Endovascular stent placement
 - Transcatheter pulmonary valve placement
 - Pulmonary hypertension studies
 - Endomyocardial biopsy
 - Interventional treatments for adult patients with congenital heart disease

WE PERFORM MORE THAN **250**
NON-ELECTROPHYSIOLOGY
CATHETERIZATIONS PER
YEAR AND **OUR PROGRAM**
CONTINUED TO GROW IN 2012.





// PEDIATRIC AND ADULT CONGENITAL CARDIAC SURGERY

PROGRAM CHIEF:



BENJAMIN B. PEELER, MD, FACS

Chief, Pediatric and Adult Congenital Cardiac Surgery

The Congenital Heart Center at Levine Children's Hospital offers the full spectrum of pediatric and adult congenital cardiothoracic surgical procedures with outcomes among the best in the nation. Only three years into our history, our surgical program has established excellent results as reported by the Society of Thoracic Surgeons. The Congenital Heart Center was also recognized among the nation's top programs in the 2012 *U.S. News & World Report* Best Children's Hospital rankings.

Expertise spans traditional open-heart surgery and total cardiac transplantation to minimally-invasive and video assisted techniques. Our surgeons couple a diligent focus on quality with steady precision to heal the tiniest of hearts. We have performed more than 950 surgeries in the past three years, a testament to the program's strength and the trust we have built with providers throughout the region. Our surgical team includes two attending pediatric cardiac surgeons, surgical physician assistants, nurse practitioners, clinical nurse specialists, perfusionists and pediatric cardiac anesthesiologists.

Pre-operative integration and collaboration drives our approach. We utilize collective knowledge from referring physicians, as well as our own in-house team to identify the best approach to care. Each case is reviewed during a weekly patient management conference that brings together diverse clinicians to confer on best practices and evidence-based care.

Our pediatric and adult congenital cardiac and thoracic surgical procedures offered include:

SURGICAL PROCEDURES INCLUDE:

- Complex neonatal repair
- Treatment of single ventricle defects
 - Hypoplastic left heart syndrome (HLHS)
 - Glenn shunt
 - Fontan procedure
- Simple and complex atrioventricular canal
- Aortic valve repair and replacement, including:
 - Ross procedure
 - Valve sparing aortic root replacement
 - Aortic aneurysm repair and aortic coarctation
- Aortic arch reconstruction
- Mitral valve repair
- Double switch for L-transposition of the great arteries
- Arterial Switch operation for transposition of the great arteries
- Tricuspid valve repair for Ebsteins Anomaly in children and adults
- Heart Transplant and Ventricular Assist Device (VAD)
- Tetralogy of Fallot repair
- Left ventricular outflow tract obstruction
 - Modified konno
 - Ross-Konno procedure
- Hypertrophic Obstructive Cardiomyopathy (HOCM)
- Thorax and chest wall repairs
 - Pectus excavatum
 - Pectus carinatum

// PEDIATRIC AND ADULT CONGENITAL CARDIAC SURGERY CONTINUED

PEDIATRIC HEART TRANSPLANT AND VENTRICULAR ASSIST DEVICE (VAD)

As the region's only pediatric heart transplant center, we provide hope for patients with end-stage heart failure when all alternative medical options have been exhausted. We also offer several ventricular assist device (VAD) options as a bridge to transplant for patients waiting for a viable donor. Our pediatric heart transplant program is distinguished with best-in-class 1-year and 3-year survival rates leading the state of North Carolina – and the nation. We achieved a 100% 1-year observed survival rate from 2008 to 2010, and a 100% 3-year survival rate from 2006 to 2008. We attribute our success to our experienced team and the long history of transplant and VAD expertise at Carolinas HealthCare System. Each patient undergoes a rigorous work-up before transplant guided by a dedicated transplant coordinator with visits to dietitians, physical, and respiratory therapists. The same clinicians follow-up post-transplant to monitor growth and progress.

