

cham

THE MAGAZINE OF THE CHILDREN'S HOSPITAL AT MONTEFIORE

INTRODUCING

CHAM's Pediatric Heart Center Team

SAVING CHILDREN'S LIVES ONE HEART AT A TIME

EXCLUSIVE
cham
PEDIATRIC HEART
CENTER DVD INSIDE

The
Children's
Hospital
at Montefiore

cham

THE CHILDREN'S HOSPITAL AT MONTEFIORE PEDIATRIC CARDIOLOGY

EXCLUSIVE
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PEDIATRIC CARDIOLOGY
DVD ENCLOSED

A message from the chairman

Dear Colleagues:

I am excited to introduce the inaugural issue of *CHAM Magazine* which highlights our Pediatric Heart Center, one of the outstanding programs at The Children's Hospital at Montefiore (CHAM). CHAM is one of the nation's top hospitals for children, earning the distinction of being included in *U.S. News and World Report's* "Best Children's Hospitals" rankings for the third consecutive year.

In this issue, we have highlighted some of our capabilities such as advances in electrophysiology and ablation procedures that can eliminate the need for arrhythmia medications, hybrid treatment approaches that avoid open heart and bypass surgeries in neonates and the Montefiore-Einstein Center for Cardio Genetics.

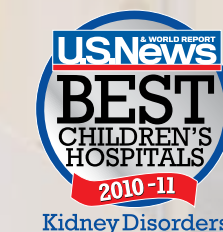
Our commitment to provide the best available care to children with heart disease is exemplified by our commitment to recruit nationally renowned experts from the nation's most elite institutions. We welcome pediatric cardiologist Daphne T. Hsu, MD, and pediatric cardiothoracic surgeon Francois Lacour-Gayet, MD, as Co-Directors of CHAM's Pediatric Heart Center. I am certain they will move us closer to our vision of transforming the health of children throughout the region and across the nation.

Sincerely,



Philip O. Ozuah, MD, PhD
Physician-in-Chief
The Children's Hospital at Montefiore

Professor and University Chairman
Department of Pediatrics, Albert Einstein College of Medicine





WORLD CLASS CHAM'S PEDIATRIC CARDIAC CARE HEART CENTER TEAM

left to right: front row

Emily Jackness, MD, Samuel Weinstein, MD,
Philip O. Ozuah, MD, PhD, Daphne Hsu, MD,
Jacqueline Lamour, MD, Christine Tracy, MD,
Francois Lacour-Gayet, MD

back row

Nicole Sutton, MD, Robert Pass, MD,
Rajesh Shenoy, MD, Leo Lopez, MD,
Myles Schiller, MD, Eric Fethke, MD,
Scott Ceresnak, MD, Christine Walsh, MD.

Emily Jackness, MD

Attending Physician
Assistant Clinical Professor of Pediatrics
Albert Einstein College of Medicine

Medical School: Columbia University,
College of Physicians and Surgeons

Fellowship: Pediatric Cardiology, Babies Hospital,
Columbia Presbyterian Medical Center

[Area of Expertise: Pediatric Cardiology]

Samuel Weinstein, MD

Director, Pediatric Cardiothoracic Surgery
Director, Adult Congenital Cardiac Surgery
Associate Professor of Cardiothoracic Surgery
Albert Einstein College of Medicine

Medical School: State University of New York
at Stony Brook

Fellowship: Chief Fellow, Pediatric Surgery—
Extracorporeal Membrane Oxygenation Service, Babies
Hospital, Columbia Presbyterian Medical Center

[Area of Expertise: Transplant, Adult
Congenital Heart Disease]

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Physician-in-Chief
University Chairman
Professor of Pediatrics
Albert Einstein College of Medicine

Medical School: University of Ibadan, Nigeria

Doctoral Studies: Educational Leadership and
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Fellowship: Pediatrics, University of Southern
California-School of Medicine

Daphne T. Hsu, MD

Division Chief, Pediatric Cardiology
Co-Director, Pediatric Heart Center
Professor of Pediatrics
Albert Einstein College of Medicine

Medical School: Yale University School of Medicine

Fellowship: Pediatric Cardiology, Babies Hospital,
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[Area of Expertise: Cardiomyopathy, Heart Failure,
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Director, Pediatric Advanced Cardiac Therapies
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Medical School: SUNY-Health Science Center
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[Area of Expertise: Electrophysiology]

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[Area of Expertise: Cardiac Catheterization]

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Director, Pediatric Electrophysiology
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[Area of Expertise: Fetal Cardiology]



CHAM'S PEDIATRIC HEART CENTER TEAM *(continued)*

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Myles Schiller, MD

Attending Physician
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Medical School: The Chicago Medical School

Fellowship: Pediatric Cardiology, New York

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Eric D. Fethke, MD

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Scott R. Ceresnak, MD

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Assistant Professor of Pediatrics
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Fellowship: Pediatric Cardiology,

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Senior Clinical Fellowship: Pediatric

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Christine A. Walsh, MD

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University, College of Physicians and Surgeons

NIH Post-Doctorate: Cardiac

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College of Physicians and Surgeons

[**Area of Expertise:** Electrophysiology]

Team Members Not Pictured



Sarika Kalantre, MD

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Medical Center

[**Area of Expertise:** Pediatric Cardiology]



George K. Lui, MD

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Albert Einstein College of Medicine

Medical School: Yale University School of Medicine

Fellowship: Adult Cardiology, Columbia

University Medical Center

[**Area of Expertise:** Adult Congenital
Heart Disease]



Dimitrios P. Papavassiliou, MD

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Assistant Clinical Professor of Pediatrics
Albert Einstein College of Medicine

Medical School: Aristotle University of
Thessaloniki, School of Medicine

Fellowship: Pediatric Cardiology, Medical
College

of Georgia Hospitals and Clinics

Senior Fellowship: Echocardiography,

Egleston Children's Hospital at Emory

University School

of Medicine

[**Area of Expertise:** Pediatric Cardiology]



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Knight Rides into the Bronx to Save the Tiniest Hearts





new options

for children with complex heart disease

Groundbreaking renovation to enrich
pediatric patients' experience

When leaders at The Children's Hospital at Montefiore (CHAM) converged to plan a multi-million dollar renovation for the Pediatric Heart Center, families and patients became the central focus. "We wanted to take CHAM's core value of family-centered care to the next level for pediatric heart patients," explains Daphne T. Hsu, MD, Co-Director of the Pediatric Heart Center and Division Chief of Pediatric Cardiology at CHAM. "This meant carefully planning comforts and conveniences for patients and families, as well as state-of-the-art technology and overall design."



The Pediatric Heart Center manages patients with complicated congenital defects, rare arrhythmias, syndromic cardiac pathologies, cardiomyopathy and end-stage heart failure.

