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For access to Texas Children’s Heart Center outcomes, informative videos, physician profiles and more, visit texaschildrens.org/heartoutcomes.
Dear colleagues, parents and friends:

We are very pleased to present the 2013 Texas Children’s Heart Center Outcomes Book. Here you will find highlights from our Heart Center programs, important data about patient outcomes and information about our innovative research programs.

Texas Children’s Heart Center strives to provide every procedure available for patients with pediatric and congenital heart disease. Through our innovations in research and commitment to improve all aspects of patient care, our goal is the very best possible treatment for every patient.

We care for children of every age, and we are beginning to care for patients earlier than ever before. Texas Children’s Heart Center works hand in hand with physicians in our Fetal Center to identify and choose the best treatment plans for patients and their families. Surgery completed while the fetus is still in the womb is a cutting-edge treatment that gives the patient additional developmental time in the uterus, setting the stage for a healthier entry into the world.

One of the joys of our work is seeing children thrive. In this year’s edition, we check in on three congenital heart patients who have become part of our extended family. These young people have not let heart disease hold them back from living full and active lives. As our patients enter adulthood, many of them continue into our adult congenital heart program where our cardiologists are experienced in treating patients with mended hearts.

You will also find information about optimizing neurologic outcomes for children who require cardiac interventions through state-of-the-art monitoring, focused research and routine neurodevelopmental follow-up. Our teams have already uncovered important factors that contribute to developmental outcome, including brain immaturity, early brain injury and anesthetic drug exposure. The long-term impact of early brain injury will be better understood as we continue to follow patients throughout childhood.

We hope you find this information useful. Thank you for your interest in our center.

Sincerely,

Charles D. Fraser, Jr., M.D.
Surgeon-in-Chief, Texas Children’s Hospital
Donovan Chair and Chief of Congenital Heart Surgery, Texas Children’s Hospital
Susan V. Clayton Chair in Surgery, Baylor College of Medicine
Professor of Surgery and Pediatrics, Baylor College of Medicine

Daniel J. Penny, M.D., Ph.D., M.H.A.
Chief of Cardiology, Texas Children’s Hospital
Professor of Pediatrics, Baylor College of Medicine

Emad B. Mossad, M.D.
Director of Pediatric Cardiovascular Anesthesiology, Texas Children’s Hospital
Professor of Anesthesiology and Pediatrics, Baylor College of Medicine

Chief of Critical Care, Texas Children’s Hospital
Professor of Pediatrics, Baylor College of Medicine
Texas Children’s Hospital and Baylor College of Medicine

Texas Children’s Hospital is committed to creating a community of healthy children by providing the finest pediatric patient care, education and research. Renowned worldwide for its expertise and breakthrough developments in clinical care and research, Texas Children’s Hospital was ranked #4 among top children’s hospitals in the nation in 2013 and was also ranked in all 10 subspecialties in U.S. News & World Report’s list of America’s Best Children’s Hospitals.

The main campus of Texas Children’s Hospital is located in Houston and is part of the Texas Medical Center, the largest medical center in the world. Texas Children’s Hospital West Campus opened in 2011 to serve Houston’s rapidly growing population in West Houston. Texas Children’s operates Texas Children’s Pediatrics, the nation’s largest primary pediatric care network, with nearly 50 offices throughout the greater Houston community, as well as Texas Children’s Health Plan, the nation’s first health maintenance organization (HMO) created just for children.

Texas Children’s Hospital is affiliated with Baylor College of Medicine in the areas of pediatrics, pediatric surgery and obstetrics and gynecology. Baylor is ranked by U.S. News & World Report as one of the nation’s top 25 medical schools for research. Throughout our 60-year partnership, Texas Children’s Hospital has served as Baylor’s primary pediatric training site, and Baylor faculty have served as the division chiefs and staff physicians of Texas Children’s patient care centers. In 2013, Texas Children’s and Baylor renegotiated and reaffirmed our long-standing relationship and partnership. The collaboration between Texas Children’s Hospital and Baylor is one of the top 10 partnerships for pediatric research funding from the National Institutes of Health.

More than 1,500 board-certified pediatricians, pediatric subspecialists, pediatric surgical subspecialists and dentists, offering the highest level of pediatric care in more than 40 subspecialties, programs and services, practice at the hospital with a support staff in excess of 9,000.
Texas Children’s Heart Center is located in the hospital’s main inpatient building, the West Tower, on floors 15 and 17 through 20. The close proximity of the Heart Center’s treatment and administrative areas, perhaps unique in pediatric cardiac care, enables team members to respond quickly to patient and family needs or emergencies and promotes collaboration among our multidisciplinary team.

20th FLOOR – Heart Center clinics and diagnostic facilities, including the echocardiography lab, and cardiovascular clinical research core

19th FLOOR – Heart Center administrative offices and conference rooms

18th FLOOR – 21-bed cardiovascular intensive care unit; dedicated Heart Center pharmacy; three state-of-the-art cardiovascular operating rooms; three state-of-the-art cardiac catheterization labs; eight-bed holding/catheterization recovery unit

17th FLOOR – Cardiovascular anesthesiology administrative offices; Ronald McDonald® Family Waiting Room with additional private rooms for families to consult with their child’s physicians or to wait during procedures; support services, including social work and child life staff

15th FLOOR – 35-bed inpatient unit including six “step-down” beds for patients who are healthy enough to leave intensive care but still need close monitoring
Pioneers in Pediatric Cardiac Care

Texas Children’s Hospital has been a leader in pediatric heart care for more than 50 years. Led by Denton Cooley, M.D., and Dan McNamara, M.D., the hospital started performing heart surgery in children in 1956. Dr. McNamara, a patriarch of pediatric cardiology, and Dr. Cooley, a pioneer heart surgeon, were among the first to demonstrate that small children could safely undergo heart surgery.

Today, Texas Children’s Heart Center is one of the nation’s leading providers of pediatric cardiac care. In 2013, U.S. News & World Report ranked the Heart Center #3 in the nation for pediatric cardiology and heart surgery. Composed of several multidisciplinary teams working in conjunction with pediatric subspecialists throughout the hospital, Texas Children’s Heart Center provides unparalleled care at every point from diagnosis through treatment and follow-up.
As we honor the 60th anniversary of Texas Children’s Hospital, we are reminded of our groundbreaking history in pediatric cardiology and surgery. The physicians and surgeons who began this program set the groundwork for a legacy of excellence in cardiovascular care.

Dan Goodrich McNamara, M.D. (1922-1998) Emeritus Chief of Pediatric Cardiology at Texas Children’s Hospital

In 1953, the city of Houston welcomed its first pediatric cardiologist, Baylor University School of Medicine alumnus Dan Goodrich McNamara, M.D. Dr. McNamara was a well-trained physician who had just completed a two-year fellowship at Johns Hopkins Hospital with the renowned pediatric cardiologist, Helen Taussig, M.D., before returning to Texas to begin a practice.

Texas Children’s Hospital opened in February 1954, just after Dr. McNamara’s arrival. Russell Blattner, M.D., the hospital’s first physician-in-chief, convinced Dr. McNamara to move his offices to Texas Children’s, where he founded the Pediatric Cardiology section. He held the position of chief of Cardiology for 31 years.

“Dr. McNamara set the culture and vision for our division,” said Daniel J. Penny, M.D., Ph.D., M.H.A., chief of Cardiology at Texas Children’s Hospital. “We are proud every day that we are custodians of his precious legacy, which we aim to protect and build on.”

Dr. McNamara was an educator and mentor who trained an entire generation of physicians. Many hold leadership positions as pediatric cardiology division heads, medical school deans and leaders at every level of medicine. Authoring and co-authoring nearly 300 articles and textbooks during his career, Dr. McNamara was a sought-after consultant throughout his career with colleagues around the world.

The American College of Cardiology elected Dr. McNamara president in 1981. He was the second of three pediatric cardiologists to serve as its president. He received multiple lifetime teaching awards and honors, including awards from Baylor University, Baylor College of Medicine, the American College of Cardiology and the Academy of Pediatrics.