PEDIATRIC CARDIAC ANESTHESIA

Recognizing the sensitivity of invasive procedures on a young body, our pediatric anesthesiologists have specialized training, expertise and experience in pediatric cardiac care. They are experts in evaluating patients to identify the appropriate method of sedation. Our center is one of the first to perform all invasive imaging and cardiac catheterization procedures with anesthesia support.

ECMO

Extracorporeal Membrane Oxygenation (ECMO) provides heart-lung bypass for pediatric and adult congenital surgical patients before and after surgery when necessary. We also provide ECMO as a bridge to transplant and/or implantation of a ventricular assist device (VAD). ECMO is administered by our collaborative team including surgeons, intensivists, nurses and respiratory therapists. Each team member receives annual ongoing training. In 2012, the congenital heart program at Levine Children's Hospital received the esteemed Award of Excellence from Extracorporeal Life Support Organization (ELSO), an honor bestowed to ECMO programs with the highest level of performance, innovation, satisfaction and quality. The ELSO Award of Excellence is recognized by *U.S. News & World Report* and *Parents* magazine as a criterion for top institutions.

IN **2011**, WE PERFORMED **302**
CONGENITAL CARDIOTHORACIC
SURGERIES WITH A MORTALITY
RATE OF **2.4%** - BETTER THAN THE
NATIONAL STS AVERAGE OF **3.2%**.



// PEDIATRIC CARDIOVASCULAR INTENSIVE CARE UNIT (CVICU)



KSHITIJ P. MISTRY, MD, MS
Medical Director, Pediatric Cardiovascular ICU

Safe recovery is the fundamental goal for our young surgical patients. Levine Children's Hospital is home to our region's first and only dedicated Pediatric Cardiovascular Intensive Care Unit (CVICU), with 10 dedicated beds for children with heart disease. Using the latest technology and up-to-date approaches in clinical management, our nurturing and attentive team monitors the most critical moments of a child's recovery.

Led by Medical Director Kshitij P. Mistry, MD, MS, the care team in the CVICU is composed of board-certified pediatric critical care physicians, acute care trained nurse practitioners and dedicated critical care nurses who have received specialized training in congenital heart disease, including advanced modalities such as extracorporeal membrane oxygenation (ECMO) and ventricular assist devices. Our program recently was designated as a Center of Excellence by the Extracorporeal Life Support Organization (ELSO) – recognizing programs that reach the highest level of performance, innovation, satisfaction and quality. We're also a recipient of the Bronze Beacon Award for Critical Care Excellence from the American Association of Critical Care Nurses (AACN) for consistent evidence-based practices that improve outcomes.

Other key members of this specialized team include individuals from pharmacy, respiratory therapy, child life, social work and palliative care. This expertise is especially important as the treatment of children with congenital heart disease increasingly moves toward early intervention in newborns and infants.



OUR PATIENTS ALSO RECEIVE **EXCELLENT CARE** IN OUR NEONATAL INTENSIVE CARE UNIT AND PROGRESSIVE CARE UNIT.



family-centered care and support

In the spirit of family-centered care, our compassionate, extended team of allied health professionals and support staff guides patients and their families through each step of congenital heart care. The Congenital Heart Center at Levine Children's Hospital offers a variety of support services, like the Little Mended Hearts support group. Programs are designed with the unique needs of families in mind.

CHAMP: The Complex Congenital Heart At Home Monitoring Program (CHAMP) is an at-home monitoring program designed to help parents carefully monitor high risk babies while they are out of the hospital between surgeries. This program was initiated in 2010 and is utilized for infants who have Hypoplastic Left Heart Syndrome (HLHS) or other complex heart defects in which pulmonary blood flow is shunt-dependent. The CHAMP program was designed to help families draw early attention to any problems. Infants who participate in the CHAMP program are at a significantly lower risk of developing complications between the first and second surgeries.