A global leader for advanced cardiovascular care for children with acquired or congenital heart disease, CHAM has pioneered some of the most innovative advancements in the field. The highly specialized, multidisciplinary team at CHAM performed the first hybrid procedure in the state of New York and the first pediatric heart transplant in the Bronx.

For more than 50 years, CHAM has remained on the cutting edge of all critical developments in pediatric heart care, which has substantially increased survival rates. As this population of surviving infants with congenital heart disease continues to grow, CHAM has responded with a massive makeover to embrace the growing demand for pediatric heart services.

CHAM's new 5,300 square-foot Pediatric Heart Center will feature a state-of-the-art hybrid surgical lab, spacious treatment rooms and physician offices, an expansive kid-friendly waiting room outfitted with Internet access and interactive activities, four echocardiography imaging rooms, the fully-integrated GetWell Network in patient rooms, and a new telecommunications system to relay up-to-the-minute echocardiograms, MRI and CT images and other pertinent



“We understand that children’s heart disease places tremendous stress and responsibility on parents, as well as the patients. Hence, we’ve devised a holistic approach to pediatric heart care with additional staff, services and forward-thinking solutions.”—Daphne T. Hsu, MD

data to primary care physicians. For extra support, parents can depend on the Pediatric Heart Center’s child life specialists, nurse practitioners and a wide range of psychosocial services.

“We understand that children’s heart disease places tremendous stress and responsibility on parents, as well as the patients,” Dr. Hsu explains. “Hence, we’ve devised a holistic approach to pediatric heart care with additional staff, services and forward-thinking solutions.”

CHAM is developing the first transitional program in the New York Metropolitan region to help teenagers seamlessly transfer from

pediatric to adult congenital heart care. Hybrid procedures are another area of concentration, as bridging surgeons and interventional cardiologists in one room is extremely beneficial for appropriate candidates. “Hybrid surgery eliminates the need for multiple appointments, minimizes invasive procedures and reduces potential risks of neurological complications later in life that can stem from cardiopulmonary bypass,” Dr. Hsu explains. “It is the future for conducting ventricular repairs on pediatric patients. And CHAM is paving the way for a very bright outlook.”

■ To refer a patient to Dr. Hsu or for more information about the Pediatric Heart Center, please call 718-741-2343 or email: dhsu@montefiore.org.



The Children's Hospital at Montefiore unveiled its new 5,300 square-foot Pediatric Heart Center in Spring 2010.

physician profile

Daphne T. Hsu, MD
Division Chief, Pediatric Cardiology
Co-Director, Pediatric Heart Center

“I enjoy having long-term relationships with my patients and their families.”

a conversation with

**DAPHNE T.
HSU, MD**

Chief of Pediatric Cardiology
Co-Director Pediatric Heart Center

When it comes to matters of the heart, every minute and nanosecond counts. Advancing expertise, technology and new therapies can equip staff at most children's hospitals with the ability to effectively treat patients with heart disease. However, at CHAM, the difference lies in the emphasis placed on multidisciplinary care and planning for the near and long-term future.

Since joining CHAM as Division Chief of Pediatric Cardiology in 2008, Dr. Hsu has expanded staff, doubled patient visits and overseen the renovation of CHAM's Pediatric Heart Center.

Q. You're one of the country's leading children's heart failure and transplant cardiologists. What drew you to this subspecialty?

Dr. Hsu: I love my work because it allows me to take care of the sickest children in pediatrics. They have life-threatening heart diseases. You have to determine what type it is and treat it quickly. And when you do it well, the patients do extremely well. Then you can follow them for the rest of their lives. I like being there when they need me for critical problems. And I like being there when the kids do well. I enjoy having long-term relationships with my patients and their families.

Q. Do adults with Congenital Heart Disease require subspecialized care?

Dr. Hsu: An adult with congenital heart disease is a patient whose heart has been repaired early in life. Twenty or thirty years ago, a child who survived open-heart surgery was considered a medical miracle. No one thought they'd live past infancy. Now they are surviving, but they come to our attention with residual complications. They might need a valve replacement, or have an arrhythmia due to scar tissue from heart surgery. Sometimes their heart muscle weakens or they might have heart failure. When patients come to CHAM, they receive the best children's and adult electrophysiology services in the country. We can manage end-stage heart failure and transplant—and seamlessly transition patients from children's to adult divisions. That kind of coordinated care is difficult to find elsewhere.

Q. How do you manage consultative services?

Dr. Hsu: We evaluate kids, process them into the system, and then direct them back to their physicians with a treatment plan and intermittent monitoring. Attending physicians are available 24/7, and referring physicians can also speak with a subspecialist 24/7, if needed. There's one number to reach us and we return calls and answer email.

Q. What advances lie ahead for pediatric cardiologic care?

Dr. Hsu: Surgical care for kids with Congenital Heart Disease (CHD) saw tremendous growth from the 1970s to the 1990s. Now a surgeon's level of expertise is so advanced, change is incremental. But we need to improve long-term outcomes—studying patients' development, intelligence and quality of life. The need for a transplant will continue to grow because we've repaired so many hearts. I recently saw a patient who required transplantation. She had heart surgery as a baby and is now 20 years old. I told her mother, “This isn't forever—heart transplants last about 20 years.” And her mom replied, “Twenty years ago my daughter had surgery and the cardiologist told me surgery wouldn't last forever. But she he told me when my daughter needs something else—it will be there. So now here we are 20 years later. You're telling me the same thing. I believe in 20 years you'll have something for my daughter.”

A fresh approach to asymptomatic Wolff-Parkinson-White Syndrome

Leading pediatric electrophysiologist in the New York region speaks of safety and success—not risks of arrhythmias and sudden death.

Wolff-Parkinson-White Syndrome (WPW) is a condition that predisposes patients to an arrhythmia called supraventricular tachycardia. In some cases, this arrhythmia can be severe—and possibly fatal.

“Just five years ago, it was believed that conducting an electrophysiology test and cardiac ablation procedure posed a higher risk than not doing it at all,” explains Robert H. Pass, MD, Director of Pediatric Electrophysiology, CHAM. “Unless a child actually experienced an arrhythmia, we’d sort of cross our fingers and hope

our patient wasn’t one of the approximated one percent of WPW patients who were at high-risk for sudden death.”

A change of heart with electrophysiology and ablation

Dr. Pass’s perspective about procedural risks has changed, thanks to his vast experience with the more than 1,000 electrophysiology studies and ablations he has performed. “We have realized that the risk is not high; we now believe that the risk of not knowing whether a patient’s risk is high or low is higher than the procedure,” he explains.

“Once patients reach adolescence, we now recommend they undergo formal electrophysiology testing in our state-of-the-art laboratory. If our tests reveal a risk for sudden death, we conduct an intracardiac ablation and eliminate that risk.”

On the other hand, “If electrophysiology tests show a low-risk pathway for sudden death, we remove the catheter and tell the patient’s parents, ‘We’re done—your child’s risk is low.’”