In 1988, Dr. McNamara became chief emeritus at Texas Children’s Hospital. He continued treating patients until his death in 1998.
# 2013 Texas Children’s Heart Center Overview

## Surgical procedures

<table>
<thead>
<tr>
<th>Procedure</th>
<th>2013</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiac operations</td>
<td>810</td>
<td>889</td>
</tr>
<tr>
<td>Heart transplants</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>Lung transplants</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td>Adult congenital heart disease operations</td>
<td>45</td>
<td></td>
</tr>
</tbody>
</table>

## Cardiac catheterizations

<table>
<thead>
<tr>
<th>Procedure</th>
<th>2013</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnostic cardiac catheterizations</td>
<td>417</td>
<td>959</td>
</tr>
<tr>
<td>Interventions</td>
<td>341</td>
<td></td>
</tr>
<tr>
<td>Electrophysiology studies and ablations</td>
<td>142</td>
<td></td>
</tr>
<tr>
<td>Pacemaker and defibrillator implants</td>
<td>59</td>
<td></td>
</tr>
</tbody>
</table>

## Diagnostic testing and cardiac imaging

<table>
<thead>
<tr>
<th>Procedure</th>
<th>2013</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Echocardiograms</td>
<td>23,192</td>
<td>63,392</td>
</tr>
<tr>
<td>Fetal echocardiograms</td>
<td>1,578</td>
<td></td>
</tr>
<tr>
<td>Electrocardiograms</td>
<td>32,631</td>
<td></td>
</tr>
<tr>
<td>Cardiac MRIs</td>
<td>509</td>
<td></td>
</tr>
<tr>
<td>Holter® monitors</td>
<td>4,364</td>
<td></td>
</tr>
<tr>
<td>Stress tests</td>
<td>1,118</td>
<td></td>
</tr>
</tbody>
</table>

## Cardiovascular anesthesia

<table>
<thead>
<tr>
<th>Procedure</th>
<th>2013</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Catheterizations and electrophysiology patients</td>
<td>880</td>
<td>2,436</td>
</tr>
<tr>
<td>Cardiovascular operating room patients</td>
<td>910</td>
<td></td>
</tr>
<tr>
<td>Interventional radiology patients</td>
<td>184</td>
<td></td>
</tr>
<tr>
<td>MRI patients</td>
<td>462</td>
<td></td>
</tr>
</tbody>
</table>

## Cardiovascular intensive care

<table>
<thead>
<tr>
<th>Procedure</th>
<th>2013</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgical admissions</td>
<td>552</td>
<td>910</td>
</tr>
<tr>
<td>Medical admissions</td>
<td>358</td>
<td></td>
</tr>
</tbody>
</table>

The outpatient clinic at Texas Children’s Heart Center had more than 20,000 patient encounters in 2013.
Congenital Heart Surgery Service

The Congenital Heart Surgery Division provides individualized and comprehensive surgical care for all aspects of pediatric and adult congenital heart disease. We are experienced in the rarest of cases such as ectopia cordis and other infrequently seen conditions. Texas Children’s Heart Center performs more than 800 surgical procedures annually with outcomes among the best in the country.

We treat children of all ages, including preterm and low-birth-weight newborns, and we personalize treatments and procedures to best suit the situation of each child and family. This tailored approach includes cardiopulmonary bypass and neuroprotection strategies focused on the patient’s condition and needs, helping to achieve optimal functional outcomes. The center’s Heart, Lung and Heart-Lung Transplant Programs, among the largest and most successful in the United States, are also part of the Congenital Heart Surgery Division outcomes.

Cardiovascular and thoracic surgery cases

<table>
<thead>
<tr>
<th>Year</th>
<th>Volume</th>
</tr>
</thead>
<tbody>
<tr>
<td>2004</td>
<td>755</td>
</tr>
<tr>
<td>2005</td>
<td>708</td>
</tr>
<tr>
<td>2006</td>
<td>784</td>
</tr>
<tr>
<td>2007</td>
<td>769</td>
</tr>
<tr>
<td>2008</td>
<td>816</td>
</tr>
<tr>
<td>2009</td>
<td>912</td>
</tr>
<tr>
<td>2010</td>
<td>834</td>
</tr>
<tr>
<td>2011</td>
<td>837</td>
</tr>
<tr>
<td>2012</td>
<td>767</td>
</tr>
<tr>
<td>2013</td>
<td>889</td>
</tr>
</tbody>
</table>

Since 1995, Charles D. Fraser, Jr., M.D., and the Congenital Heart team have performed more than 12,000 operations on children and adults with congenital heart disease.

According to the Society of Thoracic Surgeons National Database Program, congenital heart surgery programs are considered high-volume programs if they perform more than 250 index operations per year on average.
More than 62 percent of operations performed require the use of cardiopulmonary bypass. Our incidence of mechanical circulatory support postcardiotomy is less than 1 percent.

Our patients include children of all ages as well as adults who have been treated since infancy or who have been diagnosed with a congenital heart defect later in life.
### Mortalities by RACHS-1 classification in 2013

<table>
<thead>
<tr>
<th>Primary procedure</th>
<th>Number of procedures</th>
<th>Number of discharge mortalities</th>
<th>% mortality</th>
<th>STS national benchmark</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total for Risk Category 1</td>
<td>83</td>
<td>0</td>
<td>0.0%</td>
<td>0.5%</td>
</tr>
<tr>
<td>Total for Risk Category 2</td>
<td>220</td>
<td>0</td>
<td>0.0%</td>
<td>1.1%</td>
</tr>
<tr>
<td>Total for Risk Category 3</td>
<td>188</td>
<td>4</td>
<td>2.1%</td>
<td>3.3%</td>
</tr>
<tr>
<td>Total for Risk Category 4</td>
<td>47</td>
<td>2</td>
<td>4.3%</td>
<td>7.1%</td>
</tr>
<tr>
<td>Total for Risk Category 5-6</td>
<td>17</td>
<td>3</td>
<td>17.6%</td>
<td>14.3%</td>
</tr>
<tr>
<td><strong>Grand total</strong></td>
<td><strong>555</strong></td>
<td><strong>9</strong></td>
<td><strong>1.6%</strong></td>
<td><strong>3.1%</strong></td>
</tr>
</tbody>
</table>

Overall risk-adjusted hospital mortality rate for our program in 2013 was 1.6%. Data collected by the Society of Thoracic Surgeons (STS) shows the national hospital discharge mortality rate at 3.1%.

---

2. 007-RACHS-1 Index Surg CHD Volume.
Mortalities by age and operation type in 2013

<table>
<thead>
<tr>
<th>Primary procedure</th>
<th>CPB cases</th>
<th>Non-CPB cases</th>
<th>CPB discharge mortalities</th>
<th>Non-CPB discharge mortalities</th>
<th>% Mortality</th>
<th>STS national benchmark</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neonate (0 - 30d)</td>
<td>63</td>
<td>28</td>
<td>4</td>
<td>0</td>
<td>4.4%</td>
<td>8.9%</td>
</tr>
<tr>
<td>Infant (31d - 1y)</td>
<td>145</td>
<td>38</td>
<td>4</td>
<td>0</td>
<td>2.2%</td>
<td>2.9%</td>
</tr>
<tr>
<td>Child (&gt;1y - &lt;18y)</td>
<td>240</td>
<td>14</td>
<td>1</td>
<td>0</td>
<td>0.4%</td>
<td>1.0%</td>
</tr>
<tr>
<td>Adult (18y+)</td>
<td>27</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0.0%</td>
<td>1.7%</td>
</tr>
<tr>
<td>Grand total</td>
<td>475</td>
<td>80</td>
<td>9</td>
<td>0</td>
<td>1.6%</td>
<td>3.2%</td>
</tr>
</tbody>
</table>

Age-appropriate surgical planning and management allows for outcomes in patients of all ages to be better than the national benchmarks. Patient grand total combines CPB and non-CPB cases (N=555).
The Congenital Heart Surgery Division performs an average of 24 ASD closures annually. This includes patients with secundum, coronary, sinus and sinus venosus ASDs. Our hospital survival rate is 100 percent. Our service also offers a minimally invasive approach to ASD closure.

Ventricular septal defects are the most commonly diagnosed congenital heart defect, and surgical treatment remains the standard of care for children with this disease. These data include patients having perimembranous, supracristal, inlet or muscular VSDs. They also include patients with double-chambered right ventricle. The Congenital Heart Surgery Division performs an average of 58 VSD closures each year and in 2013 had a survival rate of 100 percent.

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4. Hospital mortality is calculated over the last four years from 2010-2013.
5. STS benchmark data is from 2009-2012.
The Congenital Heart Surgery Division performs an average of 30 operations each year for partial, intermediate and complete atrioventricular canal defect.

Our surgical approach to the repair of tetralogy of Fallot is individualized for each patient based on age, anatomy and symptoms. This allows us to repair the defect and preserve critical parts of the cardiac anatomy, thereby optimizing the patient’s cardiac function over the long term. The Congenital Heart Surgery Division performs an average of 28 TOF repairs each year.

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6 Hospital mortality is calculated over the last four years from 2010-2013.
7 STS benchmark data is from 2009-2012.
Arterial switch operation (ASO)

Volume by year

The arterial switch operation is offered to patients with simple transposition of the great arteries, complex transposition of the great arteries and Taussig-Bing anomaly. Historically, this operation has not been viewed as a viable treatment option for some children due to their size, complex coronary anatomy and associated cardiac malformations. Our outcomes have demonstrated that these characteristics are not associated with increased operative risk. Our hospital survival rate is 100 percent.