Child Life Department: Tests, treatments and procedures to treat congenital heart disease can be confusing and scary for our young patients. The Child Life Department at Levine Children's Hospital, a team of more than 30, helps children and their families understand congenital heart disease, prepares them for each test and procedure, and reduces stress throughout the journey.

Family Advisory Council: Levine Children's Hospital strives to create an environment where family members and professionals collaborate at every level to provide the best care for patients. Feedback from parents and family members is essential to helping us deliver an excellent patient experience. Our Family Advisory Council is composed of adult family advisors and Levine Children's Hospital employees who meet regularly to discuss the family perspective of care and make recommendations for enhancements.

Camp LUCK: Co-founded by our own James René Herlong, MD, Camp LUCK is a 501c3 not-for-profit, medically supervised camp for children with heart disease and their families. Camp LUCK is held in the mountains of North Carolina. It offers two different summer camp experiences: family camp and kids only camp. Our campers are able to enjoy all of the things kids remember most about their childhood - swimming, climbing, exploring and enjoying time with friends. But perhaps most importantly, campers are able to connect with other children just like them who have received care for congenital heart disease, all in a medically supervised environment. Camp LUCK is evidence of our commitment to family-centered care that extends well beyond the walls of our hospital.



PATIENT TRIUMPHS

Murphy's Story

"Pink or blue?" That was the only question on their minds when Casey and Charles Clark visited her OB/GYN office for a routine ultrasound. They were thrilled to learn they were having a boy who would be named Murphy—but weren't ready for the life-changing results that followed.

The technician couldn't see all four chambers of their baby's heart. A fetal echocardiogram at Sanger Heart & Vascular Institute helped confirm that Murphy had hypoplastic left heart syndrome (HLHS), a rare congenital heart defect that is fatal without treatment. The Clarks then met with Drs. James René Herlong and Benjamin Peeler. The Clarks were overwhelmed and scared, but the team at The Congenital Heart Center at Levine Children's Hospital gave them the confidence to continue with Murphy's treatment.

Dr. Peeler explained that the path to correcting Murphy's heart defect would be a planned three-part reconstruction. The first surgery, the Norwood procedure, is typically performed within the first few days after birth. A complex operation, it carries the highest risk of all three surgeries. "It's a challenging procedure, in which the aorta is enlarged and a small tube is placed from the right ventricle to the lung's blood vessels," Dr. Peeler said. The second surgery, the Glenn procedure, is typically performed when a child is about 4 months old. "We have to ensure the heart is strong enough and the pulmonary arteries have grown enough," Dr. Peeler added. The third surgery, the Fontan operation, is usually performed when a child is about 3 years old. The Glenn and Fontan surgeries move blood from the heart directly to the lungs.

Dr. Peeler's Norwood survival rate is 100 percent for the 17 surgeries performed since he's been treating HLHS patients at Levine Children's Hospital. Murphy's first surgery took place only six days after birth, and immediately he showed amazing progress. A few months later, Murphy returned for his second procedure. His echocardiogram in October 2011 looked good.

"We're so thankful for how well he has done so far," Casey said. "We can't thank Dr. Peeler and the congenital center staff enough," Charles added.



"WE CAN'T THANK
DR. PEELER AND
THE CONGENITAL
CENTER STAFF
ENOUGH."

CHARLES CLARK

Murphy's Dad



PATIENT TRIUMPHS

Katherine's Story

Katherine Aristizabal Navia is a happy and healthy 7-year-old. She loves Barbie dolls and wants to be a model. She is her mother's "miracle baby." Looking at her, it would be hard to imagine that just a few months ago she underwent a complicated double-switch procedure.

During the heart surgery at Levine Children's Hospital, Andrew Bensky, MD, said the surgical team redirected veins draining the lungs and body back to the heart into the opposite pumping chamber. Arteries leading from the pumps to the lungs and body were switched. The coronary arteries were moved as well.

"Dr. Bensky is the best," said Jessica Aristizabal, Katherine's mom. "He and Dr. Peeler were awesome. They explained everything and took great care of her."