Advanced technology has also played a role in the impressive 95 percent success rate. Prior to intracardiac ablation, children with arrhythmias were required to take medication for an indefinite period of time. Now, the majority are drug-free for the first time in their lives.

This was the case of a young teenager who recently came to CHAM from Panama. He had undergone a failed procedure at a large university medical center in the Midwest, and Dr. Pass conducted a complex ablation on him. “Prior to this procedure, his mother and teachers would not allow him to play soccer or any other sports because of his condition,” Dr. Pass recalls. “He also has congenital heart disease, which made him become sicker faster than the average patient whenever he had an episode of tachycardia.

“It’s now been 13 months since the intracardiac ablation procedure. He takes no arrhythmia medications for the first time in six years and is playing a lot of soccer. We have many patients who come to us with restrictions from activities due to supraventricular tachycardia. Now, they have a lot of hope—and they do a lot of running.”

■ To refer a patient to Dr. Pass or for more information about WPW, please call the Pediatric Heart Center at 718-741-2343 or email: rpass@montefiore.org.



Robert H. Pass, MD
Director, Pediatric Electrophysiology

Identifying Pediatric Heart Failure: All that wheezes is not asthma

Children’s cardiac dysfunction requires exceptional diagnosis and care expertise.

Infants and children in heart failure can present with respiratory distress, abdominal pain, nausea, vomiting, a fast heart rate and an array of other symptoms easily mistaken for common childhood illnesses.

Jacqueline Lamour, MD, Director of Pediatric Advanced Cardiac Therapies at CHAM, has managed hundreds of children with heart failure. She recently treated a baby initially misdiagnosed with bronchiolitis, who was suffering from dilated cardiomyopathy. The infant was experiencing severe heart failure and required an immediate cardiac transplant. (See page 14.)

A pediatric heart failure diagnosis may be elusive, not only because the symptoms mimic other pediatric ailments, but also because the pathology is so rare among children.

“The incidence of pediatric cardiomyopathies is about one in 100,000 children,” Dr. Lamour explains. “About half of all children with cardiomyopathy are a dilated cardiomyopathy.”

Critical components for successful outcomes: early recognition and treatment at a pediatric heart center

Children with dilated cardiomyopathy demonstrate some of the poorest outcomes in pediatric cardiology, as approximately 50 percent will either receive a heart transplant or die within two years of the diagnosis. Hence the continuous pursuit of causation and treating each patient as early as possible becomes exponentially pertinent to successful results.

Pediatric cardiologic researchers have identified the etiology of only a handful of cardiomyopathies to date. Most cardiomyopathies will likely prove genetic in origin, but occasionally a viral infection, metabolic derangement or arrhythmia can cause heart dysfunction. In these instances, damage may be reversible.



Jacqueline Lamour, MD
Director, Pediatric Advanced Cardiac Therapies

“Early evaluation at a heart failure program is critical,” asserts Dr. Lamour. “Expert examination may reveal a potentially treatable cause of the cardiomyopathy. We can often start medical therapy to stabilize the patient and avoid or delay the need for heart transplantation.”

Should a patient’s condition begin to deteriorate, Dr. Lamour says it is best to be treated at a dedicated pediatric heart center with veteran experts. “We can provide immediate intervention, mechanical support and, if needed, a heart transplant.”

■ To refer a patient to Dr. Lamour or for more information about CHAM’s Heart Failure Program, please call the Pediatric Heart Center at 718-741-2343 or email: jlamour@montefiore.org.



CHAM CARDIAC
TEAM RACES TO

beat the clock

Bronx Baby Makes History as the Borough's First Pediatric Heart Transplant Patient

“Adrian is very sick. We are going to need to list him on UNOS.” Those were the axis-altering words Dr. Daphne Hsu, Division Chief of Pediatric Cardiology at CHAM, conveyed to transplant coordinator Arzellra Walters at 8:15 am on March 6th. It was only nine hours prior to that decision that five-month-old Adrian Flores was rushed by ambulance to CHAM's Pediatric Heart Center with a life-threatening dilated cardiomyopathy and stabilized by Dr. Jacqueline Lamour, Director of Advanced Cardiac Therapies.

Ms. Walters met with Adrian's parents, Sandra and Juan that same day at 9:45 am to discuss the transplant evaluation. By 4 pm, the critically ill infant was registered as a Status 1A on the UNOS waiting list for a new heart.

The days and weeks of waiting for a life-saving donor organ can be riddled with anxiety for parents. But thanks to the swift and seamless actions of CHAM's team at every step of the journey, Adrian's story has a happy ending.

A multidisciplinary team of cardiologists, attendings, registered nurses in the PICU, and a nutritionist vigilantly monitored Adrian's vitals and caloric intake 24/7, while a social worker and financial coordinator consulted with his parents. A pharmacist was also always reachable to adjust his medications. “Communication was constant and ongoing with all the members of the team throughout the day and week,” Ms. Walters recalls.

“For kids who present acutely to the hospital, this is typical. I am extremely impressed with the entire multidisciplinary team,” said Dr. Hsu. So are Adrian's parents.

The following is a detailed account of how CHAM's transplant team raced to beat the ticking clock—and the donor's heart—in order to save Adrian's life.

March 5, 2009, 8:30 pm

Differential diagnosis: Bronchiolitis—or heart failure?

Sandra and Juan Carlos Flores hurry into Bronx Lebanon Hospital (BLH) with their infant, Adrian. The five-month-old boy is in respiratory distress. Adrian was previously diagnosed with bronchiolitis. The BLH cardiologist orders a chest X-ray—and is shocked when it reveals the baby's dangerously dilated cardiomyopathy (DCM). Next an echocardiogram reveals Adrian's poor cardiac function, and the specialist immediately calls Dr. Lamour.

11:05 pm Rushed by ambulance to CHAM's Pediatric Heart Center, Adrian arrives in the PICU in severe respiratory distress. To stabilize him Dr. Denise Nunez, critical care attending physician, intubates the child and Dr. Lamour administers medication to support cardiac function.

March 6, 7:30 am

Adrian's condition has not improved. A multidisciplinary heart transplant evaluation, led by Dr. Lamour and Dr. Hsu, is initiated.

Transplant evaluation: Members of CHAM's Transplant Evaluation Team hurriedly cycle in and out of Adrian's room all day. They unanimously recommend transplant.

4:37 pm UNOS lists Adrian as Status 1A for a heart donation.

March 6–11

Adrian's parents anxiously begin the waiting period. His cardiac team knows it's impossible to predict when a donor heart will become available; it could be days—or weeks. Forty-eight hours after admission to CHAM, Adrian suffers a seizure. However, a subsequent CT scan reveals no brain abnormalities. Throughout the watch, Dr. Lamour adjusts cardiac medications to support Adrian's heart.

