

# HEART CENTER

2013–2014 OUTCOMES REPORT

  
children'shealth<sup>SM</sup>  
Children's Medical Center  
Dallas





# Letter to Colleagues

Dear Colleagues,

I'm pleased to present the 2013-2014 outcomes report for the Heart Center at Children's Medical Center, the flagship hospital of Children's Health<sup>SM</sup>. During the past year, the Heart Center at Children's Medical Center has strengthened its position as an international destination for complex pediatric cardiac care and transplantation. Our team of 24 cardiologists and surgeons, along with more than 300 nurses, managers and support staff, are motivated by the trust that parents place in us to continuously pursue, discover and apply knowledge to take better care of their children.

The Heart Center offers a comprehensive program of specialized care for children with congenital and acquired heart diseases. A multidisciplinary group of specialists work together to meet the full range of pediatric cardiac needs, while also considering the needs of the family from both a medical and an emotional perspective.

The Heart Center's focus on quality, innovation and outcomes has resulted in a number of notable accomplishments:

- The surgical team performs more than 600 operations and nearly 400 open heart procedures annually,

treating some of the most complex cases in the world, including hypoplastic left heart syndrome (HLHS) and ABO-incompatible heart transplantation.

- The catheterization team performs more than 1,000 catheterizations annually, and is only one of three in the nation equipped with state-of-the-art imaging that significantly reduces radiation levels.
- The Heart Center offers the only Pediatric Ventricular Assist Device (VAD) program in North Texas, an aggressive approach that bridges patients to an eventual transplant.

- The Cardiac Intensive Care Unit in the Heart Center is the largest dedicated pediatric CICU in Texas with 32 beds.

A vital component of our program at the Heart Center is our commitment to provide detailed cardiac education and support services for our patients and their families. Equally important is our commitment to sharing our practices for use as educational tools for other cardiothoracic surgeons and cardiology professionals.

We hope you find the information in this report useful and informative. Even as we reflect on a year of progress and growth, we are continuing to raise the bar for ourselves, to ensure we remain focused on our mission – to make life better for children. Thank you for your interest in the Heart Center at Children's Medical Center.

Sincerely,

*Chris Durovich*

Christopher J. Durovich  
President and Chief Executive Officer  
Children's Health System of Texas

# Letter to Colleagues

Dear Colleagues,

**We are excited to share with you the excellent patient outcomes we have achieved recently in the uniquely comprehensive Heart Center at Children's Medical Center, the flagship hospital of Children's Health<sup>SM</sup>.**

Outstanding patient experiences begin with the providers, including the medical staff, nurses and ancillary support services. Our clinical expertise provides a continuum of care for patients from birth to young adulthood with commitment and compassion.

The medical staff in the Heart Center are faculty of UT Southwestern, a world-renowned medical center. This collaboration with UT Southwestern enhances the integration not only of the cardiovascular subspecialties but also of vital colleagues in anesthesia, critical care, neonatology and all of the pediatric subspecialties.

Thanks to the academic association with UT Southwestern, Heart Center physicians also have the opportunity to educate the next generation of physicians and conduct innovative, leading-edge research that seeks to find novel approaches to providing cardiovascular care.

Specialized nursing also is a primary point of patient interaction at Children's Medical Center. As a designated Magnet Program, there is a strong foundation for skilled development. Nurses, advanced practice nurses and physician assistants specialize in all of the clinical areas including surgery, critical and inpatient care, anesthesia, intervention, transplantation, electrophysiology, fetal and adults with congenital heart disease.

The patient outcomes in the Heart Center are among the best in the nation, particularly when they are critically reviewed with attention to survival for the most complex conditions, including hypoplastic left heart syndrome and those associated with heterotaxy. We also have extensive experience with ventricular assist devices and are one of the largest transplant programs in the country. We have pioneered innovation in hybrid operations and minimally invasive surgery.

Innovative clinical programs have further improved patient outcomes. *Safe At Home* is a program to closely attend to our most fragile patients, those with single ventricle physiology, particularly after the Norwood operation, the first stage of surgical palliation. Traditionally, mortality after this stage, and prior to the next, has been very high. A dramatic reduction followed the institution of this program. As more patients have undergone successful surgery, our focus has widened to optimize the health of our patients. Routine neurodevelopmental assessment early in life allows us to provide specific intervention.

All of our results and innovations are supported by a world-class facility. We are completing a \$76 million expansion of the Heart Center. Our state-of-the-art catheterization laboratories have flat-panel technology that is present in only three pediatric cardiac centers in the U.S.

A dedicated MRI within the Heart Center is directly adjacent to our catheterization laboratory and will spearhead the next generation of diagnostic and interventional procedures. Our new 32-bed intensive care environment is one of the largest in the nation.

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Unique research is underway to dramatically impact the care we deliver. Highlights of our research efforts include development of biodegradable stents that will revolutionize cardiac intervention. As the sole institution engineering a percutaneous ventricular assist device, we hope to avoid the need for surgical placement in the future.

We hope you share our enthusiasm for the future of pediatric cardiovascular medicine. The Heart Center at Children's Medical Center is helping to lead the way.

Joseph Forbess, M.D.



*Professor of Cardiothoracic Surgery  
at UT Southwestern Medical Center  
Pogue Distinguished Chair  
in Pediatric Cardiac Surgery Research  
Division Director of Cardiothoracic Surgery  
Co-Director of Heart Center*

William A. Scott, M.D., M.S.



*Professor of Pediatrics  
at UT Southwestern Medical Center  
Chief of the Division of Cardiology  
Co-Director of Heart Center*

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## Mission Statement

The mission of Children's Health<sup>SM</sup> has always been to make life better for children. Our beginnings in 1913 were humble, but even then, our vision was big. Today our team takes great pride in being the seventh-largest pediatric health care provider in the country, and the only academically affiliated pediatric hospital in the Dallas area.

Throughout our history, whether treating common pediatric conditions or giving lifesaving care, the heart of Children's Health is our people. Our unique skills and experience, combined with the latest techniques and technology, provide the most comprehensive health care available. These attributes help us to achieve our vision to make Children's Health among the very best medical centers in the nation.

Our mission yesterday, today and tomorrow is to make life better for children. We believe there is no better affirmation of our mission than seeing happy, healthy patients leave the hospital.

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## Academic Affiliation

Since 1961, Children's Medical Center has been the primary pediatric clinical partner for UT Southwestern Medical School (UT Southwestern) – one of the leading medical education and biomedical research institutions in the country.

In addition to extending our academic mission of teaching the next generation of doctors and advancing patient care through quality and research, this partnership also affords our patients access to world-renowned expertise in every aspect of pediatric cardiac care.

# Updated Heart Center Space

In February 2014, Children's Medical Center unveiled the first phase of its new Heart Center space. Part of a four-year, \$76 million plan, this investment significantly expands capacity and introduces significant advances in clinical efficiency and improved patient experience.

The new space includes:

- CICU expansion from 20 to 32 beds
- The revolutionary Artis Q.Zen Biplane Catheterization Lab, which utilizes ultra-low doses of radiation to produce superior images. Children's Medical Center is the first hospital in the southern United States to utilize this technology.
- The latest Philips Ingenia 1.5T MRI system. Children's Medical Center is one of few centers in the country with a scanner dedicated exclusively to pediatric cardiac patients. This system was strategically placed adjacent to the interventional suite to allow for intra-Cath MRI capabilities.
- Pre- and post-procedure rooms
- 3 new surgical suites
- 2 new hybrid interventional suites

- Sophisticated audio-visual (AV) capabilities throughout the Heart Center space (STORZ system) that facilitate unique conferencing capabilities and remote access to patient data

Upon completion in Summer 2016, the fully renovated Heart Center space will encompass 100,000 square feet.

Additional features will include:

- New clinic space, doubling current capacity
- New diagnostic labs for echo and EKG
- Dedicated fetal heart program space for prenatal consultation in a private, nurturing environment
- New physician offices
- New conference center with integrated technology to facilitate telehealth and educational opportunities

One of the most exciting features of the new space is that all functions are architecturally adjacent to one another, resulting in a truly integrated clinical setting. Children's Medical Center is one of only a handful of pediatric centers in the country with

this distinction, the greatest benefit of which is the ability to consistently deliver high-quality patient care with the utmost efficiency:

- New AV capabilities allow intraoperative access to a patient's scans and conferencing with other clinicians within the Heart Center
- AV capabilities also allow live streaming of procedures to other areas of Heart Center such as the CICU, allowing the department to better anticipate and prepare for patient transfers within the department
- Nursing teams are now centrally located, allowing a level of unprecedented collaboration and ensuring a consistent level of care across the patient encounter
- Close proximity of physician offices and clinic space to inpatient and procedure areas means that physicians can quickly provide in-person consultation and intervention when needed
- In both the inpatient and outpatient setting, patients can receive all the care they need in one physical location



# Heart Center Overview

The Heart Center at Children's Medical Center offers a comprehensive program of specialized care for children with congenital and acquired heart diseases. Ranking among the country's top cardiology and cardiothoracic surgery programs, a multidisciplinary group of subspecialists works together to meet the full range of pediatric cardiac needs, including:

- Prenatal consultation
- Non-invasive diagnostic imaging
- Interventional catheterization
- Electrophysiology (including catheter ablation and device therapy)
- Preventive cardiology
- Cardiothoracic surgery (including heart transplantation and congenital heart defect repair)

Heart Center physicians are world-class subspecialists from UT Southwestern Medical School. This team includes:

- **20** cardiologists
- **4** interventional cardiologists
- **3** cardiothoracic surgeons
- **3** cardiac radiologists
- **4** cardiac anesthesiologists

- **11** cardiac intensivists
- **165** registered nurses specialized in cardiac care
- **24** advanced practice nurses

With nearly 13,000 outpatient clinic encounters and over 900 inpatient admissions in 2014 alone, Children's Medical Center is a leader in all aspects of pediatric cardiac care, with outcomes that rank among the country's elite programs.