Doctors at Levine Children's Hospital discovered Katherine's congenital heart lesion prior to birth. She was diagnosed with an extremely complex lesion, L-transposition of the great arteries (L-TGA) with Ebsteins malformation of her systemic tricuspid valve. Because of this anatomic arrangement, it was felt that Katherine would eventually be best served by a double-switch procedure.

Katherine's mom remembers her daughter's first surgery at age 4, in which a pulmonary artery band was placed, and then the second at age 5 when the band was tightened.

Her morphologic left ventricle had been doing the easier work of pumping to her lungs for several years, so it had to be prepared for the double switch. This was accomplished by placing a pulmonary artery band to raise the left ventricular (LV) pressure. After a year, the band was tightened to continue the training of the ventricle. As the LV pressure increased, the interventricular septum moved toward the right ventricle, reducing the tricuspid insufficiency.

After echo and MRI suggested that the LV had thickened appropriately, the double switch was performed. The pulmonary veins were routed to the mitral valve, and the systemic veins were routed to the tricuspid valve (a Senning procedure). The great arteries were switched, and the coronaries were transferred (an arterial switch procedure). Katherine has done very well since surgery, with good LV function and mild tricuspid insufficiency. This successful operation restored the normal blood flow through the ventricles.

Dr. Bensky said that Katherine has returned to a normal activity level.

Besides dolls, Katherine likes the second grade and loves her big brother.

"The nurses at the hospital were great," Jessica said. "It was a very hard experience. But Katherine did great, and she's doing great. She's a beautiful little girl."

"THE NURSES AT THE HOSPITAL WERE GREAT. IT WAS A VERY HARD EXPERIENCE. BUT KATHERINE DID GREAT, AND SHE'S DOING GREAT."

JESSICA ARISTIZABAL

Katherine's Mom

PATIENT TRIUMPHS

Victoria's Story

In Victoria Waters short life, she has fought a long time. She was born five weeks premature, had cancer and survived a heart transplant.

With each fight, her family, skilled doctors and caring nurses have surrounded Victoria. The expert cardiology team at Levine Children's Hospital (LCH) took this heart journey with the Waters family step by step, providing exceptional care along the way.

"The Peds Cardiac Team did not just treat our daughter, they treated our family," said Cyndi Waters, Victoria's mother. "They were attentive to our needs and gave us confidence in their ability to care for our child. As a result, we had the strength to entrust our child in their care and were able to rest more than expected during a stressful time. Today, thanks to the quality of care provided at Levine Children's Hospital, our daughter is an inspiration to other children and families."

Victoria's first fight began when she was born prematurely and spent the first days of her life in the neonatal intensive care. At one month old, Victoria was diagnosed with acute myelogenous leukemia (AML). While her aggressive treatment with chemotherapy was successful against the cancer, Victorias heart function had been diminished by the anthracyclines which needed to be used as part of the regimen.

Ultimately, in late June 2009, the LCH cardiac team determined it was time to discuss a heart transplant at The Congenital Heart Center at Levine Children's Hospital - home to the only pediatric heart transplant program in western North Carolina.

On Jan. 8, 2010, Victoria received her new heart.

Victoria's heart transplant procedure went very well and she made an exceptional recovery. Dr. Benjamin B. Peeler and the surgical team were very optimistic about the outcome of the transplant, and eight days following surgery, Victoria went home with her mom and dad.

She will continue to see her congenital heart team regularly for checkups.

The availability of heart transplantation and advanced treatment for heart failure, including ventricular assist device technology is an important facet of a full service congenital heart center. Heart transplantation in all ages and sizes of patients from neonate to adult has been performed at Sanger Heart & Vascular Institute and Carolinas HealthCare System for decades, and now patients benefit from the state-of-the-art facilities available at Levine Children's Hospital.

Today, Victoria enjoys life as a little girl who loves tea parties and doing cartwheels. And the future looks bright.