March 12, 5:04 pm

Going the distance to secure the new heart

A donor heart is available. Dr. Lamour and Samuel Weinstein, MD, Director of Pediatric Cardiothoracic Surgery, evaluate the donor heart and compare blood type and heart size. They have just 60 minutes to decide whether or not to take the heart.

5:55 pm The transplant team accepts the heart and awaits final approval. To the relief of Adrian's physicians and family, UNOS green lights Adrian as the recipient within hours.



5.5.09 11:05 PM

5.12.09 5:04 PM

11:10 PM

5.13.09 4:45 AM

6:02 AM

6:55 AM

11:10 pm The donor heart is located in the Midwest. To secure and deliver it, Montefiore’s Procurement Team travels by ambulance and Learjet. With lights flashing and sirens screaming, they speed across the George Washington Bridge toward New Jersey’s Teterboro Airport.

March 13, 1:00 am

Minutes before winging westward, the team reports take-off time to Ms. Walters. From the Bronx, she will coordinate the transplant’s minute-by-minute schedule.

2:48 am The jet touches down in a Midwestern city. The Procurement Team travels by ambulance to a nearby hospital. They find the OR crowded with organ procurement teams from around the country. The donor’s generous parents are donating all their baby’s organs.

3:30 am Before accepting the donor heart, the Procurement Team confirms brain death, reconfirms blood type and “visualizes” the heart. An anticoagulant is administered and the transection of the superior vena cava begins. Ischemic time: Six hours and counting.

4:04 am The donor heart’s aorta is cross-clamped and cardioplegia administered for immediate arrest. The team moves through their tasks with new urgency, as the heart now rests in ischemic time. The surgeons have only a few hours to safely transplant it.

4:45 am With the donor heart in a sterile container of iced preservation solution, the Procurement Team rushes back to the airport and the Learjet takes off.

5:00 am Back in the Bronx, Adrian is wheeled into the OR.

6:02 am “The heart has landed,” reports Ms. Walters, who has been closely tracking the Procurement Team.

History is made at CHAM

6:22 am Dr. Weinstein makes a midline incision in Adrian’s chest and connects the baby to the heart-lung bypass machine.

6:40 am Arriving with the donor heart, a Procurement Team member makes the required formal announcement, “This is donor heart, blood type A.” Dr. Weinstein replies, “This is patient Adrian Flores, blood type A positive.”

6:55 am Dr. Weinstein eases the heart into Adrian’s chest. It’s tight—the donor heart is slightly larger than Adrian’s—but it fits. The surgeon begins to stitch. The OR is crowded with cardiac experts, witnesses to the historic first pediatric heart transplant in the Bronx. “It was really ‘business as usual,’” Dr. Weinstein remarks, downplaying his role in saving Adrian’s life.

8:37 am Adrian’s heart is secure. Dr. Lamour administers a large dose of steroids to assure his tiny body does not reject his new heart. Dr. Weinstein releases the clamps. Everyone pauses. “You’re always worried the heart may not restart,” says Dr. Hsu. “But Adrian’s heart started up right away.”

9:00-9:12 am Dr. Weinstein finishes the surgery. Forty-five minutes later Adrian is transferred to the PICU.

March 14–17

Rejecting rejection

In the days following his transplant, Adrian’s cardiac team administers immunosuppressants to prevent the child’s body from rejecting his new heart. Slowly and carefully, the PICU nurses wean him from cardiac support medications. On the morning of his extubation, Ms. Walters peeks into the PICU to find Adrian fussy. “But you don’t mind hearing them cry,” says Ms. Walters. “It’s a beautiful thing to hear them cry.”

March 26, 12 pm

Going home—and starting a fuller, healthier life

Just 13 days after receiving the heart that saved his life, Adrian charms reporters at a press conference. That afternoon he returns home with his family.



Today Adrian and his family return to CHAM frequently for regular appointments. Dr. Lamour and her team monitor for signs of infection and perform heart biopsies to detect any evidence of rejection. The team is happy to see Adrian reach each developmental milestone.

Now that this extraordinary surgery has been performed, will Adrian lead a normal, healthy life? “Yes, he will,” says Dr. Hsu without hesitation. “People who have transplants climb mountains, run marathons and play sports. Adrian will, too.”

The Flores family pictured with CHAM’s Pediatric Heart Center team including surgeons, physicians, nurses, child life specialists, social workers, nurse practitioners and administrators.

New hybrid procedure gives neonates

a pass on bypass.

CHAM cardiac surgeons and catheter interventionalists work side by side on hybrid procedures that save infants born with complex Hypoplastic Left Heart Syndrome

“25 years ago we had no treatment

for the condition known as Hypoplastic Left Heart Syndrome (HLHS),” says Daphne Hsu, MD, recalling the tragedy of babies born with HLHS. “We would tell the parents there was nothing we could do, and the babies would die shortly after being born,” recalls Dr. Hsu, Division Chief of Pediatric Cardiology, The Children’s Hospital at Montefiore (CHAM).

Today, however, cardiologic and surgical innovations have helped push HLHS survival rates to more than 85 percent. And at CHAM, catheter interventionists and surgeons advance a hybrid approach for neonates with HLHS that may improve long-term outcomes. The hybrid approach avoids the risks of a complicated open heart surgery in a newborn baby.

HLHS newborns’ brief window of viability

The normal heart is a model of hemodynamic efficiency.

“Blue” blood moves through the right heart chambers and out to the lungs in order to become oxygenated. Oxygenated blood returns to the heart’s left chambers to be pumped to the rest of the body by the left ventricle—ordinarily the strongest chamber of the heart.

A missing or underdeveloped left ventricle—as found in HLHS—is a serious problem.

At birth, an infant with HLHS can be stable for a few hours because a blood vessel, the ductus arteriosus, is open and allows the body to receive blood from the right heart. When the ductus arteriosus closes—usually within hours of birth—the body begins to fail and death is usually imminent.

Since the late 1980s, HLHS babies have been palliated with open heart surgery known as a Norwood procedure that “accomplishes some pretty major goals,” says Samuel Weinstein, MD, Pediatric Cardiothoracic Surgeon, CHAM. “The first step of the Norwood allows the right ventricle to do the work of the underdeveloped left ventricle and pump the blood to the body. In addition, the surgery creates a connection to provide blood flow to the lungs and opens up the wall between the two upper chambers of the heart to let the blue and red blood mix.”

Hybrid approach lets neonates bypass the bypass

The Norwood surgery is one of the most complicated open heart surgeries to perform and requires stopping the baby’s heart and supporting the circulation using bypass machinery that pumps oxygenated blood to the body.