- As the only pediatric ventricular assist device (VAD) program in North Texas, Children's Medical Center offers a comprehensive range of devices and is pioneering work to make advanced technologies available to small children.
- Using the Society of Thoracic Surgeons' European Association for Cardio-Thoracic Surgery Congenital Heart Surgery Mortality (STAT) categories, Children's Medical Center exceeds median survival rates in all forms of heart surgery.
- An international class transplant program representing some of the best outcomes in the state.

- A dedicated support program for parents of single ventricle patients that has significantly decreased interstage mortality.
- Catheterization labs with advanced technology that decreases patients' radiation exposure. This technology is only available in a handful of centers across the country.
- An award-winning medical transport team with certification in all modes of transport (helicopter, airplane and ambulance) from the Association of Air Medical Services.

Sharing a medical campus side by side with Parkland Memorial Hospital, Zale Lipshy University Hospital and William P. Clements University Hospital, Children's Medical Center provides specialty and subspecialty care for any type of cardiac condition, including rare congenital conditions and adult congenital heart defect care. Children's Medical Center delivers care at its flagship location in the Southwestern Medical District as well as several satellite locations throughout the state.

## Surgical Procedures 2013<sup>1</sup>

Cardiac Operations	577	Total <b>615</b>
ACHD Operations	25	
Heart Transplants	13	

## Diagnostic Testing & Cardiac Imaging 2013<sup>2</sup>

Electrocardiograms	16,513	Total <b>30,766</b>
ECHO	12,307	
Holters	1,094	
Fetal ECHO	498	
Cardiac MRIs	198	
Stress Tests	156	

## Cardiovascular Anesthesia 2013

Cath Lab	871	Total <b>1,863</b>
Cardiovascular Operating Room	573	
Cardiac MRI	377	
Cardiac ICU	42	

## Cardiac Catheterizations 2013

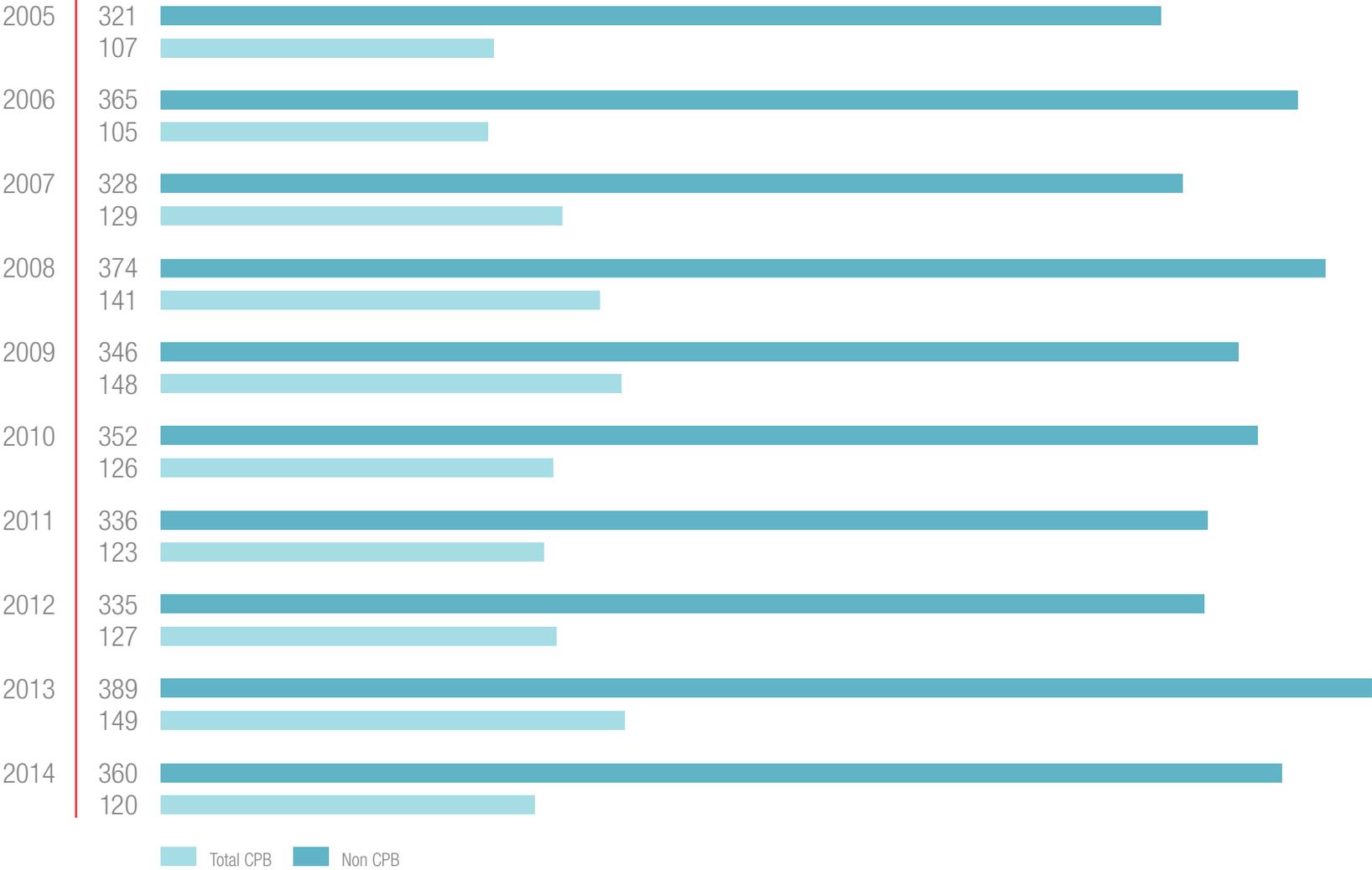
Interventional Cardiac Caths	439	Total <b>1,069</b>
Biopsy Cardiac Caths	233	
Diagnostic	192	
EP Studies & Procedures	167	
Pacemaker & Defibrillator Implants	38	

## Outpatient Clinic Patient Encounters<sup>3</sup>

Dallas	8,272	Total <b>12,849</b>
Plano	3,322	
Outreach	867	
Southlake	388	

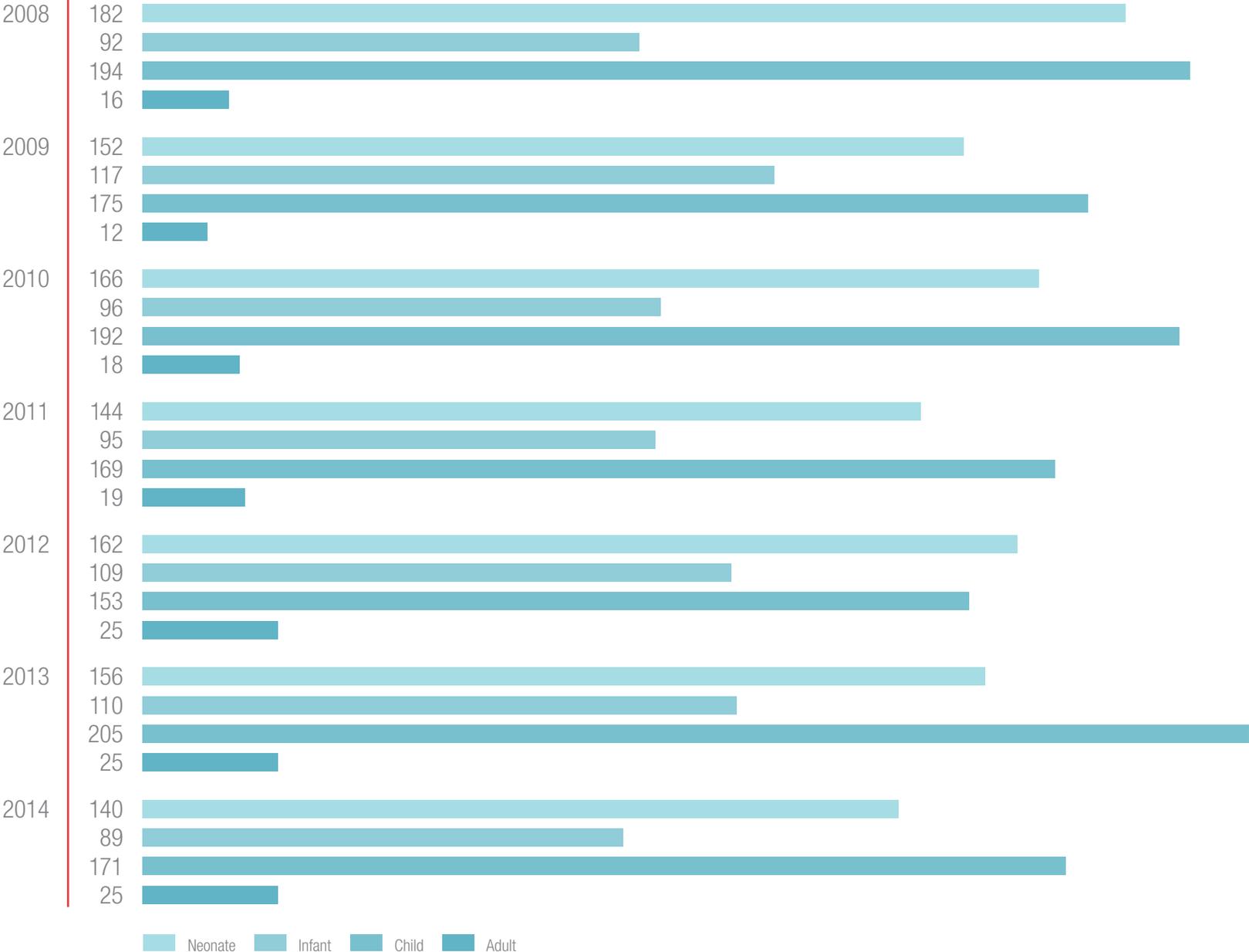
# Surgical Volumes

Total Cardiopulmonary Bypass (CPB) vs. Non CPB Cases (volume by year)