"THE PEDS
CARDIAC TEAM
DID NOT JUST
TREAT OUR
DAUGHTER,
THEY TREATED
OUR FAMILY."

CYNDI WATERS

Victoria's Mom

clinical research and publications

Our physicians are actively involved in clinical research, participating in some of the most exclusive trials for congenital heart defects. In 2011, Sanger Heart & Vascular Institute's clinical research program enrolled more than 2,000 patients in 45 ongoing trials. We embrace the importance of research and publishing our best practices so that patients far and wide can benefit from the power of collective knowledge.

// SELECT RESEARCH

Closure of Atrial Septal Defects With the AMPLATZER SeptalOccluder, Post-Approval Study

PRINCIPAL INVESTIGATOR: Joseph Paolillo, MD

GORE HELEX Septal Occluder for Patent Foramen Ovale Closure in Stroke Patients – The Gore REDUCE Clinical Study

PRINCIPAL INVESTIGATOR: Joseph Paolillo, MD

GORE Septal Occluder Clinical Study: A Study to Evaluate Safety and Efficacy in the Treatment of Transcatheter Closure of Ostium Secundum Atrial Septal Defects

PRINCIPAL INVESTIGATOR: Joseph Paolillo, MD

A Prospective, Multi-center, Single Arm Study to Assess the Safety and Probable Benefit of the Berlin Heart EXCOR Pediatric Ventricular Assist Device [EXCOR Pediatric]

PRINCIPAL INVESTIGATOR: Benjamin B. Peeler, MD

// SELECT PUBLICATIONS

René J. Herlong, Meryl S. Cohen, Norman H. Silverman. "Echocardiographic imaging of anomalous origin of the coronary arteries" *Cardiology in the Young*, Volume 20, Supplement S3, 2010, pp 26-34

Mistry KP, Chen JG, Wright MC, Smith PB, Jagers J. "Adaptation of a postoperative handoff communication process for children with heart disease: a quantitative study." *American Journal of Medical Quality*. 2011 Sep-Oct; 26(5):380-6

Mistry KP, Rehder KJ, Uhl TL, Meliones JN, Turner DA, Smith PB. "Targeted interventions improve shared agreement of daily goals in the pediatric intensive care unit." *Pediatric Critical Care Medicine*. 2012 Jan;13(1):6-10

Mistry KP, Chen JG, Wright MC, Turner DA. "Postoperative handoff communication: a simulation-based training method." *Simulation in Healthcare*. 2010 Aug; 5(4):242-7

Anitha Jayakumar K., D'Souza M, Vergales J. "Hypoplastic Left Heart Syndrome and Pulmonary Veno-occlusive Disease in an Infant." *Pediatric Cardiology*. 2012 Sept

Paolillo J, Saidi A, Reiss A, Breiting P, Black E, Collins S. "Web-based Learning: Is it an Effective Method for Educating Pediatric Residents About Transition to Adult Subspecialty Congenital Heart Disease Care?" *International Journal of Child and Adolescent Health*, 2011, 3(4):585-59.

Jayakumar KA., Peeler BB, Seckler MD, Mery CM, Gangemi JJ. "An Angiographic Predictor of Pulmonary Artery Stenosis After the Norwood-Sano Operation for Hypoplastic Left Heart Syndrome." *Pediatric Cardiology* (2012) 33:1281-1287

Paolillo JA, Kleman ME, Estrada AH, Maisenbacher HW, Prosek R, Pogue B, Shih A. "How to Perform Cutting Balloon and High Pressure Balloon Valvuloplasty for Dogs with Subaortic Stenosis." *Journal of Veterinary Cardiology*, 2012, 14(2):351-361


// SELECT PRESENTATIONS

Poster Presentation: *The Rounding Tool*; nurse presentation in multidisciplinary rounds at the Pediatric Cardiac Intensive Care Society Meeting in Miami, December 2012



referral guide

// MAKE A REFERRAL OR REQUEST A CONSULT



WE ACCEPT REFERRALS FROM PHYSICIANS FAR AND WIDE, AND LOOK FORWARD TO TRANSITIONING EACH PATIENT BACK TO THEIR PEDIATRICIAN OR PRIMARY CARE PROVIDER FOR ONGOING CARE POST-TREATMENT.