“With a hybrid approach for that first stage of the Norwood,” says Dr. Weinstein, “there is no need for a newborn baby to have open heart surgery and bypass.” The hybrid procedure is performed by the surgeon and the interventional cardiologist working together to achieve the same result as open heart surgery. The surgeon places bands around the arteries to the lungs that normalize the blood flow to the lungs and then the interventional cardiologist places a stent in the ductus arteriosus to keep that blood vessel open and directing blood to the body.

Avoiding bypass may be particularly advantageous to babies with HLHS who can have learning difficulties as they grow older.

“Today, cardiologic and surgical innovations have helped push HLHS survival rates to more than 85%.”



(left) **Samuel Weinstein, MD**
Director, Pediatric Cardiothoracic Surgery and Adult
Congenital Cardiac Surgery
(right) **Robert H. Pass, MD**
Director, Pediatric Interventional Cardiology
Director, Pediatric Electrophysiology



Surgeon and interventionist work together to expand use of hybrid

At CHAM, the cardiologists and surgeons are working together to expand the hybrid approaches beyond neonates with HLHS. Dr. Weinstein and Robert Pass, MD, Director of Pediatric Interventional Cardiology, CHAM, recently worked together to treat an infant born with another type of Congenital Heart Disease, an interrupted aortic arch and complex ventricular septal defect.

The procedure unfolded similarly to their earlier hybrid palliation of a HLHS patient—the first step of treatment was essentially the same for both patients.

After opening the chest, Dr. Weinstein banded the pulmonary arteries to control blood flow. Banding helps prevent pulmonary hypertension—always a risk as next-step stenting dramatically increases blood flow.

Once Dr. Weinstein set the bands, he positioned a vascular sheath in the infant's main pulmonary artery. Under fluoroscopic guidance, Dr. Pass carefully placed a stent in the ductus arteriosus.

Both patients would need second surgeries later, but the hybrid first-step avoided the need to perform open heart surgery in a newborn baby, postponing open-heart surgery until a later stage of development when the infant is bigger and more stable.

New hybrid lab will minimize invasive procedures

The cardiac team looks forward to expanding services when CHAM's new hybrid surgical lab opens in late 2010. The surgically sterile hybrid suite will include a cradling table, OR lighting and plenty of space for bypass, fluoroscopic and catheter equipment.

In addition to treating babies with complex disease, Dr. Pass and his team plan to use the hybrid lab to perfect simpler procedures and reduce more invasive operations. For large atrial septal defects, for example, “We can start with catheter closure—and if that doesn't work, switch quickly to a surgical approach,” says Dr. Pass, adding, “One way or the other, the patient will come out of the room repaired.”

■ To refer a patient to Dr. Pass or Dr. Weinstein or for more information about Hybrid Procedures, please call the Pediatric Heart Center at 718-741-2343 or email: rpass@montefiore.org or sweinste@montefiore.org.

Building Partnerships to Support Meaningful Kids' Cardiac Research

Congenital heart disease (CHD) affects less than one percent of all infants born in the U.S., but the small numbers have a direct impact on clinical research. “Historically research in drug therapy or mechanical assist devices for children with heart disease has been sparse,” says Jacqueline Lamour, MD, Director of Advanced Pediatric Cardiac Therapies at CHAM. “Because the number of children requiring these therapies is low, it becomes difficult for medical companies to turn a profit.”

At CHAM, resourceful cardiac clinicians are drawing on their prominence in the cardiologic and surgical field to build collaborative relationships with other pediatric institutions. Together, they are gathering critical data to conduct various research studies to improve technology, therapies, and outcomes for children with CHD.

Current CHAM multi-center trials

Pediatric Cardiology Quality of Life Index

The purpose of this multi-center study is to determine the feasibility, reliability and validity of the pediatric quality of life inventory (PedsQL™) among children with heart disease. pediatrics.aappublications.org/cgi/content/full/123/4/e708

Pediatric Cardiomyopathy Registry

This database was established to describe the epidemiologic features and clinical course of selected cardiomyopathies in patients aged 18 years or younger and to promote the development of etiology-specific treatments. The National Heart, Lung and Blood Institute funded the Pediatric Cardiomyopathy Registry from 1994 to 2010. www.pcmregistry.org

Pediatric Heart Transplant Study Group (PHTS)

A nonprofit organization, the PHTS is dedicated to the advancement of the science and treatment of children during listing for, and following, heart transplantation. The purposes of the group are to establish and maintain an international, prospective, event-driven database for heart transplantation, to use the information to encourage and stimulate basic and clinical research in the field of pediatric heart transplantation and to promote new therapeutic strategies. www.uab.edu/ctsresearch/phts

Alloantibodies in Pediatric Heart Transplant (CTOT-C 4)

The Clinical Trials in Organ Transplantation in Children (CTOT-C) project is a cooperative research program sponsored by the National Institute of Allergy and Infectious Diseases (NIAID), with co-funding from the National Heart, Lung and Blood Institute (NHLBI). CTOT-C is an investigative consortium for conducting multi-institutional clinical and associated mechanistic studies that will lead to improved outcomes for pediatric transplant recipients. The purpose of these studies is to improve short- and long-term graft and patient survival in children who have undergone heart, lung or kidney transplantation. www.ctotc.org

CHAM's plans for future multi-center trials include:

The Aristotle Score

CHAM's Division Chief of Pediatric Cardiac Surgery, Francois Lacour-Gayet, MD (See page 30) created the Aristotle Score, an international surgical complexity rating system. At CHAM, he will take the system to the next level. www.aristotleinstitute.org

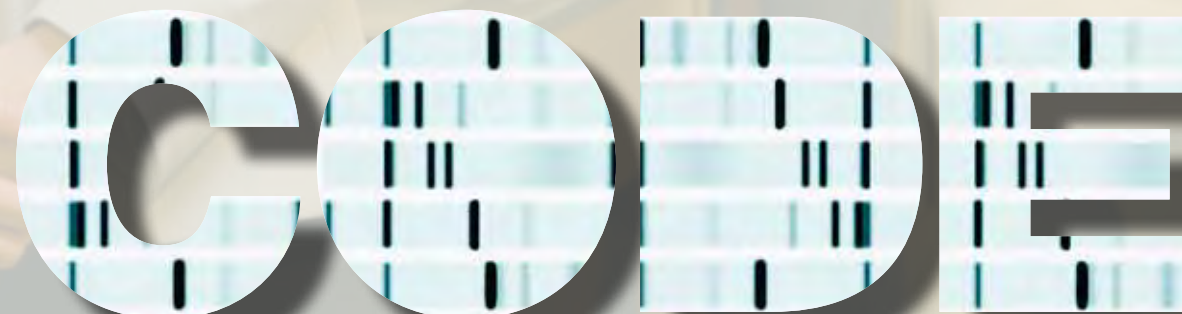
Artificial Heart for Left Ventricle

CHAM's Pediatric Heart Center applied for \$10 million in NIH and other grants to continue work on a cardiac device for babies with little or no left ventricles.