### Number of Cardiovascular (CV) and Thoracic Surgical Cases (volume by year)



## Mortality by STAT Classifications<sup>1</sup>

January 2010 – December 2013

Primary Procedure	Number of Procedures	Number of Operative Mortalities	% Mortality	STS National Benchmark
RISK CATEGORY 1	412	2	0.5%	0.7%
RISK CATEGORY 2	542	9	1.7%	1.9%
RISK CATEGORY 3	141	1	0.7%	3.1%
RISK CATEGORY 4	351	21	6.0%	7.6%
RISK CATEGORY 5	77	7	9.1%	16.9%
<b>Total</b>	<b>1,523</b>	<b>40</b>	<b>2.6%</b>	<b>6.0%</b>

## Risk Adjusted Mortality Rate<sup>1,2</sup>

2013

Primary Procedure	Number of Procedures	Number of Operative Mortalities	% Mortality	STS National Benchmark
RISK CATEGORY 1	98	0	0.0%	0.6%
RISK CATEGORY 2	168	3	1.8%	1.6%
RISK CATEGORY 3	30	0	0.0%	2.6%
RISK CATEGORY 4	101	5	5.0%	7.4%
RISK CATEGORY 5	23	2	8.7%	15.2%
<b>Total</b>	<b>420</b>	<b>10</b>	<b>2.4%</b>	<b>5.5%</b>

# STAT Mortalities by Age and Operation Type<sup>1</sup> 2013

Age	CATEGORY 1				CATEGORY 2				CATEGORY 3				CATEGORY 4				CATEGORY 5			
	Mortalities	Procedures	%	STS National Benchmark	Mortalities	Procedures	%	STS National Benchmark	Mortalities	Procedures	%	STS National Benchmark	Mortalities	Procedures	%	STS National Benchmark	Mortalities	Procedures	%	STS National Benchmark
<b>NEONATE</b> (0 - 30d)	0	2	0.0	4.4	0	14	0.0	3.5	0	5	0.0	3.4	5	57	8.8	10.0	2	22	9.1	17.1
<b>INFANT</b> (31d - 1y)	0	26	0.0	0.8	1	76	1.3	2.0	0	22	0.0	3.2	0	26	0.0	6.7	0	0	0.0	6.0
<b>CHILD</b> (1y - 18y)	0	60	0.0	0.3	2	71	2.8	0.9	0	2	0.0	0.8	0	15	0.0	3.3	0	1	0.0	4.5
<b>ADULT</b> (18y +)	0	10	0.0	0.7	0	7	0.0	1.7	0	1	0.0	2.3	0	3	0.0	7.1	•	•	•	•

## Atrial Septal Defect (ASD) Repairs<sup>1</sup> primary procedure (volume by year)



Overall Mortality<sup>2</sup>

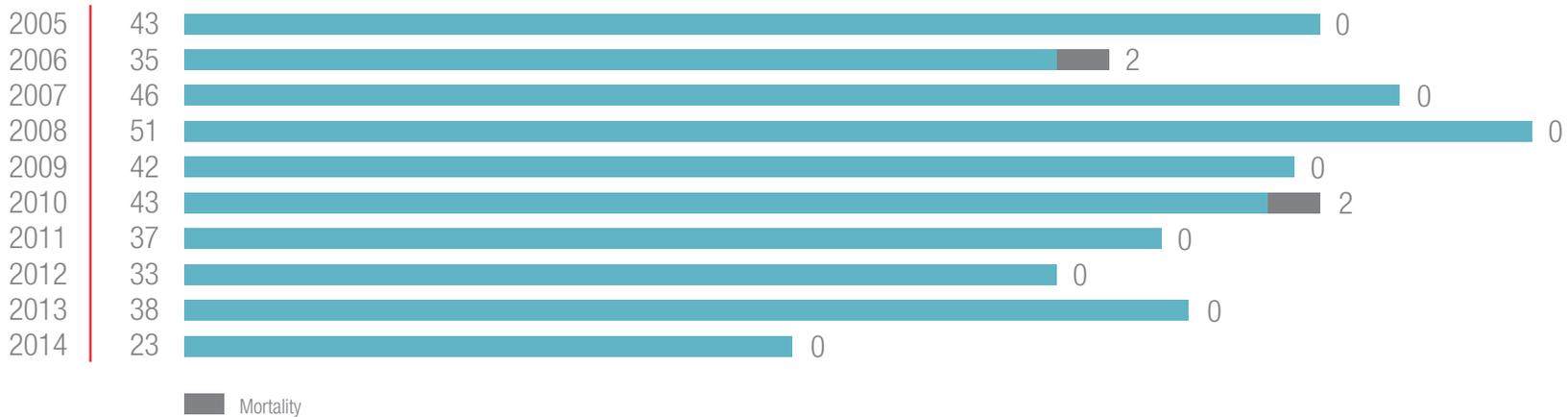
# 0%

STS National Benchmark

## <1%

<sup>1</sup> Published June 2014 – second revision STS report. Reporting time frame January 2013 – December 2013      <sup>2</sup> January 2010 – December 2013

### Ventricular Septal Defect (VSD) Repairs<sup>1</sup> primary procedure (volume by year)

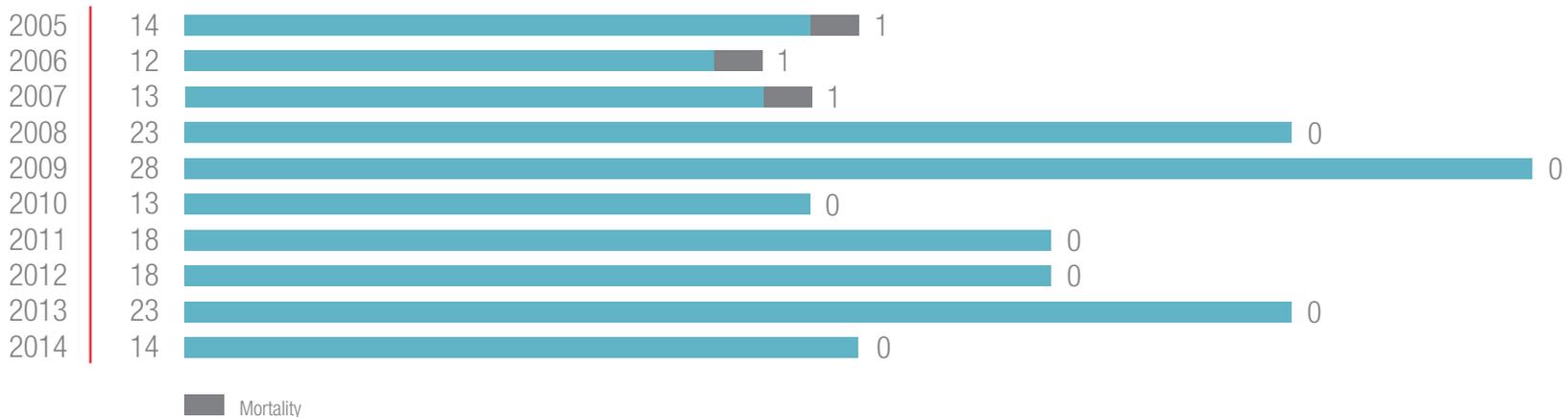


Overall Mortality<sup>2</sup>  
**1.4%**  
STS National Benchmark  
0.7%

Post Operative Median Length of Stay  
**5 days**  
National Benchmark  
8.2 days



### Atrioventricular Canal (AVC) Repairs<sup>1</sup> primary procedure (volume by year)



Operative Mortality<sup>2</sup>

0%

STS National Benchmark  
3.0%

Post Operative Median Length of Stay

9 days

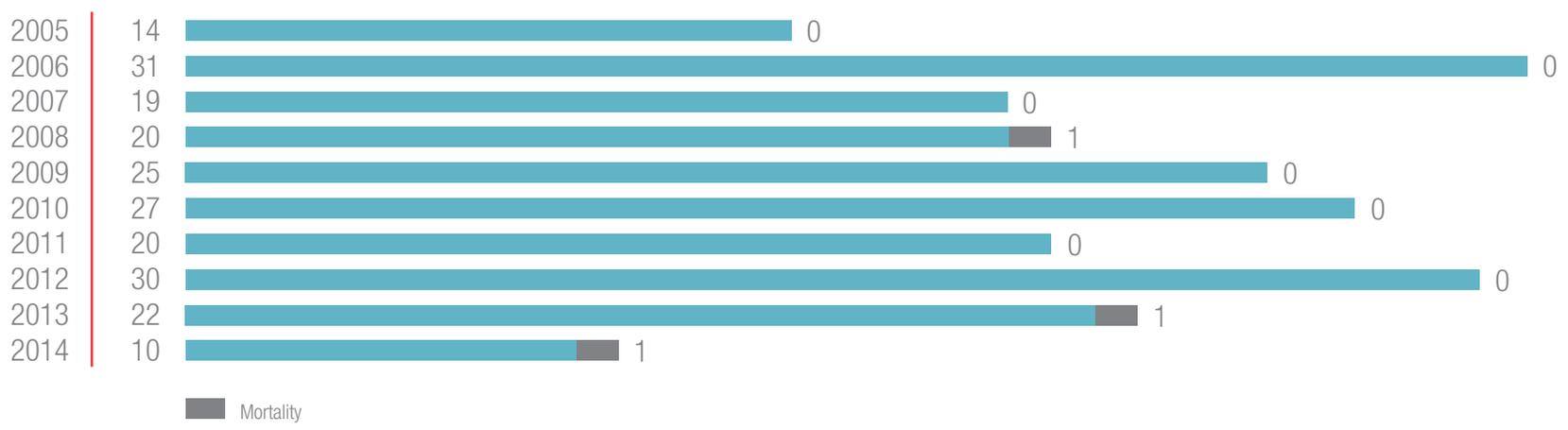
STS National Benchmark  
16 days

Incident of Arrhythmia Requiring Permanent Pacemaker

0%

STS National Benchmark  
2.3%

Tetralogy of Fallot (TOF) Repairs<sup>1</sup> primary procedure (volume by year)



