

# Congenital Heart Center

UNIVERSITY OF MICHIGAN C.S. MOTT CHILDREN'S HOSPITAL CLINICAL ACTIVITY REPORT





YEARS
43
STATES
17
COUNTRIES

TO MAKE A REFERRAL OR SPEAK WITH ONE OF OUR SPECIALISTS, CONTACT M-LINE 24 HOURS A DAY, 7 DAYS A WEEK.

M-LINE 800.962.3555

www.mottchildren.org/congenital

RICHARD G. OHYE, MD, HEAD, SECTION OF PEDIATRIC CARDIOVASCULAR SURGERY JOHN R. CHARPIE, MD, PHD, DIRECTOR, DIVISION OF PEDIATRIC CARDIOLOGY



# EXTRAORDINARY HEART CARE FOR CHILDREN **AROUND THE NATION** AND **ACROSS THE GLOBE**



# Leaders in cardiac care, discovery and education

As an international referral center for children with complex congenital heart disease, the University of Michigan Congenital Heart Center at C.S. Mott Children's Hospital is one of the largest and best congenital heart programs in the United States. From diagnosis and medical management of the most common cardiac disorders to application of the most complex and innovative therapies available, our pediatric specialists are committed to providing the most advanced, evidence-based care for infants, children and adolescents with all forms of congenital and acquired heart disease, as well as for adults with congenital heart disease.

# Discover the Michigan Difference



STRENGTH IN NUMBERS ON MARCH 27, 2012, DR. EDWARD BOVE PERFORMED HIS 10,000TH CARDIAC PROCEDURE AT THE UNIVERSITY OF MICHIGAN.

#### **Experience matters**

Research shows that clinical volume and experience are key determinants of quality of care. The breadth and depth of our program results in a unique level of experience across the spectrum of congenital heart conditions—from fetus to adult—as well as expertise in the full range of treatments and therapies. Our goal is to consistently offer you and your patients access to the latest emerging technologies and therapies through clinical trials and cutting-edge research.

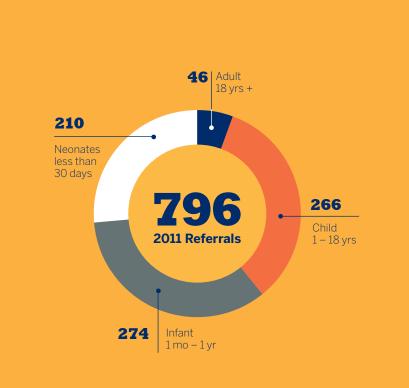
### Important discoveries and bold new approaches to care

As one of the nation's best funded pediatric research programs, our physicians are known for their relentless pursuit of innovation and quality improvement. From our work in the 1970s to develop Extracorporeal Membrane Oxygenation (ECMO) to our more recent work to redefine approaches to treat Hypoplastic Left Heart Syndrome, our driving focus is to continue to improve the procedures, processes and equipment that change the lives of congenital heart patients around the world.

### Focused on kids being kids

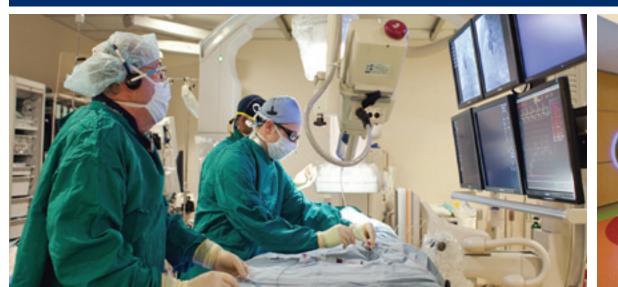
C.S. Mott Children's Hospital was the first pediatric hospital in the country to create a Child Life program to preserve the ability of children to "just be kids," even when they are sick. Our internationally recognized team of pediatric-specific cardiac surgeons, cardiologists, cardiac nurses, anesthesiologists and allied health professionals specializes in caring for this unique group of patients.

We strive always to deliver highly competent, skilled and knowledgeable health care services guided by respect for children and families. Our work is characterized by our commitment to focus beyond survival to offer patients the best chance at a robust quality of life, improved long-term outcomes and reduced morbidity.