■ For more information about CHAM's Clinical Research Programs, please call the Pediatric Heart Center at 718-741-2343 or email: jlamour@montefiore.org or dhsu@montefiore.org.



CRACKING THE GENETIC



FOR CONGENITAL HEART DISEASE

A pioneering Human Genome Project researcher partners with CHAM to decode cardiac disease's chromosomal connections.

Economy-battered hospital budgets often call for a reduction in funds allocated to areas such as translational research. However, The Children's Hospital at Montefiore believes that strengthening its foundation in investigative activities during tough times will lead to a greater competitive advantage in the long run. Leveraging our resources, we've forged powerful intercollegiate ties with our academic medical center partner, Albert Einstein College of Medicine, to facilitate this component of our mission without relying heavily on internal or external funding.

"We are very committed to research on the genetics of cardiac disease," says Daphne Hsu, MD, Division Chief of Pediatric Cardiology and Co-Director of the Pediatric Heart Center, CHAM.

For two translational initiatives aimed at demystifying the chromosomal mechanisms of the heart, Dr. Hsu is collaborating with Bernice Morrow, PhD, Director, Division of Translational Genetics, Department of Molecular Genetics, Albert Einstein College of Medicine. A participant in the Human Genome Project in 1999, Dr. Morrow was among the handful of elite geneticists who decoded Chromosome 22—the first step in the unraveling of the entire human genome.

Spotlight on copy number variations

For a separate CHAM study, Dr. Morrow and Dr. Hsu are developing "a program that will allow us to evaluate children and their families for cardiomyopathies and other cardiovascular defects," explains Dr. Hsu. "Cardiomyopathy is a familial disease. Between 20–30 percent of children with cardiomyopathy have an affected family member and Dr. Morrow has a very specific way of looking at gene typing."

Dr. Morrow is studying a form of genetic variability known as copy number variation (CNV). "CNVs are small genetic deletions,

duplications or amplifications," explains Dr. Morrow. "They can occur in individual chromosomes—but at a size too small to be detected by chromosome analysis under a microscope."

CNVs only came to light recently with advancements in microarray technology. "New high-resolution tools, chiefly microarray platforms and soon, next-generation sequencing will allow all CNVs to be seen," says Dr. Morrow, "both those causing disease and those influencing heritable traits."

Crunching chromosomal numbers to identify heart disease carriers

Sophisticated computational tools at Albert Einstein College of Medicine and Montefiore help Dr. Morrow rapidly sort and compare large segments of DNA. After crunching the numbers, the team can identify chromosomal copy number variants.

By using DNA collected from Dr. Hsu's young congenital heart disease patients, the team notes critical regions of certain well-defined genetic syndromes—and rule CNVs in or out as causative factors, says Dr. Morrow.

Sequence variants play a part in Velocardiofacial/ DiGeorge Syndrome (VCFS/DGS)

VCFS/DGS is a syndrome caused by a CNV on chromosome 22. Members of the Pediatric Division of Genetics, Dr. Hsu and Dr. Morrow have partnered for a second study with Children's Hospital of Philadelphia. The scientists are performing genome-wide association studies to understand the causes of varied heart defects in association with VCFS/DGS.

Each year one in 2,000–4,000 children in the U.S. are born with VCFS/DGS. More than 90 percent of these young patients will be missing about three million base pairs on one copy of chromosome 22 in each cell.

Children with this syndrome exhibit craniofacial anomalies, immunologic dysfunction and various learning disabilities. The chromosomal deletion is also responsible for a wide range of complex cardiac defects.

"The goal of our study," Dr. Morrow says, "is to determine whether sequence variants could account for why some patients, all with the same sized deletion on chromosome 22, are severely or mildly affected."

"Because if we can figure out why," notes Dr. Hsu, "we can do something early enough—and eliminate the heart disease."

■ To refer a patient to Dr. Morrow or Dr. Hsu or for more information about CHAM's Genetic Studies of Heart Disease, please call the Pediatric Heart Center at 718-741-2343 or email: bernice.morrow@einstein.yu.edu or dhsu@montefiore.org.

At CHAM's Fetal Cardiology Center,

Diagnosis of congenital heart abnormalities with fetal echocardiography offers more accuracy and advance planning for postnatal treatment.

Twenty years ago, young patients might have reached their teens before being diagnosed with congenital heart disease. However, cardiologists can now detect pediatric heart conditions as early as the mother's fourth month of pregnancy.

"It is well-documented that ductal dependant lesions, such as Hypoplastic Left Heart Syndrome (HLHS), aortic coarctation and pulmonary atresia, were not recognized prenatally and often not immediately after birth years ago," notes Rajesh Shenoy, MD, Attending Physician, Division of Pediatric Cardiology at CHAM. "Unfortunately these babies would leave the hospital and outcomes were much worse than at present, when diagnosis of congenital heart disease is often made prenatally."



Leo Lopez, MD
Director, Pediatric Cardiac Noninvasive Imaging



Rajesh Shenoy, MD
Attending Physician, Pediatric Cardiac Noninvasive Imaging

Early Detection Improves Outcomes

Thanks to 10 years of experience, a multidisciplinary approach and state-of-the-art technology, Dr. Shenoy and the team of cardiologists at CHAM's Fetal Cardiology Center can identify pediatric heart conditions within a life-saving time frame. "Before fetal cardiology was developed, most babies with serious heart defects did not survive past the first two to three days of life. Now most of them have a clinical diagnosis even before birth, and we can alert the OB and neonatal intensive care unit early enough to begin treating them immediately after birth."

Fetal echocardiography data promotes proactive treatment planning

CHAM's echocardiologists use advanced technology, such as 2D and 3D echocardiogram, Doppler imaging, speckle tracking echocardiography and fetal biometry (to track fetal growth) to gather critical information. The detailed noninvasive imaging studies provide enhanced imaging quality and copious amounts of quantitative data.

"Nobody thought we'd have use for this data in the past," explains Leo Lopez, MD, Director of Noninvasive Imaging, Pediatric Cardiology, CHAM. "But it helps assess ventricular volume and mass, myocardial velocity and other critical measures" that enable

specialists to prognosticate and customize treatment for each child with heart disease. Plus it minimizes the number of diagnostic tests and invasive procedures. "We don't want kids to incur any unnecessary risks of catheterization and general anesthesia, or even the radiation from a CT scan," remarks Dr. Lopez.

"Not only are long-term outcomes superior from a medical standpoint," Dr. Shenoy adds, "but I can't begin to describe how much better it is for the family. They have time to accept the diagnosis, think ahead and plan for their child's treatment."

Collaboration with referring physicians

The fetal cardiology team screens more than 20 patients each week from across the New York tri-state region. Many of these are same-day referrals for patients with arrhythmia or other potentially dangerous conditions.