Overall Mortality<sup>2</sup>  
**1.5%**  
 STS National Benchmark  
 1%

Post Operative Median Length of Stay  
**7 days**  
 STS National Benchmark  
 10.6 days

Incidence of Transannular Patch  
**26.8%**  
 STS National Benchmark  
 48.4%

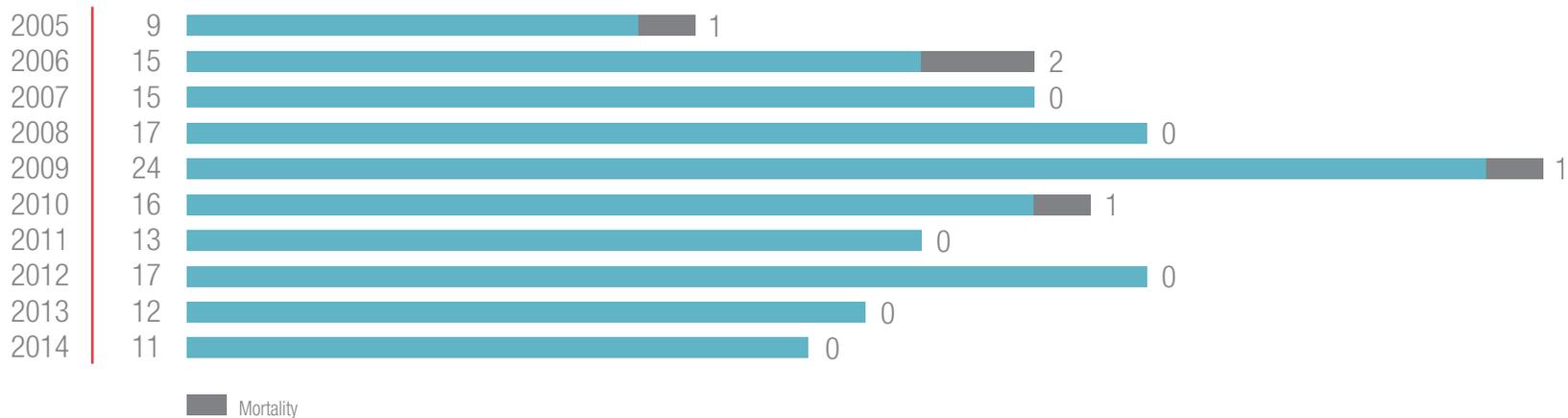
<sup>1</sup> Published June 2014 – second revision STS report. Reporting time frame January 2013 – December 2013

<sup>2</sup> January 2010 – December 2013





### Arterial Switch Operations (ASO)<sup>1</sup> primary procedure (volume by year)



Overall Mortality<sup>2</sup>  
**3.6%**  
 STS National Benchmark  
 2.6%

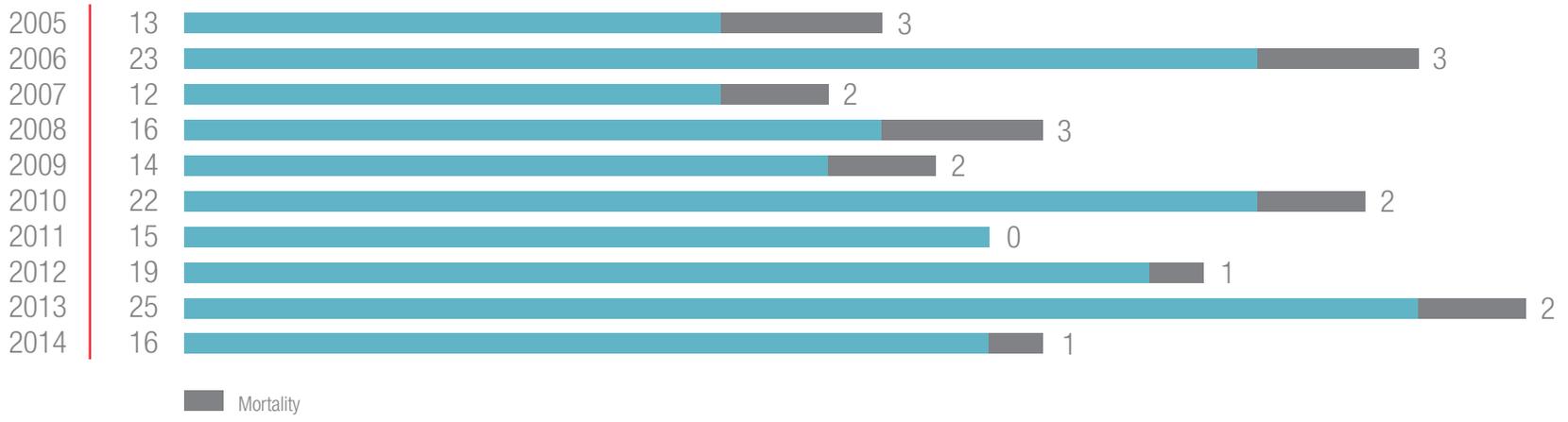
Post Operative Median Length of Stay ASO  
**9 days**  
 STS National Benchmark  
 16.4 days

Post Operative Median Length of Stay ASO+VSD  
**11 days**  
 STS National Benchmark  
 16.7 days

<sup>1</sup> Published June 2014 – second revision STS report. Reporting time frame January 2013 – December 2013

<sup>2</sup> January 2010 – December 2013

### Norwood Operations<sup>1</sup> primary procedure (volume by year)



Operative Mortality<sup>2</sup>

**4.7%**

STS National Benchmark

15.7%

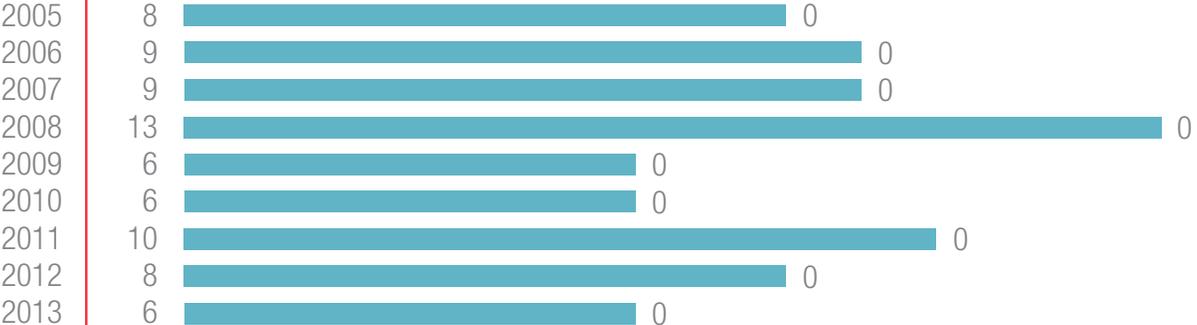
Post Operative Median Length of Stay

**33.5 days**

National Benchmark

38.3 days

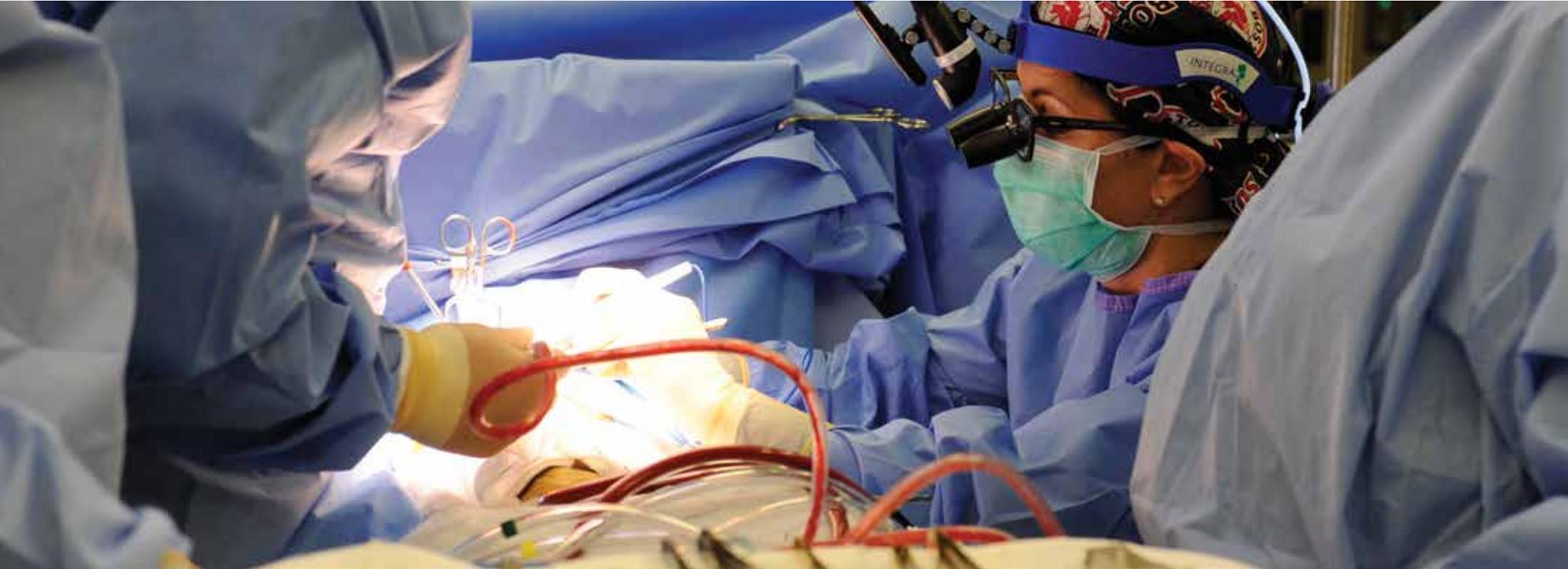
### Total Pulmonary Valve (PV) Replacements (volume by year)



Overall Mortality<sup>1</sup>

0%

<sup>1</sup> January 2010 – December 2013



# Adult Congenital Heart Disease Program

Recognized by the Adult Congenital Heart Association as one of two regional centers of excellence in Texas, Children's Medical Center offers unique expertise in the lifelong needs of adults with congenital heart disease. Caring for adults in North Texas with this condition, Children's Medical Center helps patients live to their fullest potential.