C.S. MOTT CHILDREN'S HOSPITAL WAS THE 1st PEDIATRIC HOSPITAL IN THE COUNTRY TO CREATE A CHILD LIFE PROGRAM TO PRESERVE THE ABILITY OF CHILDREN TO "JUST BE KIDS," EVEN WHEN THEY ARE SICK

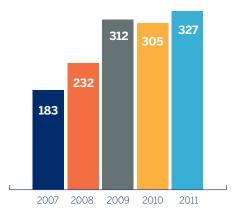




# Pediatric Cardiology

The University of Michigan is home to the Midwest's largest team of pediatric cardiologists. Our state-ofthe-art diagnostic and interventional suites in the new 12-story C.S. Mott Children's Hospital are staffed by a dedicated team of experienced pediatric cardiologists, technologists, anesthesiologists and allied health care professionals. Working seamlessly with our colleagues in pediatric cardiac surgery, we are committed to unparalleled care for our patients and a close collaboration with our referring physician partners.

#### **ELECTROPHYSIOLOGY VOLUMES**



Volume data include ablations with electrophysiology studies, pacemakers, implanted cardioverter-defibrillators (ICDs), cardioversion and other electrophysiology procedures.

#### **Electrophysiology**

U-M's team of pediatric electrophysiologists performs implantation of pacemakers or implantable defibrillators for those with life-threatening conditions. We utilize the latest mapping and robotic navigation tools for heart rhythm treatments, such as catheter ablation. All of these procedures are performed in our new, dedicated pediatric EP lab. In addition, our heart rhythm specialists provide the full range of diagnostic non-invasive tests such as stress electrocardiography, home rhythm monitoring and remote pacemaker support.

### **Fetal Heart Program**

In collaboration with the Fetal Diagnosis and Treatment Center, our multidisciplinary fetal heart specialists provide the full spectrum of fetal diagnostic, interventional and delivery planning services for mothers and families with babies diagnosed in-utero with congenital heart defects. Each member of our team is committed to optimizing long-term outcomes and helping infants develop into healthy, productive adults.

Our specialized interventional services include catheter-based fetal cardiac interventions for a small subset of babies who are candidates, including those with critical aortic stenosis, as well as Hypoplastic Left Heart Syndrome complicated by a restrictive atrial defect.

A distinctive feature of our fetal heart program is our seamless integration with U-M's Von Voigtlander Women's Hospital and its team of maternal-fetal medicine specialists, with our fetal cardiology program, private-room birth center, newborn intensive care unit (NICU) and pediatric cardiothoracic intensive care unit all co-located in one state-of-the-art building. This unique arrangement optimizes maternal and fetal well-being and ensures a smooth transition of care for the infant after birth.

We work closely with referring physicians to co-manage the pregnancy and to continue routine care close to home as much as possible.

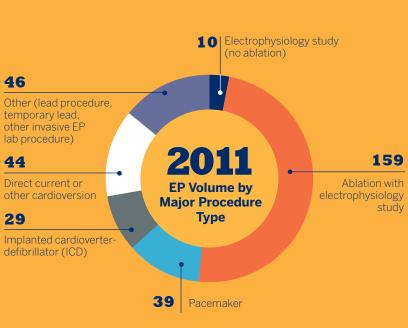






# IN 2011, OUR ELECTROPHYSIOLOGY ABLATION VOLUMES INCREASED **20%** WITH **NO COMPLICATIONS**





# Pediatric Cardiology

#### **Interventional Cardiology**

University of Michigan pediatric cardiologists offer the full range of catheter-based technologies to enable the least invasive, most effective diagnostic and treatment approaches for a variety of heart lesions. Our team of experienced cardiologists and pediatric-specific clinical staff utilizes the latest technologies to provide unparalleled interventional care.