Norwood operation

Volume by year

The Congenital Heart Surgery Service performs an average of 18 Norwood operations per year for hypoplastic left heart syndrome and other single ventricle anomalies.

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Overall Hospital Discharge Mortality Rate

- **0%**
- **STS National Benchmark**: 4.3%

The Congenital Heart Surgery Service performs an average of 18 Norwood operations per year for hypoplastic left heart syndrome and other single ventricle anomalies.

Note: Hospital mortality is calculated over the last four years from 2010-2013.STS benchmark data is from 2009-2012.
Young writer flying high after lifesaving open heart surgeries

Jack Harty doesn’t remember a lot about the delicate open heart surgeries that saved his life, but he has a crystal-clear memory of when he realized his passion was flying.

“Flying is like a bug,” said the 18-year-old. “Once you’re bitten, you can’t get rid of it.”

Jack is headed to Embry-Riddle Aeronautical University this fall to pursue a career in the business side of aviation, and he’s already well on his way to making a name for himself. For two years, he’s worked as a journalist and social media maven for a national aviation news magazine and website.

But Jack’s first headline was Christmas Day 1995 when, at 3 months old, he made the front page of the Houston Chronicle. The article detailed the complex procedure to repair Jack’s truncus arteriosus, a rare birth defect that causes a single blood vessel, or trunk, to exit the heart instead of a separate pulmonary artery and aorta.

Charles D. Fraser, Jr., M.D., chief of Congenital Heart Surgery, who had recently joined the team at Texas Children’s, performed the surgery, which utilized a conduit, or tube, to transform the trunk into a functioning aorta and repair the ventricular septal defect. At 7, Jack had a second surgery to replace the conduit.

Jack describes his childhood in suburban Houston as normal and active, filled with riding bikes, hanging out with friends and playing golf. The only thing off-limits was tackle football. His family traveled often, instilling in him a love of adventure.

Jack still sees Dr. Fraser and his cardiologist Susan Denfield, M.D., but he will transition to the Adult Congenital Heart Program as he gets older. Since the conduit does not grow with his body, he faces another surgery in the coming years to replace it — but you can bet that won’t ground him for long.
Single Ventricle Program

The Single Ventricle Program (SVP) at Texas Children’s Hospital is a multidisciplinary team that includes pediatric cardiologists, nurse practitioners, neurodevelopmental specialists, dietitians and social workers. Patients have a variety of diagnoses such as hypoplastic left heart syndrome, but no matter the diagnosis, the program offers specialized medical care, education and support. The SVP team strives to ensure the best possible outcomes for this specialized patient population.

Many of the patients who enter the program are identified before delivery during their fetal ultrasound and ultimately seen at the Texas Children’s Fetal Center at Texas Children’s Pavilion for Women. We know that having a prenatal diagnosis is important for the family and for the infant during the critical newborn period.¹⁰

One unique prenatal offering, “Parenting Your High-Risk Baby,” focuses on preparing for delivery and parenting skills needed while in the hospital. The class is presented by multidisciplinary teams from both the Pavilion for Women and Texas Children’s Heart Center. In the final session, parents meet with other families who have gone through the same experience.

After delivery, the newborn is transferred to the Cardiovascular Intensive Care Unit for further care. The SVP team works collaboratively with other teams at Texas Children’s Hospital during the transition from newborn care to open heart surgery to recovery. Many of the infants will be able to go home, but some patients, identified for a variety of reasons, will need to stay in the hospital until after their second surgery, which is usually a Bi-Directional Glenn.

As the infant recovers and progresses, the SVP team members educate and prepare the family for the transition home. Since these infants are at risk for a number of medical complications, parents are critical members of the team. Before discharge, parents receive education on the Single Ventricle Home Monitoring Program. Parents learn how to keep track of their baby’s daily progress by measuring daily weights, oxygen saturations, feeding information and heart rate.

Once parents learn and become comfortable with daily care, the baby is discharged from the hospital. The Single Ventricle Program supports them at home through phone consultations and frequent outpatient clinic follow-up visits. The SVP monitors for symptoms referred to as “red flags.” When these symptoms are noted, the patient is brought in for evaluation and sometimes readmitted to the hospital. The family has 24-hour access to a member of the team for questions or concerns.

The SVP is also an active member of the National Pediatric Cardiology Quality Improvement Collaborative, a multi-hospital collaborative focused on improving quality and outcomes for children with Hypoplastic Left Heart Syndrome (HLHS).

Heart patient began beating the odds at birth

Watching 9-year-old Isabela Falcone swim and perform gymnastics, it’s difficult to believe her chances to survive past birth were less than 10 percent.

When Isabela’s mother, Brenda, learned at a routine prenatal ultrasound that the fetus she was carrying had hypoplastic left heart syndrome, the obstetrician advised her to terminate the pregnancy. Instead, she came to Texas Children’s Hospital, where she found the perfect multidisciplinary team to provide the complex care Isabela needed.

After Isabela was born, it was discovered she had other issues as well, including heterotaxy, which caused some internal organs, including the intestines and lungs, to be reversed.

At just 19 hours old, Isabela had a 12-hour open heart surgery. A week later, she had another procedure to correct the heterotaxy and insert a feeding tube. Still in the hospital at 5 months old, she had a Glenn procedure to route unoxygenated blood from the head and upper body directly to the lungs.

Heather Dickerson, M.D., the cardiologist who began caring for Isabela immediately following the first surgery, said few children with Isabela’s complex medical problems survive.

“Isabela was one of the sicker patients I’ve seen,” Dickerson said. “She needed so many interventions – heart, gastrointestinal, infectious disease. A whole team of people was trying to save this little girl.”

By the age of 3, she needed a Fontan procedure to transport deoxygenated blood from the lower part of the body directly to the lungs, bypassing the right ventricle and allowing it to pump oxygenated blood to the rest of the body.

Although she probably will need another surgery at some point, for now Isabela is busy being an active third grader.

“We go back to Dr. Dickerson for check-ups every six months,” Brenda said. “It’s always good news, and we always feel like we’re at the best possible place.”
Coronary Anomalies Program

Inaugural conference addressed anomalous aortic origin of a coronary artery (AAOCA)

In December 2013, Texas Children’s Hospital hosted a first-of-its-kind national conference about congenital coronary anomalies. The focus was on addressing a sometimes fatal condition known as anomalous aortic origin of a coronary artery or AAOCA.

AAOCA occurs when a coronary artery arises from the wrong location on the aorta. Children and young adults with this condition can die suddenly, especially during or just after exercise. The condition is the second-leading cause of sudden cardiac death in children and young adults.

Diagnosing AAOCA can be challenging because many individuals with the condition have no symptoms. Those who do have symptoms complain most often of chest pain, palpitations, dizziness or fainting during or just after exercise.

“How to best treat a child or young adult with AAOCA is a subject of debate in the medical community,” said Carlos Mery, M.D., surgical director of the Coronary Anomalies Program, who organized the conference with the program’s medical director, Silvana Lawrence, M.D. “Most physicians agree that surgery is necessary for patients who show evidence of decreased blood flow to the heart tissue. But how to treat those AAOCA patients who have no physical complaints and who show no evidence of reduced blood flow to the heart is unclear.”

During the conference, doctors from institutions such as Stanford University and Children’s Hospital of Philadelphia discussed the most appropriate imaging and surgical techniques, identification of risk factors, various management strategies based on available evidence and how to best counsel patients and families about treatment and exercise.

Outcomes of patients with Anomalous Aortic Origin of a Coronary Artery (AAOCA)

The program began tracking outcomes in December 2012 and to date has recorded:

<table>
<thead>
<tr>
<th>Date range</th>
<th>1995-2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total patients</td>
<td>47</td>
</tr>
<tr>
<td>Surgery treatment</td>
<td>19</td>
</tr>
<tr>
<td>Mortality</td>
<td>0</td>
</tr>
<tr>
<td>Complications</td>
<td>1 (pericardial effusion requiring readmission and drainage)</td>
</tr>
</tbody>
</table>

Data as of January 31, 2014.
Since its inception in 1984, Texas Children’s Heart Center has performed more than 280 heart transplants, making it one of the largest and most successful programs in the nation. In 2013, over 400 cardiomyopathy patients were seen in our clinic. As the number of diagnoses for pediatric heart failure increases, so has our depth and breadth of experience in treating patients, as has our ability to offer the right mechanical circulatory device for each child. For more information on the Heart Transplant Program, please visit texaschildrens.org/heartoutcomes.