## Adult Cath Lab Procedures (volume by year)



## Adult Surgical Volumes (volume by year)



## Adult Congenital Heart Disease Expertise

One of only a few medical centers in the country with a team specifically trained in adult congenital heart disease, Children's Medical Center has years of experience delivering specialized care and support to patients with complex physiology.

Perfusionists, surgeons, anesthesiologists and interventional cardiologists at Children's Medical Center are equally as comfortable caring for adults as they are children.

- In fact, 15 percent of the over 1,000 cardiac catheterization procedures Children's Medical Center performs every year are on adult patients.
- In 2013, Children's Medical Center delivered surgical care to 29 adult patients.

Partnering with world renowned specialists from UT Southwestern Medical School, Children's Medical Center is uniquely positioned to offer any type of intervention, including:

- Valve replacement
- Closure of baffle leaks and management of other postoperative complications
- Treating narrowed and occluded veins
- Extracting or replacing worn out pacemaker leads
- Primary repair of congenital heart conditions diagnosed in adulthood

## Comprehensive Array of Treatment and Support

From ongoing consultation to heart transplantation, Children's Medical Center tailors treatment plans to meet each patient's unique needs.

- Patients with complex conditions who have a higher level of comfort in the hands of a pediatric cardiologist receive care at Children's Medical Center.
- Low-risk patients receive care from the adult cardiology practice of their choice with expert consultation from physicians at Children's Medical Center as needed.

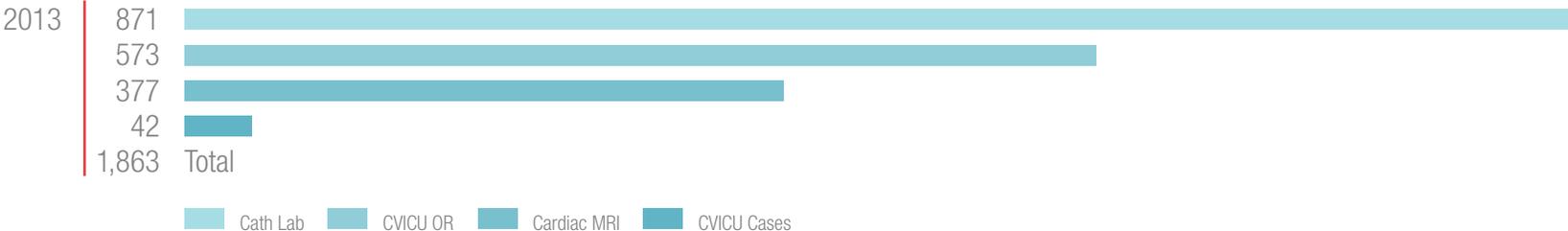
# Anesthesia



For over 20 years, the cardiac anesthesiology program at Children’s Medical Center has been delivering highly specialized sedation services for the most clinically complex cases.

The cardiac anesthesiology team includes four physicians, who are double-boarded in anesthesia and pediatric anesthesia, each of whom have 10 or more years of experience. Children’s Medical Center is also one of few hospitals in the country with a dedicated certified registered nurse anesthetist.

## Cardiovascular Anesthesia Cases (volume by year)



### Expert Cardiac Anesthesiology Care

With in-depth knowledge and experience in cardiac care, Children’s Medical Center provides expert care for the most critically ill and medically complex cases in the operating room, cardiac catheterization lab and cardiac intensive care unit. Cardiac anesthesiologists are available around the clock to provide additional care as needed.

### Coordinated Approach to Care

A certified nurse anesthetist plays a key role in care coordination, serving as a primary point of contact for consultations, maintaining the line of communication with referring physicians and other specialists as well as reviewing charts for risk certification and case assignment.

2013 case volume includes:

- Catheterization lab: **871** cases
- Cardiac ICU/operating room: **573** cases
- Cardiac MRI: **377** cases
- Cardiac ICU cases: **42**



# Nursing Highlights

In order to provide the best care for the high-acuity patient population and accommodate the range of complex diagnoses treated at Children's Medical Center, nurses maintain the highest levels of competence and education. The nursing team also includes a large number of advanced practice nurses who carry their own patient load and function as autonomous members of the clinical team.

With access to intensive, focused cardiac and non-cardiac education and training resources, including annual time away from patient care to be educated about the latest technology and care practices, the nursing team at Children's Medical Center provides highly specialized care:

- **Adult Congenital Heart Disease:** Children's Medical Center gives nurses tools and training including formal education toward certification for adult advanced life support. In late 2014, Children's Medical Center also hired a nurse practitioner dedicated to coordinating care for these patients.
- **Anesthesiology:** A dedicated certified nurse anesthetist coordinates each patient's care, with specific focus on identifying and addressing complications that could impact patient care both in and out of the procedure room.
- **Cardiac Intensive Care Unit:** Advanced practice nurses carry their own patient load, responsible for the minute-to-minute management of patients and making clinical decisions including ventilator weaning.
- **Electrophysiology:** Nurses are responsible for all pacemaker patients and are trained to recognize the early warning signs of an arrhythmia. These nurses are also

responsible for interrogating equipment during diagnostic studies.

- **Ventricular Assist Device:** A clinical nurse specialist is in charge of training a subset of nurses to expertly care for VAD patients.

In addition to patient care, the nursing staff at Children's Medical Center also contributes to elevating the overall quality of care through leadership and active involvement in quality improvement initiatives:

- **Chlorhexidine (CHG) Bathing:** In an effort to decrease blistering and rates of central venous catheter-associated bloodstream infection, nurses established a protocol that incorporated chlorhexidine wipes. As a result, rates of central line-associated bloodstream infections (CLABSI) went from 2.6 percent in 2013 to 1.3 percent in 2014.
- **Bedside Shift Reporting:** This initiative allows parents the opportunity to participate in conversations about their child's care with the incoming and outgoing nursing shifts. As a result, responses from patient experience survey data regarding parent involvement in the care of their child reached the 90th percentile on the most recent survey, up from the 25th percentile in the previous year.

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**At Children's Medical Center, nurses maintain the highest levels of competence and education.**

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# Cardiology

Cardiologists from UT Southwestern Medical Center practicing at Children's Medical Center offer expert evaluation and ongoing care for patients with a wide range of acquired and congenital heart conditions. From fetal life to adulthood, Children's Medical Center provides early intervention and delivers comprehensive treatments that improve patients' quality of life.

Admission Volumes:  
Inpatient and Observation Types

906

CLABSI

Central Line Associated  
Blood Stream Infection 2013

0%

NHSN Inpatient Ward:  
Med/Surgical Mean 2012

1.2%

CPR Event Rate

0.02 <sup>PER</sup> 100 pt days

With cardiology subspecialists in every discipline, Children's Medical Center offers comprehensive outpatient cardiology care, including:

- Advanced imaging
- Cardiac catheterization and intervention
- Critical care
- Complex care coordination
- Electrophysiology
- Fetal cardiac consultation and management
- General diagnostic services
- Heart failure
- Pre- and post-operative surgical consultation
- Preventive cardiology
- Transplantation

Consistent with our mission of making life better for children, Children's Medical Center also offers outpatient cardiology clinics at a number of satellite locations throughout the Dallas-Fort Worth and North Texas area. An imaging technology sharing system helps facilitate collaboration among clinic physicians and the team of subspecialists back at the Southwestern Medical District campus.

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**Children's Medical Center provides early intervention and delivers comprehensive treatments that improve patients' quality of life.**

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# Catheterization and Intervention



Performing nearly 1,000 catheterization procedures each year, Children’s Medical Center is one of the nation’s largest cardiac catheterization programs.

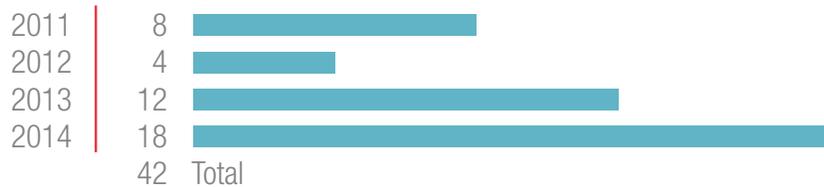


## Cardiac Cath Lab Complications<sup>1</sup>

(Diagnostic cath procedures with a major adverse event or death in 2013)

Age	CMC 2013	U.S. Hospitals 50th Percentile
<b>NEONATE</b> (0 - 30d)	12.5%	20.0%
<b>INFANT</b> (31d - 1y)	12.1%	4.1%
<b>CHILD</b> (1y - 18y)	0.7%	0.5%
<b>ADULT</b> (18y +)	0.0%	0.0%
<i>Cases Without An Adverse Effect</i>	91.0%	88.6%

## Ductal Stenting for Pulmonary Flow<sup>2</sup> (volume by year)



<sup>1</sup> Per IMPACT Outcomes report through 4th quarter 2013.

<sup>2</sup> Source: EPIC Optime report

### PDA Stents<sup>1</sup> (volume by year)



Offering every possible test and intervention, 2013 case volume includes:

- Diagnostic catheterization: **192** cases
- Biopsy: **233** cases
- Interventional cardiac catheterization: **439** cases
- Electrophysiology studies and procedures: **167** cases
- Pacemaker and defibrillator implants: **38** cases

With spacious, newly renovated catheterization labs offering the best available technology and a dedicated team of interventional cardiologists, Children’s Medical Center offers a level of care that is on par with the nation’s best children’s hospitals.

The new pediatric catheterization lab at Children’s Medical Center is one of only three of its kind in the nation, and is equipped with most advanced imaging equipment, including the revolutionary Artis Q.Zen Biplane Catheterization Lab. Utilizing ultra-low doses of radiation, this system produces superior images while also minimizing patients’ radiation exposure.

In late 2014, Children’s Medical Center implemented new technology to support magnetic resonance imaging (MRI) augmented catheterization. MRI augmented catheterization provides a three-dimensional overlay of a patient’s anatomy to help guide catheters during interventions. This technology enables a level of precision that few centers can match.