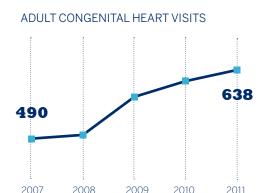
## **Adult Congenital Heart Program**

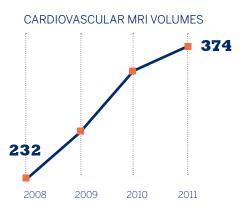
The University of Michigan treats the largest number of adult patients with congenital heart disease in the state, with extensive experience in adult congenital cardiac imaging, high-risk obstetrics, pulmonary hypertension, cardiomyopathy and heart failure management. Our adult congenital specialists are double boarded in both Pediatrics and Internal Medicine for transition of care from adolescence to adulthood.

### Non-Invasive Imaging

Our dedicated pediatric cardiac diagnostic services utilize advanced imaging to facilitate interventional and surgical care. Procedures are coordinated whenever possible to allow for convenient, same-day testing. We offer the latest in non-invasive imaging techniques including 3D echocardiography, fetal echocardiography, intracardiac and intravascular ultrasound and on-site cardiovascular MRI. All tests are interpreted by dedicated pediatric cardiologists with advanced training in non-invasive imaging.

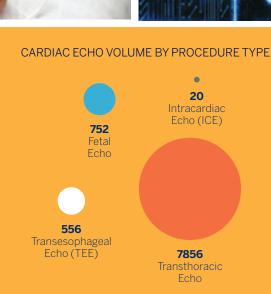
Our designation as an ICAEL-certified echocardiography laboratory attests to the quality of our imaging program, characterized by collaborative reading of studies by multiple pediatric cardiologists and consistent internal quality auditing.











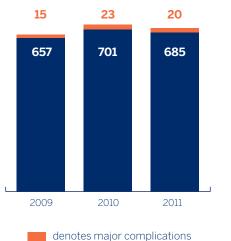
AS A REGIONAL REFERRAL CENTER, IN 2011 OUR PEDIATRIC CARDIOLOGISTS INTERPRETED RESULTS ON MORE THAN  $\ref{720}$  ECHO'S FROM PARTNER HOSPITALS THROUGHOUT MICHIGAN

# **Transcatheter Pulmonary Valve Therapy**

Transcatheter pulmonary valve implantation is a novel, cutting-edge, minimally-invasive heart valve therapy for failing right ventricular-to-pulmonary artery conduits that uses a catheter-based approach rather than traditional open-heart surgery.

C.S. Mott Children's Hospital is one of only ten U.S. centers included in the Medtronic Melody® Transcatheter Pulmonary Valve Post-Approval Study. We were the first center to implant a valve in the study and the first to complete enrollment. Today, C.S. Mott Children's Hospital is one of the highest-volume implanting centers in the U.S., having implanted 43 valves as of April 2012. (The Melody® Transcatheter Pulmonary Valve is currently approved for humanitarian use.)





IN 2011: **21** IMPLANTS | **100%** PROCEDURAL SUCCESS | **0** PROCEDURAL DEATHS | **0** RE-INTERVENTIONS

2011 QUICK FACTS

**Transesophageal Echo** (TEE)

**556** 



Adult **Congenital Heart** 

638

20

**Intracardiac Echo** 

**Cardiac ECMO** 

22





**ECHO** results interpreted from partner hospitals throughout Michigan



**Patient and Family** Satisfaction

96.9%



**Transthoracic Echo** 7856



Electrophysiology Volume

327



**Fetal Echo** 

**752** 

**Cardiovascular MRIs** 

374



**ELECTROPHYSIOLOGIC ABLATION VOLUMES INCREASED** 

with NO COMPLICATIONS



**Cardiac Catheterization** 685





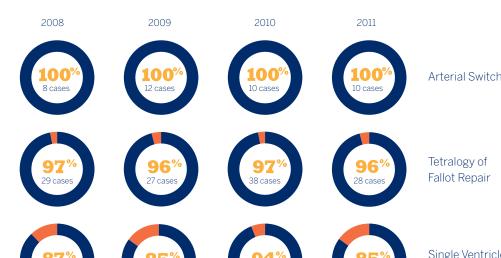
**801** 

# Pediatric Cardiac Surgery

Since our pediatric cardiac surgery program began, we have cared for more than 20,000 patients, making us one of the largest, most experienced programs in the United States. The pediatric cardiac surgeons at C.S. Mott Children's Hospital have earned international renown for their expertise in treating even the most complex congenital heart defects. Our program has become an international referral center for conditions such as Hypoplastic Left Heart Syndrome and other single ventricle lesions, high-risk biventricular repair, complex forms of Transposition of the Great Arteries and many other congenital abnormalities.