"Referring physicians partner with us to triage the patient," Dr. Shenoy explains. "If we agree the mother needs an immediate fetal echo, it's done the same day, regardless of how busy the lab is."

"Cardiologists, interventional cardiologists, cardiothoracic surgeons and our dedicated nurses work seamlessly together to help each patient. For conditions such as HLHS, we use the hybrid approach, which involves coordinated interventions by surgeons and cardiologists in the hybrid operating room," Dr. Shenoy explains.

"Our team has, by far, the most experience in the New York Metropolitan area with the hybrid approach. It offers an alternative to the traditional surgical approach, which may not be ideal for certain high-risk neonates."

This holistic approach is transforming the fetal cardiology discipline, and most importantly, lives. "It's always devastating for parents to learn of their child's diagnosis of a heart condition," Dr. Shenoy empathizes. "But knowing this far ahead of the actual birth helps families prepare and allows physicians to coordinate care. Now we have quite a few kids who have had three operations, which is the typical course, and when you see them as four- and five-year-old schoolchildren whom you've followed since fetal life, it's a wonderful feeling."

■ To refer a patient to Dr. Lopez or Dr. Shenoy or for more information about CHAM's Fetal Cardiology Program, please call the Pediatric Heart Center at 718-741-2343 or email: leolopez@montefiore.org or rshenoy@montefiore.org.

Groundbreaking Center for Cardiogenetics Offers Answers

Montefiore-Einstein Explores Channelopathies and Ethical Implications of Translating Cardiogenetic Research to Clinical Practice

Few clinical complications are as traumatic as the death of an infant or child from Sudden Infant Death Syndrome (SIDS) or Sudden Unexpected Death Syndrome (SUDS). Surprisingly, SIDS still remains a leading cause of death in the first year of life, with approximately 3,000 deaths each year attributed to it. SIDS also accounts for 80 percent of sudden unexpected deaths in the first year of life.

“Despite the success of ‘Back to Sleep’ educational campaigns and efforts to reduce certain environmental triggers, SIDS continues to devastate thousands of families across the country,” notes Robert Marion, MD, Chief of the Division of Genetics and Developmental Medicine at CHAM, who co-directs the Montefiore-Einstein Center for Cardiogenetics (MECC) alongside Christine Walsh, MD, and Thomas McDonald, MD. Almost equally difficult as the loss of a child is the lack of available information to explain its genesis. Questions about the cause, whether it could have been prevented and if it could strike another family member, relentlessly plague grieving parents.

The first and only cardiogenetics center of its kind in the tri-state region, MECC brings together physicians and scientists to answer questions about SIDS and SUDS, provide comprehensive family evaluation and offer treatment that can prevent a recurrence in other family members. “We understand that parents never fully overcome the loss of a child or family member,” explains Dr. Walsh, MECC Co-Director and Director of CHAM’s Pediatric Dysrhythmia Center. “But we are giving them the opportunity to turn their sorrow into answers and positive action.”

Channelopathies: the foundation for prevention

MECC’s interdisciplinary team of adult and pediatric cardiologists, electrophysiologists, geneticists, genetic counselors, bereavement counselors, social workers, neurologists, metabolic specialists and nurse coordinators provide thorough evaluations for families that have lost a loved one to SIDS/SUDS. Family members undergo non-invasive cardiac examinations, such as EKG and echocardiogram. When appropriate, a blood sample is collected and tested for mutations in one of the genes often associated with Long QT syndrome, a congenital heart condition with delayed repolarization that could lead to a potentially lethal arrhythmia.

“Our main focus is channelopathies, caused by mutations in genes that lead to the malfunctioning of cardiac ion channels,” explains Dr. Walsh. “The result is an imbalance in ionic currents that govern the orderly progress of the normal heartbeat leading to a variety of disturbances of the heart rhythm that may result in fainting, seizures or even sudden death.”

“We are particularly diligent in finding evidence of any contributory genetic mutations that may be present in the parents, siblings or in tissue samples taken from the infant at the time of death,” states Dr. Marion. “By identifying any genetic vulnerability, we can often

NIH grant brings ethics to the fore

An important facet to consider with cardiogenetics is how to best handle and convey genetic test results. MECC was recently awarded a two-year NIH grant to explore the ethical and social implications of genetic testing in the case of unexpected deaths. This research study, spearheaded by Siobhan Dolan, MD, MPH, aims to answer a plethora of ethical questions, such as who can give permission for a molecular autopsy, whether second-degree relatives are privy to test results, and if a child bears the right to decide if he or she can undergo a genetic evaluation, should the parents refuse it.

“Every patient and family is managed based on their specific psychological and genetic needs. In terms of both diagnosis and management, this really is the cutting edge of personalized medicine.”

(left) Christine Walsh, MD
Co-Director, Montefiore-Einstein
Center for Cardiogenetics

(right) Robert Marion, MD
Chief, Division of Genetics
and Developmental Medicine
Director, Children’s Evaluation
and Rehabilitation Center