In an ongoing effort to provide the highest quality of care, Children’s Medical Center participates in the National Cardiovascular Data Registry (NCDR) IMPACT® Registry. This registry assesses the prevalence, demographics, management, and outcomes of pediatric and adult congenital heart disease patients who undergo diagnostic catheterizations and catheter-based interventions.

Children’s Medical Center is one of the few programs in the country with four interventional cardiologists. We also work exclusively with anesthesiologists who rotate through the catheterization lab. All nurses and technicians receive ongoing training to help them deliver care at a very high level.

<sup>1</sup> Source: EPIC Optime report



# Imaging

Offering a full range of imaging studies and a large team of subspecialists dedicated exclusively to pediatric cardiac patients, the expertise at Children's Medical Center is unparalleled in North Texas. In addition to expert diagnosis, cardiac imaging subspecialists actively contribute to customized treatment plans for each child.

Children's Medical Center performs more than 30,000 imaging tests every year. Highlights of this program include:

- **Echocardiography:** As one of the first pediatric imaging labs accredited by the Intersocietal Accreditation Commission for Echocardiography Labs (ICAEL), Children's Medical Center excels in all modalities of echocardiography and is the only hospital in North Texas offering advanced echo testing including stress echoes.
- **Magnetic Resonance Imaging (MRI):** As one of few hospitals in the country with an MRI scanner dedicated exclusively to cardiac patients, Children's Medical Center features the newest Philips Ingenia 1.5T MRI system – the first ever digital broadband, wide bore scanner. This powerful magnet creates vivid images in considerably less time than any other system.

2013 case volume includes:

- Echo: **12,307** cases
- Fetal echo: **498** cases
- Cardiac MRI: **198** cases
- Electrocardiogram: **16,513** cases
- Holter scan: **1,094** cases
- Stress test: **156** cases

This team includes dedicated technicians, many with over 10 years of experience as well as training in pediatric cardiac imaging that extends well beyond what is typical in this role. Children's Medical Center also has more certified sonographers than any children's hospital in the U.S.



More than  
**30,000**  
 imaging tests  
 performed annually

# Electrophysiology

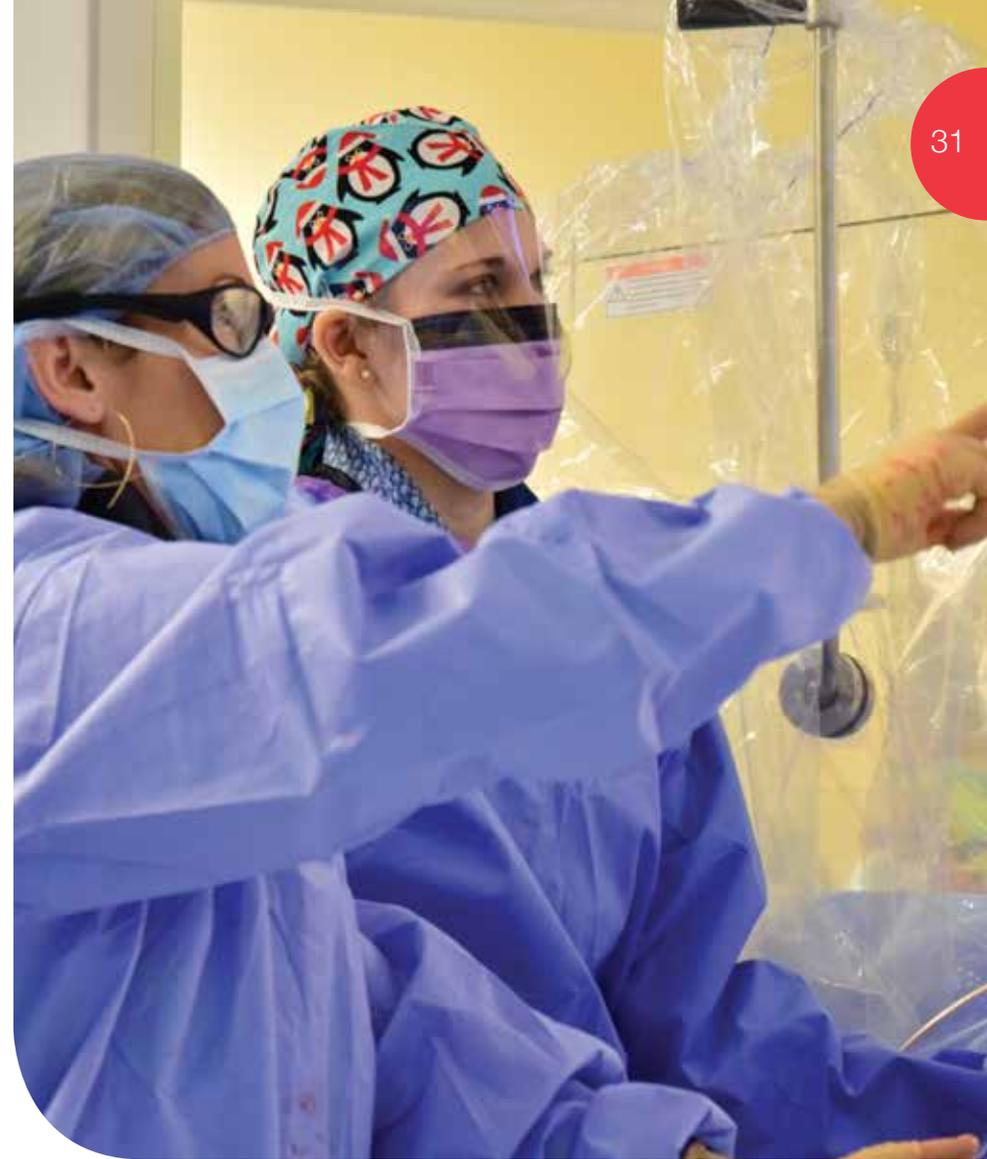
From catheter ablation to the best available monitoring devices, Children's Medical Center expertly delivers the full complement of testing and treatment for pediatric arrhythmia. Children's Medical Center performs thousands of diagnostic studies every year and delivers advanced treatments with high success rates.

As a referral center, patients come to Children's Medical Center from outside Texas as well as other countries because of our experience in successfully treating even rare forms of arrhythmia. Electrophysiologists and other specialists are available around the clock, providing emergency care to children with dangerous arrhythmias.

## Diagnosing and Treating Arrhythmias

Children's Medical Center is the only hospital in North Texas and one of only a handful nationwide using advanced imaging technology to superimpose electrical timing onto three-dimensional images from MRI or CT scans. This technology allows faster and more thorough imaging while minimizing radiation exposure.

Following cardiothoracic surgery, children can be especially vulnerable to arrhythmias. Advanced monitoring allows review of a child's arrhythmia from anywhere so immediate help is available.

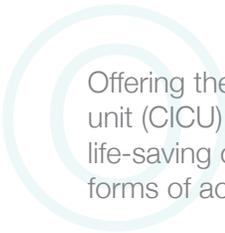


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Children's Medical Center performs thousands of diagnostic studies every year and delivers advanced treatments with high success rates.

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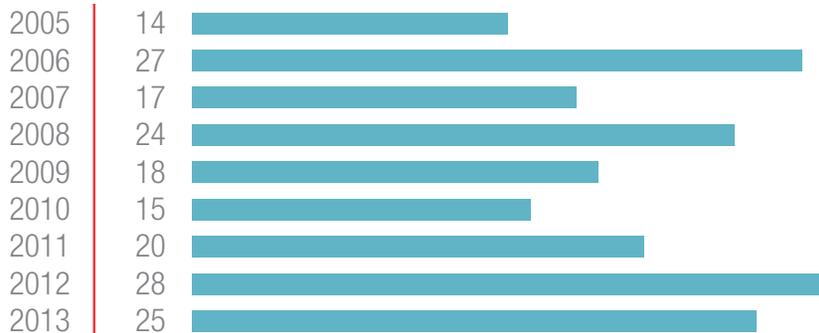
# Cardiac Intensive Care Unit



Offering the first and largest dedicated cardiac intensive care unit (CICU) in North Texas, Children's Medical Center provided life-saving care to over 600 children in 2014 with advanced forms of acquired and congenital heart disease.

Children's Medical Center is committed to improving clinical outcomes through quality initiatives. An initiative examining the role of treatment protocols in respiratory therapist-driven ventilator support and weaning following congenital heart surgery lead to improvements in medical provider efficiency and resource utilization.

## CVICU ECMO (volume by year)



### Ventilator Weaning Protocol

Average intubation time dropped from

1.6 to 0.9  
DAYS DAYS

CVICU stay decreased from

8.7 to 5.5  
DAYS DAYS

Average hospital stay decreased from

18.9 to 12.4  
DAYS DAYS

2013: Mechanical Circulatory Support within 24 hours of CPB/No CPB case.

1 in 538  
CASES

Rate = 0.19 per 100 CPB/No CPB Cases

### Expert Care for the Sickest Patients

Experts in every aspect of heart disease work together providing care, comfort and support, including:

- Child life specialists
- Critical care nurses
- Dieticians (dedicated to the CICU)
- Neurodevelopment specialists
- Pediatric cardiac intensivists
- Pharmacists (dedicated to the CICU)
- Respiratory therapists
- Social workers
- Translators

### Family Centered Care

Having a critically ill child is one of the most stressful things a parent can face. For this reason, Children's Medical Center gives parents as much information as possible and makes every effort to get them involved in their child's care.