In 2011, our new 1.1-million-square-foot children's hospital opened, including three state-of-the-art dedicated pediatric cardiovascular operating rooms staffed by sub-specialty trained pediatric cardiac anesthesiologists and a dedicated pediatric cardiovascular OR team.

#### CARDIAC SURGERY LESION SPECIFIC VOLUME AND OPERATIVE SURVIVAL















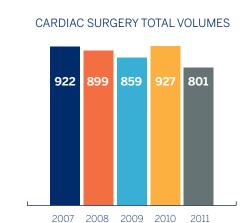






SINCE OUR PEDIATRIC CARDIAC SURGERY PROGRAM BEGAN, WE HAVE CARED FOR MORE THAN

20,000

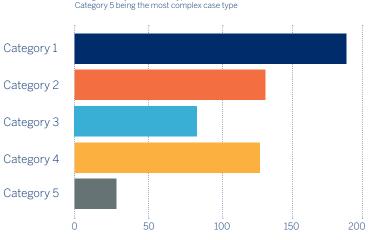




IN 2011, OUR NEW 1.1 MILLION SQUARE FOOT CHILDREN'S HOSPITAL OPENED, INCLUDING THREE DEDICATED PEDIATRIC CARDIOVASCULAR OPERATING ROOMS

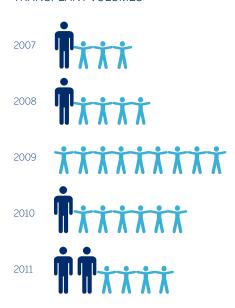
# 2011 SURGICAL PROCEDURE COMPLEXITY

Categorized by STS-EACTS type, Category 5 being the most complex case type



# Pediatric Cardiac Surgery

#### TRANSPLANT VOLUMES





#### **Hybrid Capabilities**

Pediatric cardiac surgeons and interventional cardiologists at C.S. Mott Children's Hospital collaborate to offer selected patients with Hypoplastic Left Heart Syndrome the option of a hybrid approach, combining catheter-based technology and surgery. This approach is generally reserved for patients identified as high risk for the Norwood procedure, such as preterm infants, as our outcomes for traditional staged surgical repair in standard-risk patients continues to compare favorably to those published for the hybrid procedure. Since 2009, we have performed 12 hybrid procedures with 100% procedural success and 83% survival-to-discharge in this very high risk population.

#### **Transplant and Heart Failure**

U-M pediatric cardiac surgeons have performed more than 200 pediatric heart transplants since the transplant program's beginning in 1984, consistently reporting low organ rejection rates and patient survival rates that rank among the world's best. Our dedicated, multidisciplinary team of pediatric cardiac transplant surgeons, transplant cardiologists, pharmacists, nutritionists and social workers provides coordinated and comprehensive evaluation, treatment and follow-up management, including a full spectrum of support services to children and their families. We participate in multiple transplant listings and have extensive experience performing combination transplants such as heart/kidney or heart/liver. In addition, our innovative research endeavors give patients access to the newest treatments available, including the full range of ventricular assist devices (VADs).

### **Pediatric Cardiac ECMO Program**

As the center where Extracorporeal Membrane Oxygenation was first developed, the University of Michigan has the most ECMO experience in the world. Since 1985, U-M has cared for more than 2,000 patients on ECMO. Today, C.S. Mott Children's Hospital is still the national leader in application and successful utilization of ECMO on congenital heart patients.