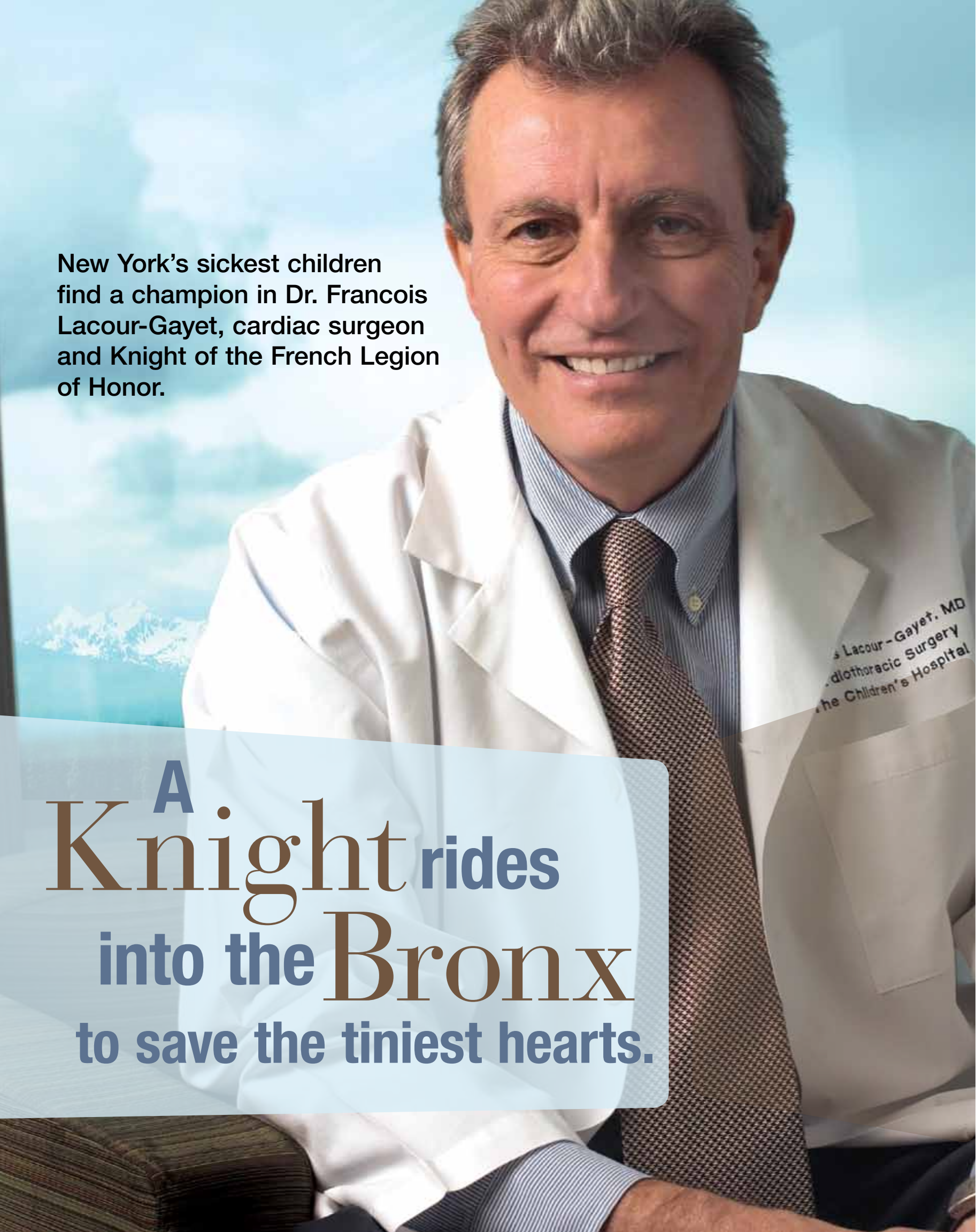
provide treatments for those who may carry the same mutations, as well as any subsequent children to prevent a recurrence of SIDS or SUDS.”

MECC is one of only a handful of centers nationwide with an all-encompassing evaluation and treatment program. “We conduct genotyping, molecular phenotyping, gene-specific management and new gene discovery to provide as many answers as possible,” explains Dr. Walsh. “Every patient and family is managed based on their specific psychological and genetic needs. In terms of both diagnosis and management, this really is the cutting edge of personalized medicine.”

An ethicist will be added to MECC’s team to address these pressing issues associated with translating cardiogenetic knowledge to clinical practice. “MECC is growing exponentially and this grant will help formulate procedures and policies moving forward to provide the best care for families,” Dr. Walsh remarks.

“Every effort of our clinic is driven by the goal of giving families who have experienced this trauma freedom from fear that another child may die from SIDS or SUDS. We want to give them control of their lives and ultimately prevent SIDS and SUDS from ever happening again.”

■ To refer a patient to Dr. Marion or Dr. Walsh or for more information about the Montefiore-Einstein Center for Cardiogenetics, please call the Pediatric Heart Center at 718-741-2343 or email: robert.marion@einstein.yu.edu or cwalsh@montefiore.org.

A portrait of Dr. Francois Lacour-Gayet, a middle-aged man with grey hair, smiling. He is wearing a white lab coat over a blue striped shirt and a brown patterned tie. The background is a soft-focus blue sky with clouds. On the left side of the image, there is a text box with a light blue background and a white border containing the headline.

New York's sickest children find a champion in Dr. Francois Lacour-Gayet, cardiac surgeon and Knight of the French Legion of Honor.

A Knight rides into the Bronx to save the tiniest hearts.

Francois Lacour-Gayet, MD, is a hero to thousands of parents. Armed with a scalpel—and formidable surgical skills—the neonatal cardiac surgeon strides forth daily to do battle with children's heart disease.

Knight in surgical scrubs

But Dr. Lacour-Gayet is more than a medical champion. The French surgeon is a knight. A real knight. He has saved thousands of kids' lives.

"It's not an aristocratic distinction," insists Dr. Lacour-Gayet, who was recently invested as a Knight of the Legion of Honor—France's highest civilian award—in recognition of his surgical achievement.

In September 2009, the distinguished surgeon joined The Children's Hospital at Montefiore (CHAM) as Division Chief of Pediatric Cardiothoracic Surgery. He also co-directs CHAM's Pediatric Heart Center with Daphne Hsu, MD, Division Chief of Pediatric Cardiology.

The two specialists share ambitious plans for CHAM's pediatric heart center.

Region makes way for new Pediatric Cardiac Center of Excellence

Formerly Chief of Cardiac Surgery at The Children's Hospital in Denver, CO, Dr. Lacour-Gayet is unequivocal about his goals for CHAM. "My purpose in coming here," he says, "is to help create a center of excellence that will make CHAM one of the five best pediatric cardiac centers in the country."

"I've always been surprised," notes Dr. Lacour-Gayet "that New York has, essentially, only one center for pediatric cardiac surgery. With more than 30 million people in the New York-New Jersey area, there's room for more."

"I think CHAM's potential is huge."

Track record for building nationally prominent cardiac programs

Dr. Lacour-Gayet clearly relishes the competitive challenges of building outstanding pediatric cardiac programs. His seven-year tenure at The Children's Hospital, Denver, coincided with the facility's rise to national prominence.

Prior to his directorship there, Dr. Lacour-Gayet served as president of the prestigious European Association of Pediatric Cardiac Surgery.

Thriving on creative complexity of children's cardiac surgery

Acclaimed for his elegant, technically exacting cardiac procedures, Dr. Lacour-Gayet has performed hundreds of bi-ventricular repairs and complicated artery transposition corrections.

He is responsible for close to 700 complex arterial switch procedures—surgery that corrects transposition of the great arteries—more than any other surgeon in the world.

Dr. Lacour-Gayet felt called to his profession very early on. "I knew I wanted to be a surgeon when I was six," he says. After choosing cardiac specialization in medical school, he "figured out pretty quickly that kids were the most interesting part about cardiac surgery."

"With adults you can perform ten different surgeries," he explains. "But with children you can perform a hundred. Imagine you are a pianist and you can choose to play ten pieces—or a hundred."

In addition to his surgical work, Dr. Lacour-Gayet is developing a neonatal artificial heart to help children born with limited ventricular function.

Champion of cardiac care for world's neediest children

Along with his surgical, research and teaching work, Dr. Lacour-Gayet serves as president of Surgeons of Hope, a non-profit organization that provides surgery to needy children around the world.

Currently he is raising funds to renovate a surgical unit of the La Mascota Children's Hospital, a facility that serves street children in Managua, Nicaragua.

Dr. Lacour-Gayet is quick to brush off heroic analogies to his work, "In pediatric cardiac surgery," he says, "doctors aren't the heroes. The kids' parents are the heroes." 



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