- Families are included in daily rounds
- In-house translators offer statement-by-statement translation to ensure accurate communication with Spanish-speaking families



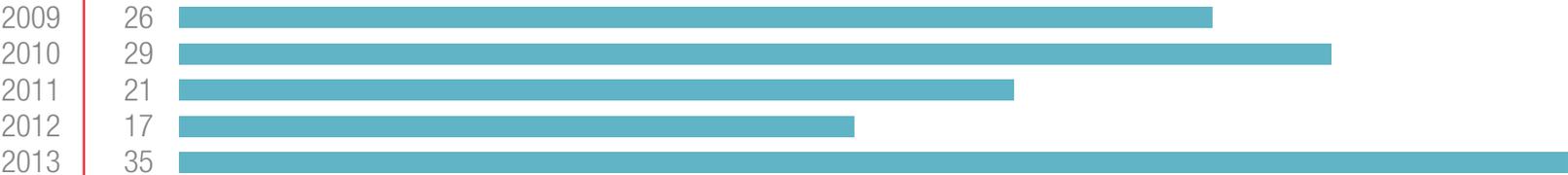
# Cardiothoracic Surgery



The surgical team at the Heart Center performs nearly 600 operations and nearly 400 open-heart procedures annually. Outcomes for highly complex heart defects are as good as and in some cases better than some of the best programs in the country:

- We perform approximately 17 to 25 Norwood procedures a year with a surgical mortality over the past four years of 4.7 percent. These are the best results in Texas; far below the national mortality rate of 15.7 percent.
- Patients undergoing repair for tetralogy of Fallot are twice as likely to undergo a valve-sparing primary repair compared to the national average.

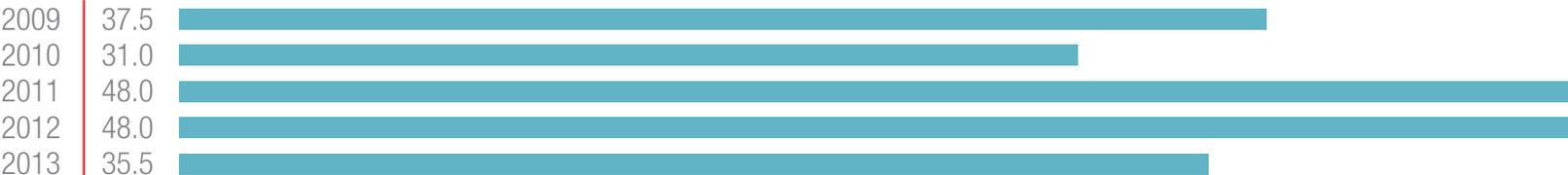
## Single Ventricle Palliation/Norwood Cases (volume by year)



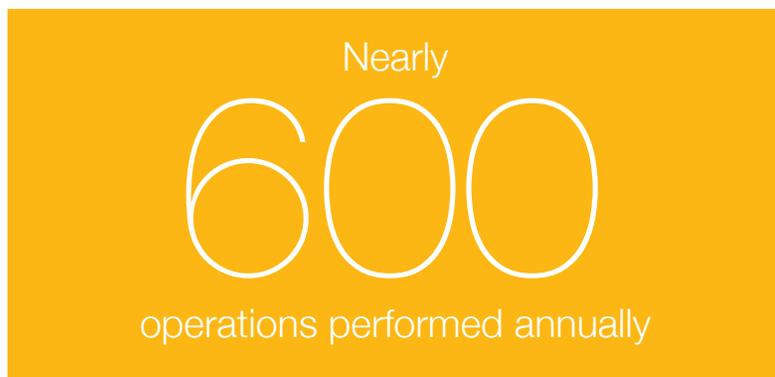
## Single Ventricle Palliation/Norwood Average Length of Stay (volume by year)



## Single Ventricle Palliation/Norwood Median Length of Stay (volume by year)



As the only hospital in North Texas offering the complete range of surgical treatments for pediatric heart disease, our large team of cardiac specialists and advanced practice nurses has years of experience delivering expert surgical care to even the smallest and sickest patients.



With in-house experts in all aspects of pediatric heart disease, Children's Medical Center meticulously plans, coordinates and delivers surgical interventions for most scenarios:

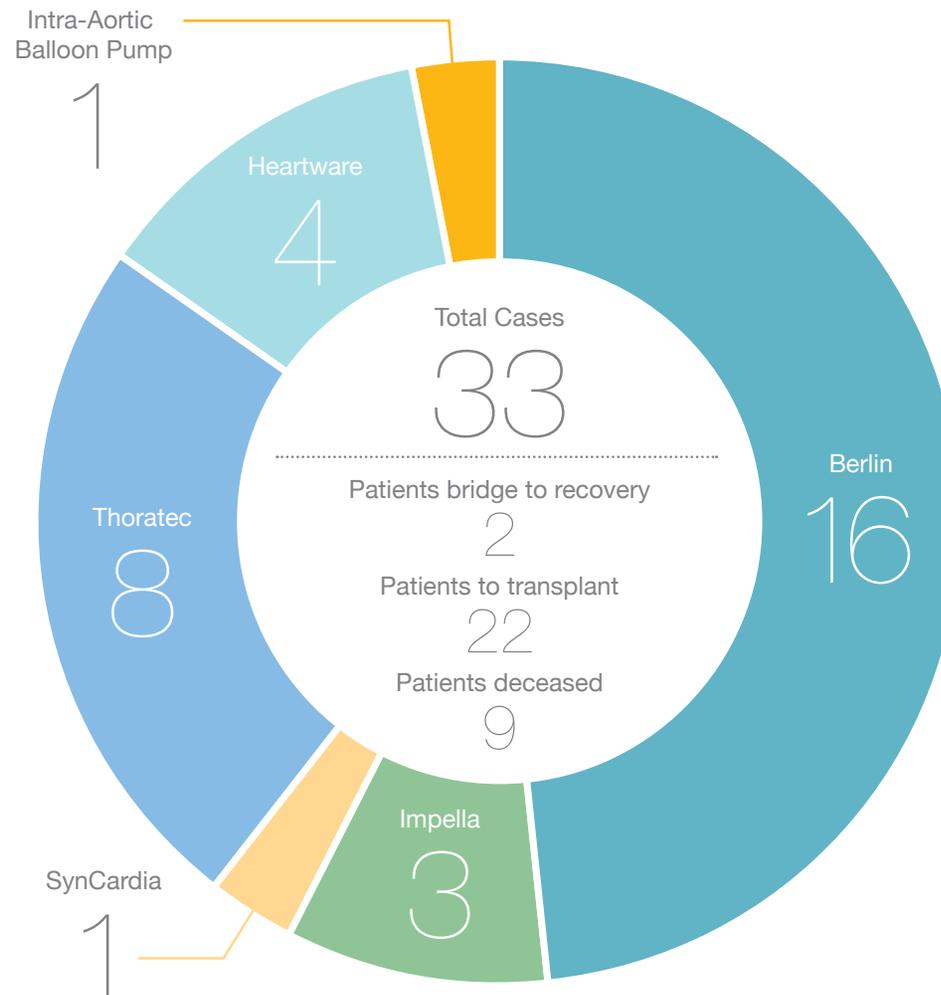
- **Heart transplant:** As one of the largest pediatric heart transplant programs in the country, few other programs can match the depth and breadth of experience at Children's Medical Center. Surgeons from the Heart Center also perform multi-organ transplants, including the world's youngest heart-liver recipient.
- **Mechanical support:** Offering a comprehensive range of devices, including pioneering work to develop new technologies for smaller children, Children's Medical Center ranks among the best pediatric VAD programs in the country. This program also features a designated extracorporeal membrane oxygenation (ECMO) team capable of running up to six circuits at any time.
- **Adult congenital heart disease:** Experts at Children's Medical Center are equally as comfortable performing surgery on adult patients as they are children. From revising previous repairs to treating patients with complex comorbidities, Children's Medical Center expertly delivers a range of adult surgical interventions.
- **Hybrid procedures:** Working closely with interventional cardiologists, surgeons perform innovative hybrid procedures such as bilateral pulmonary artery banding. Children's Medical Center was the first in the U.S. offering this technique as a method to stabilize critically ill newborn patients prior to conventional repair or palliation. It has since become a widely accepted practice.
- **Routine procedures:** With newly renovated procedure rooms, dedicated pediatric cardiac anesthesiologists and a level of expertise that is only available at high volume centers, Children's Medical Center delivers exceptional care even for routine procedures such as atrial septal defect closure.

# Heart Failure/VAD

Children's Medical Center offers every possible form of advanced heart failure treatment, including innovative bridge to transplant therapies for children awaiting heart transplant.

As one of the top VAD programs in the country, and one of only two in Texas, physicians at Children's Medical Center deliver exceptional artificial support and novel therapies.

## VAD Implantations (volume by device)



### Comprehensive Artificial Heart Support

With a 10-year history and over 30 implant operations, our depth of experience addresses the critical need for circulatory support in children of all ages. As the number of children with advanced heart failure outpaces the availability of donor hearts, Children's Medical Center offers treatments to children who would otherwise not survive.

From newborns to young adults, Children's Medical Center delivers a comprehensive range of treatments with exceptional outcomes. Highlights of this program include:

- **Expertise with single ventricle defects:** Implanting VADs in children with the most severe and high-risk conditions, such as hypoplastic left heart syndrome.
- **Best available devices:** Offering the very latest in VAD technology as well as traditional support devices.
- **Pioneering advancements in VAD technology:** Children's Medical Center is leading the field with novel research that's expanding the number of treatment options available to small children.

Children's Medical Center offers a full complement of devices including (volume since VAD program inception in 2004):

- Berlin Heart EXCOR® Pediatric VAD (**16** cases)
- HeartWare® HVAD® (**4** cases)
- Impella® (**3** cases)
- Intra-aortic balloon pump (**1** case)
- Total artificial heart (**1** case)
- Thoratec® VAD (**8** cases)
- Syncardia (**1** case)

### Pioneering New Treatments

Children's Medical Center and UT Southwestern are advancing the field of artificial heart support through research and participation in ground breaking international clinical trials. This work affords patients access to devices recently approved by the FDA that are not otherwise available.

Children's Medical Center is the first hospital in the country developing new technologies to make adult-sized VADs such as the Impella® device available to children. Research led by physician's practicing at Children's Medical Center is working to downsize components in this device, making it available to additional subsets of the pediatric population.