Since 2011, Texas Children’s Heart Center has been an active member of the Pediatric Heart Transplant Study (PHTS), which is dedicated to the advancement of the science and treatment of children during listing for and following heart transplantation. The purpose of the group is to establish and maintain an international, prospective, event-driven database for heart transplantation, to use the database to encourage and stimulate basic and clinical research in the field of pediatric heart transplantation and to promote new therapeutic strategies.

Mechanical circulatory support is often used as a bridge to transplantation in children. At Texas Children’s Heart Center, we select a ventricular assist device (VAD) from a variety of options to best meet the needs of the individual patient.

### VAD Implantations

<table>
<thead>
<tr>
<th>Device</th>
<th>Implantations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Micromed®</td>
<td>3</td>
</tr>
<tr>
<td>HeartWare®</td>
<td>8</td>
</tr>
<tr>
<td>TandemHeart®</td>
<td>3</td>
</tr>
<tr>
<td>SynCardia®</td>
<td>1</td>
</tr>
<tr>
<td>Total Artificial Heart</td>
<td></td>
</tr>
<tr>
<td>HeartMate II®</td>
<td>16</td>
</tr>
<tr>
<td>Rotaflow®</td>
<td>18</td>
</tr>
<tr>
<td>Thoratec P-VAD®</td>
<td>11</td>
</tr>
<tr>
<td>Bio-Medicus®</td>
<td>22</td>
</tr>
<tr>
<td>Berlin Heart EXCOR® Pediatric</td>
<td>40</td>
</tr>
</tbody>
</table>

12 VADs placed from 1995-March 2014.
Extracorporeal life support (ECLS)

Extracorporeal life support (ECLS) is a treatment that helps support children when their heart and/or lungs are unable to supply enough blood flow or oxygen to the body. This support may be necessary after heart surgery or in some children with heart or lung disease. ECLS is provided in the Pediatric Intensive Care Unit (PICU), Cardiovascular Intensive Care Unit (CVICU) or Neonatal Intensive Care Unit (NICU) based on each child's underlying problem. Our specially trained team of cardiac intensivists, surgeons, critical care nurses and ECLS specialists carefully monitors each child's condition while on ECLS.

To provide ECLS, we use extracorporeal membrane oxygenation, or ECMO. With ECMO, blood is pumped through the cannulae and into the machine oxygenating the patient's blood. The oxygenated blood is then returned through the circuit to the body, creating a continuous flow and doing the work of the heart and/or lungs so the patient's body can heal.

The ECMO program at Texas Children's Hospital received the Award for Excellence in Life Support from the Extracorporeal Life Support Organization and is a designated Center of Excellence.
Berlin Heart EXCOR® Pediatric

In 2012, the United States Food and Drug Administration (FDA) granted humanitarian device exemption for the Berlin Heart EXCOR® Pediatric Ventricular Assist Device, the only pediatric mechanical circulatory support device designed specifically for infants and small children. This was a landmark day for physicians who treat children dying of heart failure whose only hope is a heart transplant. Small children awaiting heart transplantation face a long time on the waiting list because of limited availability of donor organs. Mortality rate while waiting is approximately 25 percent due to progressive system organ failure.

FDA approval began with a multi-year, multi-institution study led in part by Texas Children’s Hospital. In 2005, a trans-Atlantic dialogue was initiated among the Berlin Heart Corporation, clinicians in North America and the FDA to design and conduct the first prospective pediatric ventricular assist trial in the world. The study design addressed questions of safety and benefit of the Berlin Heart in bridging children with heart failure until they received a heart transplant. This study involved detailed analysis and ongoing multicenter data collection and coordination in critically ill children with rapidly progressive heart disease.

During the course of the study, Texas Children’s implanted 27 Berlin Hearts – more than any other center in the U.S. – and our results were encouraging. Findings from this study were published in the New England Journal of Medicine13 in August 2012. Outcomes for 48 children (infants through 16 years) who received the Berlin Heart from 2007 through 2010 were compared to those of patients supported by extracorporeal membrane oxygenation (ECMO).

13Data includes patients who received heart-and-lung transplants simultaneously.
Pediatric Heart Failure Summit
Texas Children’s Hospital, in partnership with Sick Kids Labatt Family Heart Centre in Toronto and Cincinnati Children’s Heart Institute, hosted the inaugural Pediatric Heart Failure Summit in Houston in October 2013. The conference featured medical and surgical experts from leading institutions around the country and focused on the challenges of treating advanced heart failure in children.

Program topics included management strategies for acute heart failure syndromes, methods of hemodynamic and physiologic monitoring, renal protective techniques and updates on mechanical circulatory support in children.

During the three-day symposium, 17 cardiovascular surgeons, cardiologists and critical-care experts from Texas Children’s Hospital moderated and served on panels featuring pediatric cardiologists, intensivists, neonatologists, emergency department physicians and other clinicians interested in the management of advanced heart failure in children.

Dr. Lynn Warner Stevenson, director of the Heart Failure and Cardiomyopathy Program at Brigham and Women’s Hospital in Boston, delivered the keynote address. Stevenson, who is also a professor of medicine at Harvard Medical School, has served on national guideline panels for heart failure, pacing devices, patient decision-making, core measure sets and standards for the Joint Commission on Accreditation of Healthcare Organizations.
Heart transplants\textsuperscript{14}

Volume by year

<table>
<thead>
<tr>
<th>Year</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007</td>
<td>11</td>
</tr>
<tr>
<td>2008</td>
<td>16</td>
</tr>
<tr>
<td>2009</td>
<td>18</td>
</tr>
<tr>
<td>2010</td>
<td>13</td>
</tr>
<tr>
<td>2011</td>
<td>15</td>
</tr>
<tr>
<td>2012</td>
<td>14</td>
</tr>
<tr>
<td>2013</td>
<td>15</td>
</tr>
</tbody>
</table>

Heart transplant patient survival rates\textsuperscript{15}

Pediatric age <18

<table>
<thead>
<tr>
<th>Time Period</th>
<th>Survival Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 YEAR AFTER TRANSPLANT 7/1/10 TO 12/31/12 N=27</td>
<td>91.92%</td>
</tr>
<tr>
<td>3 YEARS AFTER TRANSPLANT 1/1/08 TO 6/30/10 N=37</td>
<td>83.15%</td>
</tr>
</tbody>
</table>

\textsuperscript{14}Data includes patients who received heart-and-lung transplants simultaneously.

\textsuperscript{15}Scientific Registry of Transplant Recipients (SRTR). Program Specific Reports. Table 11 – srtr.org
Heart transplant survival curves

The following graphs show the survival rates for patients by the number of years after heart transplantation. The solid line shows the expected survival rate for our patients a number of years after their transplant. Because these are estimates, the shaded area shows the 95 percent confidence limits of the expected survival rates.

Survival curves by era

This chart breaks our patients down into three categories based on when their heart transplant was performed. The expected survival rates shown on the graph for Era III are:

- 1 year: 92%
- 3 years: 85%
- 5 years: 77%

---


Texas Children’s Data:
1984 – June 2013, 275 Txs on 257 patients, Age between 0 and 20 years.

UNOS data:
1987 – April 2012, 6771 Txs on 6406 patients (3 missing data), Age between 0 and 17 years.
Survival curve vs. UNOS\textsuperscript{17}


\textsuperscript{17}Wilcoxon test: 1984-1998 vs. 1999-2004: \( p < 0.2994 \), 1984-1998 vs. 2005 – June 2013: \( p < 0.0031 \), 1994-2004 vs. 2005-June 2013: \( p < 0.0395 \).

Texas Children’s Data
1984 – June 2013, 275 Txs on 257 patients, Age between 0 and 20 years.

UNOS data:
1987 – April 2012, 6771 Txs on 6406 patients (3 missing data), Age between 0 and 17 years.
Interventional Cardiology

Texas Children’s Heart Center, the only program in the region to offer interventional and therapeutic cardiac catheterization for infants, children and adolescents, performed more than 959 cardiac catheterization procedures in 2013. To learn more about our Interventional Cardiology Program, please visit texaschildrens.org/heartoutcomes.

Innovations in valve replacement

Valve replacement in children involves the pulmonary valve in 75 percent of cases. Currently only one option via catheter approach is available and approved for use in the pulmonary position. Researchers from Texas Children’s Hospital, Baylor College of Medicine and Rice University are working to create an artificial pediatric pulmonary valve delivered using a catheter-based approach. After three years of development, the research team has a working prototype and is very close to proving success in a lab and meeting FDA valve requirements.