2011 CARDIAC ECMO VOLUME AND SURVIVAL TO HOSPITAL DISCHARGE



SINCE 2009: 12 HYBRID PROCEDURES | 100% PROCEDURAL SUCCESS | 83% SURVIVAL TO DISCHARGE

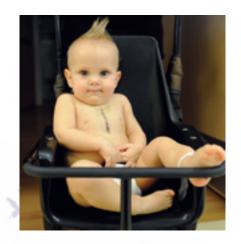








# **Patient Care**







Our Pediatric Cardiothoracic Intensive Care Unit (PCTU) and general cardiac care unit have a specialized staff of dedicated cardiac physicians, nurse practitioners, nurses, respiratory therapists, pharmacists, nutritionists, social workers, child life specialists and other support staff to deliver the optimal experience for children and their families. We strive to provide patient- and family-centered care, and are among the first academic medical centers to institute multidisciplinary family-centered rounds and involve families in all medical decisions. Families also serve on our Congenital Heart Center leadership committees.

Our continued commitment to quality improvement is demonstrated through our involvement and leadership in many national quality collaboratives such as the Children's Hospital Association (formerly known as NACHRI), Society of Thoracic Surgeons (STS), Extracorporeal Life Support Organization (ELSO), Pediatric Heart Transplant Study and the National Pediatric Cardiology Quality Improvement Collaborative.

### PEDIATRIC CARDIOTHORACIC INTENSIVE CARE UNIT PATIENT AND FAMILY SATISFACTION

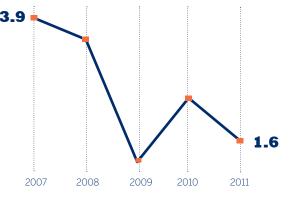






### PCTU CATHETER-ASSOCIATED **BLOODSTREAM INFECTIONS**

The CDC pooled mean for BSI is 2.1 BSIs/1000 line days



COMPLETED PATIENT TRANSPORTS IN 2011. NOT INCLUDING ORGAN PROCUREMENT

THE UNIVERSITY OF MICHIGAN IS 1 OF ONLY 2

CENTERS IN THE U.S. WITH THE CAPABILITY TO PROVIDE MEDICAL TRANSPORT SERVICES FOR PATIENTS ON ECMO.



#### SURVIVAL FLIGHT

The University of Michigan's Survival Flight air and ambulance service is able to handle emergent cases at any time. Our fleet is equipped to transport patients from all Michigan counties and can fly anywhere in the United States. Our dedicated staff is trained and equipped to transport patients on intra-aortic balloon pumps, heart assist devices and ECMO, and we maintain a dedicated helicopter for organ procurement.

### **OUTPATIENT CLINIC VISIT VOLUMES**



# Innovation + Research

The University of Michigan currently ranks 7th in NIH funding among all medical school pediatric departments across the nation. As a major contributor towards understanding the basic mechanisms involved in congenital heart disease and translation of research findings to patient care, the University of Michigan Congenital Heart Center has a dedicated, multidisciplinary research arm. M-CHORD, Michigan Congenital Heart Outcomes Research and Discovery, facilitates collaboration among investigators with an interest in and expertise related to congenital heart disease from a variety of clinical and scientific backgrounds.

Together, this multidisciplinary team of pediatric cardiologists, cardiac surgeons, critical care medicine physicians, geneticists, nephrologists, psychologists, neuropsychologists and nurse specialists, with the assistance of a team of research scientists, clinical research coordinators. data analysts and biostaticians, are focused on research that leads to improved long-term functional outcomes in patients with congenital heart disease. The ultimate goal is to utilize research findings to drive evidence-based clinical treatment decisions and interventions.

### **Pediatric Cardiac Critical Care Consortium (PC4)**

In 2009, the C.S. Mott Children's Hospital initiated and continues to lead a multi-center. international consortium of dedicated pediatric cardiac intensive care units. With more than 12 participating institutions, PC4 established a consensus set of definitions for data collection in order to share results and integrate with existing databases. The consortium aims to measure and identify processes and structures that differentiate high-performing centers and share these best practices throughout the pediatric cardiac critical care community.

### **Longitudinal Outcomes** and Neurodevelopment

Researchers at Mott are dedicated to improving long-term functional outcomes for individuals with congenital heart disease. Focusing on understanding treatment options associated not only with improved survival, but also with improved developmental and behavioral outcomes, researchers aim to determine optimal treatments for children with even the most complex heart abnormalities. By utilizing research on behavioral and developmental issues in these patients, physicians are identifying and implementing new means of early evaluation and referral. Researchers are also tracking data on transition readiness and self-care methods for adult survivors of congenital heart disease.