To coordinate a referral to The Congenital Heart Center, contact our referral coordinator at 704-373-1813. Recognizing the urgency of a heart condition, our representatives are available 24 hours, seven days a week.

Charlotte, North Carolina has experienced explosive growth in recent decades, including a sophisticated medical community. While Charlotte is the fifth fastest-growing large city in the United States, we hold on to our southern hospitality and values, welcoming all who come here from near and far.

Traveling to Charlotte is easy - and our relationships with community resources provide options that keep families together during treatment.

TRAVEL RESOURCES

Charlotte Douglas International Airport (CLT) connects the Carolinas to the world with more than 650 daily flights. It serves as a national hub for US Airways and is conveniently located just six miles from Levine Children’s Hospital.

Ronald McDonald House is located just a few blocks from Levine Children’s Hospital and welcomes out-of-town families referred by the hospital.

Hospitality House of Charlotte is located close to the hospital and offers low-cost rooms for families traveling for care.

For more information about travel and lodging, visit www.levinechildrenshospital.org.

// ACCESS TO CONGENITAL HEART CARE

The Congenital Heart Center provides unmatched access to inpatient and outpatient heart care.

// INPATIENT CARE LOCATIONS

Levine Children’s Hospital
1001 Blythe Boulevard
Charlotte, NC 28203
Phone: 704-381-2000

// SANGER HEART & VASCULAR INSTITUTE PEDIATRIC CARDIOLOGY LOCATIONS

- | | |
|---|--|
| 1001 Blythe Blvd., Suite 200 D
Charlotte , NC 28203
Phone: 704-373-1813
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Charlotte , NC 28210
Phone: 704-373-1318
Fax: 704-342-5871 |
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Phone: 704-403-2860
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Rock Hill , SC 29732
Phone: 704-373-1813
Fax: 704-381-3951 |
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// THE CONGENITAL HEART CENTER MEDICAL STAFF



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Chief, Pediatric and Adult Congenital Cardiac Surgery
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Medical School: Vanderbilt University

Residency: Vanderbilt University (General Surgery)

Fellowship: University of Virginia Health Sciences Center (Thoracic and Cardiovascular Surgery, Vascular Surgery), Emory University (Pediatric Cardiac Surgery)

Board Certified: Thoracic Surgery, Congenital Heart Surgery

Clinical Interests: Complex neonatal repair; treatment of single ventricle defects, simple and complex atrioventricular canal; aortic valve repair and replacement, including mitral valve repair; arterial switch operation for transposition of the great arteries; ventricular septal defect; atrial septal defect; aortic coarctation; aortic arch reconstruction; Ebsteins anomaly in children and adults; heart transplantation



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Medical School: Duke University

Residency: Baylor College of Medicine (Pediatrics)

Fellowship: Duke University Medical Center (Pediatric Cardiology)

Board Certified: Pediatrics, Pediatric Cardiology

Clinical Interests: Noninvasive cardiac imaging; complex congenital heart disease; congenital coronary artery anomalies



KSHITIJ P. MISTRY, MD, MS

Medical Director, Pediatric Cardiovascular ICU
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Medical School: Wake Forest University

Residency: Tufts-New England Medical Center (Pediatrics)

Fellowship: Boston Children's Hospital (Pediatric Critical Care Medicine)

Board Certified: Pediatrics, Pediatric Critical Care

Clinical Interests: Cardiac intensive care; quality improvement; clinical handovers of care; ECLS (extracorporeal life support); palliative care



A. RESAI BENGUR, MD, FACC

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Residency: UH Rainbow Babies and Children's Hospital (Pediatrics)