Cardiac catheterization laboratory complications

by rate

- Cases without complications: 98.3%
- Cases with major complications: 0.67%
- Cases with minor complications: 1.04%
Electrophysiology

The Arrhythmia and Pacing Service at Texas Children’s Heart Center offers the full complement of diagnostic and therapeutic options to evaluate and manage any heart rhythm abnormality. We have one of the highest volume pediatric centers in the country for invasive electrophysiology studies and pacemaker/defibrillator implantations and maintain success rates for ablations that exceed the national average. Innovation, research and experience have made Texas Children’s Heart Center one of the leading centers in the world for the diagnosis and treatment of arrhythmias in children and adults with congenital heart disease. To view a short video on our Electrophysiology Program, visit texaschildrens.org/heartoutcomes.

Supraventricular tachycardia ablation outcomes

| SUCCESS RATE | Texas Children’s Hospital | National benchmark
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>96.7%</td>
<td>95.2%</td>
</tr>
</tbody>
</table>

Stereotaxis

Texas Children’s Hospital is the only freestanding children’s hospital with a remote magnetic navigation (MN) system (Stereotaxis) for catheter manipulation. Stereotaxis was utilized for 17 ablation cases in 2013.

MN offers theoretic advantages in the treatment of children. The catheter is more flexible and atraumatic than standard catheters, potentially eliminating risk of heart perforation. It can also be navigated with precision, allowing for movements as small as one millimeter or deflections as small as one degree. This may result in enhanced accuracy and safety during mapping and ablation of certain arrhythmias in this patient population.

We performed a retrospective review of prospectively gathered data in children undergoing radiofrequency ablation at our institution. The efficacy and safety of an MN-guided approach and standard manual techniques for mapping and ablation of AP-mediated tachycardia were compared. Acute success rates and recurrence rates were equivalent (p=NS). There was also no difference in total procedure time. However, fluoroscopy time was significantly reduced in the MN group when compared to the manual group (p < 0.001). There were no complications in either group.

Additionally, in order to decrease morbidity associated with radiation exposure during ablation cases, the Arrhythmia and Pacing Service has established protocols utilizing non-fluoroscopic mapping techniques to minimize radiation. This has resulted in an over three-fold reduction in fluoroscopy times with over 30 procedures being performed with minimal radiation over the past year.

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Diagnostic Testing and Cardiac Imaging

The non-invasive imaging lab performs more than 21,000 echocardiograms each year for fetuses, infants, children and adults with congenital or acquired heart disease. The imaging lab provides transesophageal, epicardial, intracardiac and transthoracic echocardiogram support in the catheterization labs and operating rooms on a daily basis. The main echocardiography lab consists of 10 rooms with a four-bed sedation bay and state-of-the-art physician work area that houses five reading stations. For more on our Diagnostic Testing and Cardiac Imaging Service, visit texaschildrens.org/heartoutcomes.

Fetal cardiac interventions for HLHS
Texas Children’s Hospital has successfully completed in utero fetal cardiac interventions to treat hypoplastic left heart syndrome (HLHS). Texas Children’s Fetal Center at Texas Children’s Pavilion for Women is one of only a few centers in the world capable of performing this complex fetal intervention, which involves a coordinated effort among a large, multidisciplinary team of fetal cardiologists, obstetricians and gynecologists, interventional cardiologists, congenital heart surgeons, fetal imaging experts, maternal and fetal anesthesiologists and other clinical specialists. Babies receiving this unique fetal procedure continue treatment at Texas Children’s Heart Center immediately after delivery.

Following each procedure, physicians monitor the mother and baby through multiple fetal ultrasounds and echocardiograms so that the mother may carry the baby as close to full term as possible, giving the lungs, brain and other vital organs a chance to mature prior to birth and allowing the child to be more stable before his or her first heart surgery.
HLHS treated in utero: a fetal intervention
Two years ago, Aiden Balsamo was one of the first to benefit from a pioneering fetal cardiac procedure at Texas Children’s. Today, after two subsequent newborn heart surgeries, he is an active toddler with a bright future.

Aiden’s mother, Jennifer, was 20 weeks into an otherwise uneventful pregnancy when a routine ultrasound revealed the fetus had hypoplastic left heart syndrome (HLHS). This dangerous defect causes underdevelopment of the left ventricle. In addition to this, Aiden also had an intact atrial septum, a type of HLHS newborns rarely survive even with surgery immediately after birth.

Experts at Texas Children’s, the first hospital in the southwestern United States to develop a fetal cardiac intervention program to treat HLHS, performed a complex procedure in which a specialized needle is used to access the fetal heart and inflate a balloon catheter, allowing the passage of blood from the underdeveloped left atrium into the right atrium. The hope was that Aiden would survive birth and be strong enough for a series of lifesaving newborn cardiac surgeries.

The fetal intervention was a success, and Aiden weighed more than 6 pounds when he was born. A few days later, surgeons performed the Norwood procedure to reconstruct his heart to allow the right ventricle to pump blood to his body and lungs. The Heart Center team has an almost 90 percent success rate with this procedure, one of the best outcome rates in the nation.

When Aiden was 3 months old, he had a second surgery, a Glenn procedure. A week later, he was able to go home for the first time.

“Aiden has since been back to the hospital only for regular cardiologist appointments and has done miraculously well,” Jennifer said. “We have been blessed with amazing family, friends and especially the medical professionals who have come in contact with him.”

Hypoplastic left heart syndrome
Adult Congenital Heart Disease Program

The Adult Congenital Heart Disease (ACHD) Program enables patients with congenital heart disease to manage care from birth to adulthood. Our program offers the full range of adult congenital heart disease services and specialties including surgery, diagnostic and interventional cardiac catheterization, noninvasive imaging (including cardiac MRIs and coronary CT angiography), transcranial doppler electrophysiology and arrhythmia services, and more. For more information on the ACHD Program, visit texaschildrens.org/heartoutcomes.

ACHD clinic encounters

<table>
<thead>
<tr>
<th>Clinic visits</th>
<th>2059</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unique patients</td>
<td>1503</td>
</tr>
</tbody>
</table>

ACHD program volumes

by procedure

- 91% Echocardiograms
- 5% Cardiac MRIs
- 4% EP & Interventional Procedures
Cardiac Resource Utilization in Adults at a Freestanding Children’s Hospital\textsuperscript{19,20}

Despite the growing population of adults with congenital heart disease, a gap remains in published information looking at the care these patients receive at pediatric institutions. With this in mind, a group of cardiologists at Texas Children’s Hospital recently evaluated the experience and resource utilization these adult patients had at our institution from January 2006 through December 2010.

<table>
<thead>
<tr>
<th>Adult patients (18 years or older)</th>
<th>2794</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age</td>
<td>23.5 +/- 8.4 years</td>
</tr>
<tr>
<td>% with congenital heart disease</td>
<td>62.6%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Procedures</th>
<th>Number</th>
<th>Minor adverse events</th>
<th>Major adverse events</th>
<th>Mortality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Catheterization lab</td>
<td>525</td>
<td>4.8%</td>
<td>0.7%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Surgical procedures</td>
<td>104</td>
<td>6.7%</td>
<td>1.9%</td>
<td>0.0%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Visits</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinic</td>
<td>5489</td>
</tr>
<tr>
<td>Emergency department</td>
<td>162</td>
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</table>

<table>
<thead>
<tr>
<th>Diagnoses - Most common</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tetralogy of Fallot</td>
<td>228</td>
<td>13.0%</td>
</tr>
<tr>
<td>D-Transposition of the great arteries</td>
<td>208</td>
<td>11.9%</td>
</tr>
<tr>
<td>Single ventricle physiology</td>
<td>187</td>
<td>10.7%</td>
</tr>
<tr>
<td>Atrial septal defect</td>
<td>128</td>
<td>7.3%</td>
</tr>
<tr>
<td>Ventricular septal defect</td>
<td>117</td>
<td>6.7%</td>
</tr>
</tbody>
</table>

**Complexity of congenital heart disease**

\textsuperscript{19}Data collected from Jan. 2006 – Dec. 2010
Cardiovascular Anesthesia

Pediatric Cardiovascular Anesthesia at Texas Children’s Hospital provides sedation and anesthesia services for all congenital cardiac operations and for children with congenital heart disease undergoing various non-cardiac procedures. Services are also provided for catheterization and electrophysiology procedures as well as imaging studies in MRI, CT and interventional radiology. Find out more about the Cardiovascular Anesthesia Division at texaschildrens.org/heartoutcomes.