# **Protein Losing Enteropathy (PLE) and Plastic Bronchitis (PB)**

With an ongoing commitment to improving care of patients with complex heart disease, C.S. Mott Children's Hospital is developing treatments for some of the most challenging clinical problems. Researchers are collecting information from people around the world who have been treated for PLE or PB in an effort to centralize information and establish methods for preventing and managing these relatively rare conditions that may occur after Fontan palliation of a single ventricle defect.

#### **Pediatric Heart Network Core Site**

The University of Michigan C.S. Mott Children's Hospital has long been a part of the National Heart, Lung and Blood Institute-funded Pediatric Heart Network (PHN), and is now one of nine international PHN core sites. Under leadership from U-M, the PHN completed the Single Ventricle Reconstruction trial in 2011, the first multi-center congenital heart surgery clinical trial ever accomplished. The main results were published in the New England Journal of Medicine. In addition, C.S. Mott Children's Hospital has been given the responsibility of housing the PHN's biorepository, which manages DNA storage for all the network's ongoing and planned studies.

# **Innovation** Spotlights

#### **Therapeutic Ultrasound**

Scientists and physicians at the University of Michigan are continuing to advance and optimize histotripsy, an innovative ultrasonic technique invented at U-M that selectively and non-invasively—without scalpels, incisions or catheters—removes targeted tissue using high intensity ultrasound pulses. Doctors hope to develop a non-invasive, alternative technique to provide essential life-saving therapy to infants, and even fetuses, with various types of congenital heart disease such as Hypoplastic Left Heart Syndrome or Transposition of the Great Arteries. Investigators are currently working towards regulatory approval from the Food and Drug Administration to initiate an inaugural clinical trial using this novel technology.

### Wireless, battery-free implant

U-M researchers and physicians have partnered with Ann Arbor-based Integrated Sensing Systems, Inc. to develop a miniature, wireless, battery-free, cardiac pressure sensor implant for patients with complex forms of congenital heart disease, including Hypoplastic Left Heart Syndrome and congenitally corrected Transposition of the Great Arteries. The team recently received a \$1.5 million grant from the National Institutes of Health (NIH) to complete the final preclinical testing required before seeking approval under the Food and Drug Administration's Humanitarian Device Exemption pathway. Once implanted, doctors can measure pressure inside the heart while the patient is being seen in the outpatient clinic without having to do a heart catheterization. In the future. such technology may allow for the patient to be monitored remotely from home without the need to come to the hospital for evaluation.







University of Michigan C.S. Mott Children's Hospital Congenital Heart Center

# The Michigan Difference: where and when you need it.



**EXECUTIVE LEADERSHIP OF THE UNIVERSITY OF MICHIGAN HEALTH SYSTEM:** Ora Hirsch Pescovitz, M.D., Executive Vice President for Medical Affairs and CEO, U-M Health System; Douglas Strong, Chief Executive Officer, U-M Hospitals and Health Centers; James O. Woolliscroft, M.D., Dean, University of Michigan Medical School; Kathleen Potempa, D.N.Sc., R.N., F.A.A.N., Dean, University of Michigan School of Nursing

President of the University of Michigan: Mary Sue Coleman, Ph.D.

**THE REGENTS OF THE UNIVERSITY OF MICHIGAN:** Julia Donovan Darlow, Laurence B. Deitch, Denise Ilitch, Olivia P. Maynard, Andrea Fischer Newman, Andrew C. Richner, S. Martin Taylor, Katherine E. White, Mary Sue Coleman, *ex officio* 

University of Michigan C.S. Mott Children's Hospital pediatric heart specialists collaborate with physicians throughout Michigan and the nation to help children with congenital heart conditions. Our goal is to coordinate with referring physicians to keep care close to the patient's home through their existing providers whenever possible.

We also offer telemedicine capabilities to connect you and your patients with team members at C.S. Mott Children's Hospital in real time, without the expense and stress of traveling far from home.

#### **Patients**

If you have questions about the C.S. Mott Children's Hospital Congenital Heart Center, would like to schedule an appointment or if we can be of further assistance in any other way, please call **877.308.9111** 

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