Fellowship: University of Michigan C.S. Mott Children's Hospital (Pediatric Cardiology)

Board Certified: Pediatrics, Pediatric Cardiology

Clinical Interests: Congenital cardiac defects; heart murmurs; echocardiography



ANDREW S. BENSKY MD, FACC

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Medical School: State University of New York (SUNY) Health Science Center

Residency: SUNY Health Science Center (Pediatrics)

Fellowship: Cincinnati Children's Hospital Medical Center (Pediatric Cardiology)

Board Certified: Pediatrics, Pediatric Cardiology

Clinical Interests: Fetal echocardiography; adult echocardiography; 3-D echocardiography; transesophageal echocardiography



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Medical School: Wake Forest University

Residency: Wake Forest University (Pediatrics)

Fellowship: Duke University Medical Center (Pediatric Cardiology)

Board Certified: Pediatrics, Pediatric Cardiology

Clinical Interests: Congenital heart defects; pediatric echocardiography; fetal echocardiography



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Medical School: Florida State University College of Medicine

Residency: Emory University School of Medicine Affiliated Hospitals Program (Pediatric Cardiology)

Fellowship: Sibley Heart Center at Children's Healthcare of Atlanta at Emory University School of Medicine (Pediatric Cardiology)

Board Certified: Pediatrics; Pediatric Cardiology

Clinical Interests: Pediatric cardiology; fetal echocardiography; pulmonary vein stenosis; pediatric chest pain management; neurodevelopmental outcomes



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Medical School: University of Madras, India
Residency: University of Connecticut (Pediatrics), Royal College of Physicians, London, UK
Fellowship: Columbia University (Pediatric Cardiology), Boston Children's Hospital
Board Certified: Pediatrics, Pediatric Cardiology
Clinical Interests: Pediatric and fetal cardiology; adult congenital heart disease; clinical research; double-outlet right ventricle; ventricular septal defect; cardiac catheterization



THOMAS S. MAXEY, MD
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Medical School: Eastern Virginia Medical School
Residency: University of South Florida (General Surgery)
Fellowship: Emory University (Thoracic and Cardiovascular Surgery), Emory University (Pediatric Cardiac Surgery)
Board Certified: Surgery, Thoracic Surgery
Clinical Interests: Pediatric cardiac surgery; adult congenital heart surgery; heart transplantation



JOSEPH A. PAOLILLO JR., MD
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Medical School: University of Connecticut School of Medicine
Residency: St. Christopher's Hospital for Children (Pediatrics)
Fellowship: Children's Hospital of Pittsburgh (Pediatric Cardiology), Children's Hospital of Philadelphia (Interventional Pediatric Cardiac Catheterization)
Board Certified: Pediatrics, Pediatric Cardiology
Clinical Interests: Diagnostic and interventional cardiac catheterization; new transcatheter therapies for congenital heart defects



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Medical School: University of Florida
Residency: Columbus Children's Hospital (Pediatrics)
Fellowship: Baylor College of Medicine (Pediatric Cardiology)
Board Certified: Pediatrics, Pediatric Cardiology
Clinical Interests: Congenital heart defects; pediatric cardiology; preventive cardiology; adult congenital heart disease



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Residency: Carolinas Medical Center (Pediatrics)
Fellowship: Vanderbilt University Medical Center (Pediatric Cardiology)
Board Certified: Pediatrics, Pediatric Cardiology
Clinical Interests: Congenital heart defects; echocardiography; preventive cardiology; exercise physiology



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Medical School: University of Florida
Residency: Medical University of South Carolina (Pediatrics)
Fellowship: Texas Children's Hospital (Cardiac Electrophysiology, Pacing, and Rhythm Management)
Board Certified: Pediatrics, Pediatric Cardiology
Clinical Interests: Catheter ablation; defibrillator implantation electrophysiology; interventional cardiology; pacemaker implantation; pediatric cardiology; heart transplantation

NURSE PRACTITIONERS

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