Cardiovascular anesthesia cases
by location

The Pediatric Cardiovascular Anesthesia Division treated more than 2,400 patients in 2013. Beyond anesthetic care, the division actively participates in the daily care of patients in the Cardiovascular Intensive Care Unit.
Cardiovascular anesthesia use during MRI by age

- 18 years or older: 2%
- 14-17 years: 5%
- 11-13 years: 34%
- 0-30 days: 1%
- 31 days-1 year: 9%
- 0-30 days: 1%
- 31 days-1 year: 9%

Cardiovascular anesthesia duration during MRI

- Less than 1 hour: 73%
- 1-2 hours: 11%
- 2-3 hours: 15%
- More than 3 hours: 1%
Cardiovascular anesthesia use during MRI
by type

- General: 76%
- Monitored Anesthesia Care (MAC): 24%
Developmental Outcomes

Texas Children’s Heart Center strives to offer the best neurodevelopmental outcomes for our patients. As leaders in the field, we are focused on improving our patients’ long-term developmental outcomes through state-of-the-art monitoring, focused research and routine neurodevelopmental follow-up of our highest risk patients.

Cerebral autoregulation monitoring

During surgery, our pediatric cardiovascular anesthesiologists work closely with surgeons and perfusionists to provide consistent care for cardiopulmonary bypass and anesthetic management. In an effort to continue improvement of cardiac outcomes, research teams are investigating a method to optimize cerebral oxygenation and brain blood flow through a new method of monitoring called cerebral autoregulation.

This unique, non-invasive approach has been designed by our cardiovascular anesthesiologists to monitor in real time the adequacy of blood flow to the brain during the highest risk parts of open heart surgery. We aim to be able to individualize cardiac bypass to provide ideal conditions to every patient at every moment during their heart operations. Our patented technology is being tested with the ultimate goal of incorporation into pediatric operating rooms across the world.

Long-term neurodevelopmental outcomes

Heart Center investigators have extensive experience in prospective outcomes research in infants undergoing heart surgery. We have published extensively on this topic in high-impact cardiac journals and have presented our findings at many national and international meetings. Our teams have already uncovered important factors that contribute to developmental outcomes, including brain immaturity, early brain injury and anesthetic drug exposure. The long-term impact of early brain injury will be better understood as we continue to follow patients throughout childhood. This will also form the basis of research aimed at providing early interventions to minimize the risk of brain injury and impaired development.

Cardiac Developmental Outcomes Program

Until recently, most neurodevelopmental follow-up has been in the context of research studies.

Our new Heart Center Cardiac Developmental Outcomes Program focuses on medical, social and developmental health in order to help children reach their maximum potential.

The Outcomes Program was launched with the intention of providing routine regular neurodevelopmental assessments and referrals to babies and children with congenital heart disease who have undergone early surgery. During its first year of operation, the Outcomes Clinic team assessed more than 100 babies and children and provided referrals to a variety of specialists including speech and language, hearing, neurology and behavioral experts. Previously these early interventions would not have been readily available.

The Outcomes Clinic team includes developmental specialists and psychologists who work with members of the Heart Center team to identify any problems at the earliest possible stage. This provides an opportunity for early intervention in order to minimize the impact of issues during childhood.

The program provides family-centered care, where the child’s parents or caregivers are directly consulted and involved in the child’s assessment and interventions for developmental progress. We also help families find resources that support their child’s development in their communities.
Leaders in cardiovascular anesthesia education

*Transesophageal Echocardiography for Congenital Heart Disease*, edited by Texas Children’s physicians Pierre C. Wong, M.D., and Wanda C. Miller-Hance, M.D., focuses on the application of imaging modality in patients with congenital heart disease. Published in early 2014, this work provides practical and instructive information, supplemented with figures/illustrations and high-quality videos. It will be a resource for clinicians and trainees who wish to obtain basic knowledge or advance their understanding of the field.

*Gregory’s Textbook of Pediatric Anesthesia* introduces the basics of the field and explains how they are applied to contemporary practice both in and out of the operating room. Co-edited by Dean B. Andropoulos, M.D., chief of Anesthesiology at Texas Children’s Hospital, the book uses an evidence-based approach and is supplemented by in-depth case studies that spotlight best practice in action across all the major subspecialties. It also contains extensive information on anesthesia care for patients with congenital heart disease.

Edited by Dean B. Andropoulos, M.D., chief of Anesthesiology, as well as Texas Children’s Hospital anesthesiologists Stephen A. Stayer, M.D., and Emad B. Mossad, M.D., *Anesthesia for Congenital Heart Disease* is the leading textbook in the field of pediatric cardiac anesthesia. This textbook contains information on the rapid advances in surgery and anesthesia for congenital heart disease that have occurred in recent years, including neonatal cardiac surgery and anesthesia, treatment of single ventricle patients, new diagnostic modalities and developments in the catheterization laboratory. It also addresses mechanical support of circulation, embryology and quality/outcomes management.

Following the inaugural American Board of Anesthesiology Pediatric Anesthesiology subspecialty board exam, Texas Children’s Hospital is now home to more than 50 subspecialty board-certified pediatric anesthesiologists.
Cardiovascular Intensive Care Unit (CVICU)

The CVICU team of cardiac intensivists, nurses, respiratory therapists, social workers, dietitians and support staff provide intensive care to newborns, infants, children and young adults with heart disease. One of the largest of its kind in the country, the 21-bed CVICU cares for patients undergoing surgery for congenital heart disease, as well as those with end-stage heart failure before and after heart transplantation. In 2013, our CVICU medical team welcomed three new faculty members and continues to expand to support our growing patient population and increasing patient complexity. For more information on the CVICU, please visit texaschildrens.org/heartoutcomes.

The CVICU at Texas Children’s Hospital is part of the Virtual Pediatric Intensive Care Unit System known as VPS. This national pediatric critical care data registry applies a predicted mortality score – PIM 2 – for every critical care admission, including children who did not have heart surgery, based upon the child’s diagnosis and other indicators of illness upon CVICU admission.

**Cases with PIM 2 data**

<table>
<thead>
<tr>
<th>Total cases</th>
<th>812</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mortalities</td>
<td>15</td>
</tr>
<tr>
<td>Actual mortality rate (medical and surgical patients)</td>
<td>1.85%</td>
</tr>
<tr>
<td>Predicted mortality rate</td>
<td>3.51%</td>
</tr>
<tr>
<td>Mortality ratio (actual/predicted)</td>
<td>0.53</td>
</tr>
</tbody>
</table>

**Education in the Cardiovascular Intensive Care Unit**

The faculty of the CVICU represent a multidisciplinary team focused on the care of the most critically ill patients with cardiac disease. Paul A. Checchia, M.D., serves as international vice president of The Pediatric Cardiac Intensive Care Society (PCICS), the largest international society of its kind. Dr. Checchia and Ronald Bronicki, M.D., have led the international symposium for the PCICS for the past eight years. Faculty also serve as editors of the leading textbooks and journals in the field, including the journal *Pediatric Critical Care Medicine* and the *Rogers’ Textbook of Pediatric Intensive Care*, 5th Edition.

The CVICU prepares future leaders in the field through a subspecialty training program in Cardiovascular Critical Care Medicine. With four positions open every year, this is the largest program of its kind in the world. Texas Children’s Hospital has also developed the first subspecialty training program in Neonatal Cardiovascular Medicine.

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32 PIM 2 data is a revised version of the Paediatric Index of Mortality.
33 Compares predicted mortality using PIM 2 risk of mortality with actual mortality. A value of 1.0 indicates that actual mortality equals predicted mortality.
Nursing care in the Cardiovascular Intensive Care Unit

The CVICU at Texas Children’s Hospital has 80 specialized pediatric intensive care registered nurses on staff. The hours per patient day equivalent in the CVICU are 23.38 compared to the national benchmark of 22.1. Benchmark data is pulled from Children’s Hospital Association of like units. All newly admitted surgical cases receive a minimum ratio of 1:1 nursing care. Ninety seven percent of the CVICU registered nurses have a bachelor’s degree in nursing with a 37 percent rate of attainment of Certification in Critical Care Nursing.

Cardiovascular Intensive Care Unit admissions
by age

- 0 to < 1 month: 16%
- 1 month to < 2 years: 35%
- 2 years to < 6 years: 17%
- 6 years to < 13 years: 14%
- 13 years to < 19 years: 12%
- ≥ 19 years: 6%
Quality, Innovation and Research

Texas Children’s Heart Center is committed to examining the quality of care we provide to patients and helping them understand our performance compared to national standards. We are active participants in the following national quality programs:

• American College of Cardiology IMPACT Registry™ (Improving Pediatric and Adult Congenital Treatment) for diagnostic and interventional catheterization procedures

• National Cardiovascular Data Registry’s ICD Registry measuring and improving care for patients receiving implantable cardioverter defibrillators (ICDs)

• Society of Thoracic Surgeon’s National Quality and Outcomes program for congenital heart surgery

• Virtual Pediatric Intensive Care Unit Performance System (VPS), including the cardiac intensive care unit program

Cardiovascular Simulation Program

Texas Children’s Heart Center developed an in situ simulation program to ensure nurses are prepared for patient emergencies and other high-risk clinical scenarios. The goals of the program are to improve patient safety through early identification of patient issues and to improve crisis resource management and teamwork skills. Program leaders established a curriculum and learning matrix in order to track objectives and progress. In addition to the “just-in-time” simulations done in the new in situ simulation room on the cardiology ward, ECMO simulations are scheduled monthly in the hospital’s state-of-the-art simulation center. In these scenarios, a large multidisciplinary team consisting of a surgeon, perfusionist and medical team with nurses and physicians gathers for four hours to simulate time-sensitive, highly critical and technical events.

Texas Children’s Hospital Outcomes and Impact Service

The Surgical Outcomes Center was established in 2011 to track, analyze and report the outcomes of procedures within Texas Children’s Hospital. It quickly became apparent that patients and families were requesting outcomes data for a variety of treatments and not just surgical procedures. Because of this, the Surgical Outcomes Center was rebranded as Texas Children’s Hospital Outcomes and Impact Service (TCHOIS). TCHOIS is not just data; it’s a service we provide. It is the starting point for a conversation about choices affecting where people seek care or are referred for care. As a hospital system, we believe a critical component of offering outstanding clinical programs is tracking the outcomes of the care delivered. The service comprises a team of outcomes nurses, computer programmers, data architects and specialists and a statistician who work closely with the clinical teams to measure, share and improve outcomes.
Congenital Cardiac Anesthesia Society Database (CCAS)
Formed in January 2010 in coordination with the Society of Thoracic Surgeons Congenital Heart Database, the CCAS captures and reports data concerning anesthesia monitoring and management, as well as adverse outcomes for congenital heart disease patients. This population is significantly more likely to suffer adverse events and cardiac arrest than patients without congenital heart disease.

Texas Children’s Hospital and other participating institutions use the data collected to determine patterns and to track adverse outcomes relative to the national experience. Local data has been used to determine the frequency of need for reintubation following in-OR extubation after congenital heart surgery and to identify unfavorable outcomes associated with the use of transesophageal echocardiography.

Pediatric Heart Network
The Pediatric Heart Network (PHN) was established in 2001 by the National Heart, Lung and Blood Institute to improve health outcomes in patients with pediatric acquired and congenital heart disease; to disseminate collaborative findings as the basis for improved evidence-based treatment options and standards of care; to train and educate new investigators; and to provide support and advocacy for families during the conduct of excellent, ethical clinical research.

The network of nine clinical sites is comprised of experienced research teams at hospitals that specialize in the care of pediatric patients with heart disease and have a data coordinating center. Texas Children’s Hospital and Baylor College of Medicine became a core site in September 2011. Texas Children’s is committed to participation in all PHN studies, including four current and six approved future studies. Current studies include the following:

- A study comparing two drug therapies (Beta Blocker Therapy (Atenolol) versus Angiotensin II Receptor Blocker Therapy (Losartan)) on Marfan syndrome patients to see which is better at slowing the speed of aortic enlargement. It will also compare side effects. The study began in February 2007 and will take approximately 7 years.

- A study on Marfan syndrome patients to see if circulating TGF Beta levels correlate with treatment arm (atenolol versus losartan) and/or clinical outcomes in the PHN Trial of Beta Blocker Therapy (Atenolol) versus Angiotensin II Receptor Blocker Therapy (Losartan). By measuring the circulating TGF Beta levels after achieving steady-state optimal dosing in this trial cohort, we will be able to determine if there is a differential effect on TGF Beta levels in the two treatment arms, and if circulating TGF Beta levels correlate with clinical response in tissues where TGF Beta has a demonstrated (aorta, mitral valve) or proposed (left ventricle, skeleton) contribution to disease pathogenesis.

- An ECHO Z-score study will develop normal reference values for echocardiogram measurements obtained from multiple centers and geographic locations and adjusted for body size, age, gender and race that currently do not exist.

- The inter-stage monitoring project will develop predictive models of impending cardiorespiratory deterioration that will reduce morbidity and mortality in children with hypoplastic left heart
syndrome and related cardiac lesions. Using sophisticated computational algorithms, we will develop multivariable predictive risk models that will analyze the physiological data that are routinely available for our patients in real time, providing clinical staff with early warning that a life-threatening event is imminent. This predictive risk model will ultimately be applicable to other patient populations across PHN institutions and in other cardiac centers caring for infants with critical congenital heart disease.

**Preventive Cardiology Program**
Focused on medically managing the risk factors of acquired heart disease in pediatric patients, the Preventive Cardiology Program cares for patients who have abnormal lipid levels or blood pressure results or who have been diagnosed with Kawasaki disease. The clinic’s goals are to prevent future cardiac disease and events such as heart attack and stroke through early and timely interventions and to learn how to better care for children with these issues.

**Research**
Texas Children’s Heart Center is expanding the boundaries of pediatric cardiac care through novel research. To learn more about how we are translating research into clinically relevant and beneficial solutions for our patients, visit texaschildrens.org/heartoutcomes.

**Real-time predictive monitoring in ICU settings**
This research involves creating computer programs that look for early warning signs of deterioration in intensive care unit patients. The programs process the physiological data recorded from patient monitoring equipment in real time. The goal is to create a system that provides advanced warning that a life-threatening event is likely to occur within the next 12-24 hours. Care providers can use this information to proactively decide how to intervene before a situation becomes life threatening, thus improving patient outcomes.
Meet Our Leaders

Charles D. Fraser, Jr., M.D., is surgeon-in-chief, co-director of Texas Children’s Heart Center and chief of the Division of Congenital Heart Surgery at Texas Children’s Hospital. His academic appointments include professor of Surgery in the Michael E. DeBakey Department of Surgery (tenured) at Baylor College of Medicine, professor of Pediatrics at Baylor College of Medicine and adjunct professor of Bioengineering at Rice University. Dr. Fraser holds the Susan V. Clayton Chair in Surgery at Baylor College of Medicine and the Donovan Chair in Congenital Heart Surgery at Texas Children’s Hospital. Dr. Fraser has a clinical appointment at the Texas Heart Institute where he serves as director of the Adult Congenital Heart Surgery Program. Dr. Fraser’s education began as an undergraduate at The University of Texas at Austin, where he graduated with honors in mathematics. He received his medical degree with honors from The University of Texas Medical Branch at Galveston. His residency and fellowship training took place at The Johns Hopkins Hospital in Maryland. He completed additional fellowship training in Congenital Heart Surgery at the Royal Children’s Hospital in Melbourne, Australia. After joining the faculty at the Cleveland Clinic, Dr. Fraser was recruited to Texas Children’s Hospital in July of 1995 to establish a dedicated pediatric congenital heart surgery program.

Daniel J. Penny, M.D., Ph.D., M.H.A., is chief of Cardiology at Texas Children’s Hospital, co-director of Texas Children’s Heart Center and professor of Pediatrics at Baylor College of Medicine. Dr. Penny obtained his medical degree from the National University of Ireland and received a doctoral degree for his thesis “Functional Analysis of Fontan Circulation” from the University of London. He completed fellowship training in Pediatric Cardiology at the Royal Children’s Hospital in Melbourne and received a second doctoral degree at Monash University, Australia for his studies on neonatal circulation. Dr. Penny worked as a pediatric cardiologist at the Royal Brompton Hospital in London and at Greater Ormond Street Hospital in London. Before coming to Texas Children’s Hospital, he was the chief of Cardiology at the Royal Children’s Hospital of Melbourne and a professor in the Department of Pediatrics within the University of Melbourne.
Emad B. Mossad, M.D., is director of Pediatric Cardiovascular Anesthesiology at Texas Children’s Hospital and co-director of Texas Children’s Heart Center. He is also a professor of Anesthesiology and Pediatrics at Baylor College of Medicine. Dr. Mossad’s training began as an undergraduate at Cairo University, Cairo, Egypt. His medical degree is from University of Cairo Medical School, Cairo, Egypt. His residency and fellowship training in cardiac anesthesia took place at the Cleveland Clinic in Cleveland, Ohio. Dr. Mossad also completed a pediatric anesthesia fellowship at Children’s National Medical Center of George Washington University and an echocardiography fellowship at the Cleveland Clinic. Dr. Mossad was the director of Congenital Cardiac Anesthesia at Cleveland Clinic for 13 years before he joined the Cardiovascular Anesthesiology team at Texas Children’s Hospital in 2008.

Lara S. Shekerdemian, M.D., F.R.A.C.P., F.J.F.I.C.M., M.H.A., is chief of Critical Care, co-director of Texas Children’s Heart Center and professor of Pediatrics at Baylor College of Medicine. She graduated from Birmingham University Medical School in 1990. She was awarded her postgraduate doctoral degree for her thesis “Cardiopulmonary Interactions in Congenital Heart Disease” from the University of Birmingham in 1997. Dr. Shekerdemian trained in pediatrics and pediatric cardiology and undertook postgraduate research in London. She trained in critical care in London and Toronto. She was previously on faculty at Great Ormond Street Hospital in London and was most recently the chief of Critical Care at The Royal Children’s Hospital in Melbourne. Her research and clinical interests include extracorporeal life support, brain injury in infants and children with heart disease and outcomes in children after admission to the intensive care unit.
## Texas Children’s Heart Center Medical Staff

To view online profiles for each of our physicians, visit [texaschildrens.org/heartoutcomes](http://texaschildrens.org/heartoutcomes).

### Congenital Heart Surgery
- **Charles D. Fraser, Jr., M.D., Chief**
- **Iki Adachi, M.D.**
- **Jeffrey S. Heinele, M.D.**
- **E. Dean McKenzie, M.D.**
- **Carlos Mery, M.D.**

### Coronary Anomalies Program
- **Charles D. Fraser, Jr., M.D.**
- **Rajesh Krishnamurthy, M.D. (Radiology)**
- **Silvana M. Lawrence, M.D., Ph.D.**
- **E. Dean McKenzie, M.D.**
- **Carlos Mery, M.D.**
- **S. Kristen Sexson Tejetel, M.D., Ph.D.**

### Developmental Outcomes
- **Lara S. Shekerdemian, M.D., F.R.A.C.P., F.J.I.C.M., M.H.A., Medical Director**
- **Daniel J. Penny, M.D., Ph.D., M.H.A., Medical Director**
- **Eboni Smith, M.D.**
- **Lisa Noll, Ph.D.**

### Heart Failure and Transplant
- **William J. Dreyer, M.D., F.A.C.C., F.A.A.P., Medical Director**
- **Jeffrey S. Heinele, M.D., Surgical Director**
- **Jack F. Price, M.D., Medical Director, MCS Program**
- **Iki Adachi, M.D., Co-Surgical Director, MCS Program**
- **E. Dean McKenzie, M.D., Co-Surgical Director, MCS Program**
- **Antonio G. Cabrera, M.D.**
- **Susan W. Denfield, M.D.**
- **Aamir Jeewa, M.D.**
- **Jeffrey J. Kim, M.D.**

### Pediatric Cardiology
- **Daniel J. Penny, M.D., Ph.D., M.H.A., Chief**
- **Hugh Allen, M.D., Ph.D.**
- **Carolyn A. Altman, M.D., F.A.C.C., F.A.S.E.**
- **Nancy A. Ayres, M.D., F.A.C.C., F.A.S.E.**
- **Manish Bansal, M.D.**
- **Judith A. Becker, M.D.**
- **Lauren Bolin, PA-C**
- **Tasha Bryant, R.N., FNP-C**
- **Leigh Carreon, R.N., PNP-AC**
- **Constance Cephus, R.N., PNP-PC/AC, NNP-BC**
- **Angela Gooden, R.N., PNP-AC/PC**
- **Mary Hoang, R.N., PNP-AC/PC**
- **Josh A. Kailin, M.D.**
- **Michele Krenck, R.N., FNP-C**
- **William Buck Kyle, M.D.**
- **Julie K. Kuzin, R.N., PNP-AC/PC**
- **M. Regina Lantin-Hermoso, M.D.**
- **Emily J. Lawrence, D.O.**
- **Silvana M. Lawrence, M.D., Ph.D.**
- **Katherine Lindle, M.D.**
- **Keila N. Lopez, M.D., M.P.H.**
- **Shiraz A. Maskatia, M.D.**
- **Douglas S. Moodie, M.D., M.S.**
- **Shaine A. Morris, M.D., M.P.H.**
- **Antonio Mott, M.D.**
- **Michael R. Nihill, M.D.**
- **Cory V. Noel, M.D.**
- **Richard E. O’Brien, PA-C**
- **Subhash Chandra-Bose Reddy, M.D.**
- **Priscila P. Reid, R.N., FNP-C, PNP-AC**
- **Alan F. Riley, M.D.**
- **Shannon M. Rivenes, M.D.**
- **Alexia B. Santos, M.D.**
- **David W. Sapire, M.D.**
- **Thomas J. Seery, M.D.**
- **S. Kristen Sexson Tejetel, M.D., Ph.D.**
- **Amy Sims, M.D.**
- **Thomas A. Vargo, M.D.**
- **Lauren Wilder, R.N., PNP-AC**
- **Steven B. Wolfe, M.D.**

### Preventive Cardiology
- **Constance Cephus, M.S.N., C.P.N.P.**
- **Douglas S. Moodie, M.D.**
- **Thomas J. Seery, M.D.**
- **S. Kristen Sexson Tejetel, M.D.**

### Interventional Cardiology
- **Henri Justino, M.D., C.M., F.R.C.P.C., F.A.C.C., F.S.C.A.I., Director**
- **Lauren Bolin, PA-C**
- **Asra Khan, M.D.**
- **Aimee Liou, M.D.**
- **Dhaval R. Parekh, M.D.**
- **Athar M. Qureshi, M.D.**

### Electrophysiology and Pacing
- **Caridad De La Uz, M.D.**
- **Jeffrey J. Kim, M.D.**
- **Michele Krenck, R.N., FNP-C**
- **Christina Miyake, M.D.**
- **Santiago O. Valdes, M.D.**

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*Mechanical Circulatory Support (MCS)*
Cardiovascular Imaging
Nancy A. Ayres, M.D., F.A.C.C., F.A.S.E., Director
Carolyn A. Altman, M.D., F.A.C.C., F.A.S.E.
Judith A. Becker, M.D.
Josh A. Kailin, M.D.
M. Regina Lantin-Hermoso, M.D.
Emily J. Lawrence, D.O.
Keila N. Lopez, M.D., M.P.H.
Shiraz A. Maskatia, M.D.
Wanda C. Miller-Hance, M.D.
Shaine A. Morris, M.D., M.P.H.
Cory V. Noel, M.D.
Ricardo H. Pignatelli, M.D.
Shannon M. Rivenes, M.D.
Alexia B. Santos, M.D.
S. Kristen Sexson Tejtel, M.D., Ph.D.
Giles W. Vick III, M.D., Ph.D.

Adult Congenital Heart Disease
Wayne J. Franklin, M.D., Medical Director
Charles D. Fraser, Jr., M.D., Surgical Director
Allison Mahlstedt, PA-C
Douglas S. Moodie, M.D., M.S.
Dhaval R. Parekh, M.D.

Cardiovascular Anesthesia
Emad B. Mossad, M.D., Director
Dean B. Andropoulos, M.D.
Beth Barraza, R.N., C.P.N.P.
Kenneth M. Brady, M.D.
Lisa A. Caplan, M.D.
R. Blaine Easley, M.D.
Erin A. Gottlieb, M.D.
Stuart R. Hall, M.D.

Cardiac Intensive Care
Douglas J. Miller, M.D.
Wanda C. Miller-Hance, M.D.
Princy Mohan, R.N., C.P.N.P.
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Premal Trivedi, M.D.
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Jennifer Yborra, RN, PNP-AC

Quality
Eric A. Williams, M.D., M.S., M.M.M., F.A.A.P., Medical Director
Kathleen E. Carberry, R.N., M.P.H., Director, Outcomes & Impact Service
Texas Children's Heart Center Publications


Belshe RB, Checchia PA. Meeting the challenge of respiratory syncytial virus infections. Inf Disease Child. 2013 March (suppl.):3-8.


Makari D, Checchia PA, DeVincenzo J. Rationale for full-season dosing for passive antibody prophylaxis of respiratory syncytial virus. Hum Vaccin Immunother 2013 Dec 6;10(3). [Epub ahead of print]


For more than 50 years, Texas Children’s Heart Center has been saving lives with the best possible pediatric cardiac care. Our multidisciplinary team of pediatric cardiologists, cardiovascular surgeons, cardiovascular anesthesiologists, perfusionists, adult congenital heart specialists, cardiac intensivists, nurses, child life specialists and support staff work together to surround patients with expertise at every point from diagnosis through treatment in order to provide the best possible results.

Meet the Texas Children’s Heart Center Team.
Texas Children's Heart Center
Texas Children’s Heart Center Referrals

The Congenital Heart Surgery service at Texas Children’s Hospital participates in the same-day surgical consultation program. To schedule an appointment for same-day consultation, call 832-82-HEART (832-824-3278).

Heart Transplant Program
866-683-8032

Cardiology, Adult Congenital Heart Disease and Cardiovascular Intensive Care Unit
832-82-HEART (832-824-3278)

Cardiovascular Anesthesia
832-826-5831