# Heart Transplant



Children’s Medical Center is proud to be the largest pediatric heart transplant facility in Texas. Since performing the first pediatric heart transplant in North Texas over 25 years ago, specialists from UT Southwestern have implanted nearly 200 new hearts in children of all ages.

### Expert Heart Transplant Care

The program extends beyond clinical care to include comprehensive support services and lifelong care that brings to bear the best possible outcomes: 1-year and 3-year survival rates exceed UNOS standards.

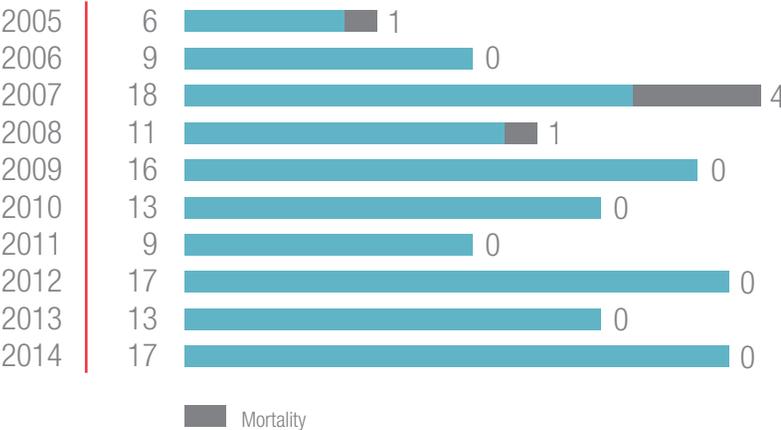
### Full Spectrum Transplant Services

Since 1988, when the Organ Procurement and Transplantation Network began recording transplant activity across the nation, Children’s Medical Center has consistently ranked among the top 10 busiest and most successful programs.

Children’s Medical Center offers a comprehensive range of heart transplant services:

- **SynCardia Total Artificial Heart:** Offering the only complete heart replacement device approved by the FDA, Children’s Medical Center is a SynCardia certified center.
- **Traditional transplant:** Children’s Medical Center ranks among the top 15 programs in the country in terms of transplant volume. As a referral center, Children’s Medical Center delivers exceptional care to children from all over Texas and surrounding communities.
- **Re-transplantation:** As it is not uncommon for children to require subsequent heart replacements, Children’s Medical Center’s expertise also includes re-transplantation procedures.
- **ABO incompatible heart transplantation:** Children’s Medical Center is one of very few centers in the country offering ABO incompatible heart transplants.

### Heart Transplants (volume by year)



Number of Heart Transplants Since Beginning of Program

199





# Fetal Heart

As one of only two fetal heart programs in Texas and the only program in the country with disease-specific certification from the Joint Commission, the fetal heart program at Children's Medical Center expertly coordinates care to ensure children with congenital heart disease get the treatments they need at precisely the right time.

With 482 clinic visits in 2013 alone, Children's Medical Center has helped hundreds of families prepare to provide care for an infant with congenital heart disease. Using echocardiography, dedicated fetal heart experts diagnose congenital heart conditions with a high degree of accuracy. In fact, the program maintained a 97 percent correct correlation of prenatal and postnatal echo studies in 2013.

Only fetal program to have  
Joint Commission:  
Disease Specific Certification  
in Fetal Cardiac Monitoring

## Children's Medical Center Fetal Heart Program

Working with subspecialists from UT Southwestern, Children's Medical Center plans safe deliveries and coordinates services to help ensure that infants receive high-acuity care starting the moment they are born.

- **Birth Plan:** Working within the risks and limitations of a child's condition, Children's Medical Center assists in identifying the most appropriate hospital for a family to deliver their baby, supporting delivery at a family's preferred community hospital whenever possible.
- **Patient Education:** Helping parents understand their child's condition and explaining what to expect helps parents feel comfortable and take an active role in making decisions about their unborn child's care.
- **Care Coordination:** Advanced practice nurses help families transition their child's care to the Heart Center team after birth, with special focus on finding the right cardiologist to meet their child's unique needs.
- **Support:** Children's Medical Center connects parents with much needed support and resources through the help of dedicated social workers.

## Specialty Support Clinics – Neurodevelopment

With mortality rates steadily decreasing over the past 25 years, there has been greater focus on improving quality of life among children with complex congenital heart defects. In 2014, Children's Medical Center initiated a pilot neurodevelopment program to support the early identification of developmental delays in children with hypoplastic left heart syndrome.

### Early Diagnosis Is Key to Successful Intervention

Using a customized protocol, developmental assessments are conducted during a child's stay in the CICU. Patients with identified risks are then referred to the Neurodevelopment Clinic for a more comprehensive assessment.

One of few programs of its kind, the cardiac neurodevelopment program leverages the full complement of expertise and resources within Children's Medical Center, including:

- Speech therapy
- Physical therapy
- Occupational therapy
- Cognitive therapy

Children's Medical Center has become the medical home for children with confirmed developmental delays in order to facilitate seamless coordination of clinical care, social support and therapy services.





# Specialty Support Clinics – Prevention & Screening

The preventive cardiology clinic at Children's Medical Center lays the foundation for lifelong treatment and helping at-risk children avoid cardiac events later in life.

## Child-Centered Preventive Cardiology

As one of the first preventive cardiology clinics in North Texas, Children's Medical Center has been caring for children with hypertension and hyperlipidemia for over 20 years.

Part of what makes this program stand out is the flexibility with which we approach each case:

- Pediatric cardiologists are skilled in explaining medical concepts using plain language and customized visual guides to help children understand and take ownership of their condition
- Working within each family's financial means to prescribe the most efficacious and cost effective medications
- Listening to older children's preferences and tailoring treatments accordingly
- Encouraging the best possible outcome for each child, by setting realistic goals and accommodating patients' changing needs

## Comprehensive Early Intervention

Children's Medical Center expertly treats children with acquired heart disease using tried and true methods, and a customized approach for each patient. This includes:

- Thorough evaluation of new patients that pays close attention to their family history and lifestyle
- Working with Clinical Nutrition services, Children's Medical Center helps children and their families commit to dietary changes when necessary. Dietitians are available for ongoing support as needed.
- Long-term follow up and monitoring until a child is old enough to transition to adult cardiology care



**ANTHONY HERMAN**

Melody valve in 2010  
to transplant in 2014.

# Safe at Home

With dedicated congenital heart disease specialists available around the clock, the *Safe at Home* program makes it possible for children undergoing staged palliation for hypoplastic left heart syndrome to recover at home while receiving our best follow-up care and support.

Part of a national quality improvement initiative, Children's Medical Center uses a team approach to give families all the tools and information they need to help their children stay healthy between surgeries. Since its inception, interstage mortality rates have decreased by more than 75 percent.

## Specialized Care for the Most Vulnerable Patients

The *Safe at Home* program augments outpatient clinical care by enabling parents to take an active role in their child's daily care during the interstage period. Parents receive thorough education on aspects of their child's recovery with special emphasis on the early warning signs of potential complications. Dedicated nurse practitioners offer additional guidance and support and are accessible around-the-clock by phone.

## Safe at Home Program Outcomes

Experience has shown that when parents feel confident about caring for their child and have access to expert support, their child spends less time in the hospital and suffers fewer complications.

- Prior to starting the *Safe at Home* initiative, interstage mortality was at 17 percent.
- Since the program's inception in 2010, 118 patients have been enrolled.
- Norwood mortality has dropped to 4.7 percent, which is far below the national benchmark of 15.7 percent.
- The median length of stay in 2013 was 35.5 days, down 12.5 days from the previous year.

## Program Volumes

2010-2014 YTD Enrolled

118

Currently Interstage

13

## Interstage Mortality

$3/105 = 3\%$

## Pre Safe at Home Mortality

17%

## Interstage Serious Adverse Events

3%

# HeartGift Foundation



Pursuant to our mission to make life better for children, Children’s Medical Center recently partnered with HeartGift Foundation, an organization providing funding, coordination of care, and medical services for children with congenital heart disease living in developing countries where specialized medical intervention is scarce or nonexistent.

Children’s Medical Center is the sole partner of the HeartGift Foundation in Dallas, forming one of the largest chapters in the country. From medical screening to life-saving repair procedures, experts at Children’s Medical Center deliver care that is second-to-none. In the first full year of service, Children’s Medical Center achieved chapter capacity, accommodating 12 patients from all over the world.



**JOSEPH SAINCLAS**  
Came in with undiagnosed Complex DORV/TGA. We provided surgery/ recovery despite increased costs.



# Meet Our Team

## Anesthesiologists

Jennifer Hernandez  
Gary Turner  
Sana Ullah  
Luis Zabala

## Pediatric Cardiologists

Sara Blumenschein  
Bibhuti Das  
Vasiliki Dimas  
Adrian Dyer  
David Fixler  
Candace Gibbin  
Lisa Heistein  
Catherine Ikemba  
Amy Juraszek  
Colin Kane  
Matthew Lemler  
Lynn Mahony  
Claudio Ramaciotti  
Surendranath Veeram Reddy  
William Scott  
Kavita Sharma  
Poonam Thankavel  
Shawyntee Vertilus  
Thomas Zellers  
Ilana Zeltser

## Intensivists

Samuel Davila  
Carole Deally  
Erin Gordon  
Michael Green  
Joshua Koch  
Shai Manzuri  
Jessica Moreland  
Susan Morris  
Alan Nugent  
Joshua Wolovits  
Maria Zuluaga

## Pediatric Cardiothoracic Surgeons

Joseph Forbess  
Kristine Guleserian  
Vinod Sebastian



# Research and Clinical Trials

In addition to our commitment to provide the highest quality clinical and surgical care, Children's Medical Center is committed to elevating the practice of pediatric cardiac care through innovation and research.

Through our affiliation with UT Southwestern, Children's Medical Center has formed a unique collaboration: Children's Medical Center Research Institute at UT Southwestern (CRI). CRI was established in 2011 with a mission to lead transformative biomedical research to better understand the biological basis of disease. Children's Medical Center is one of only 14 national pediatric research centers sanctioned by the National Institutes of Health.

Children's Medical Center takes great pride in developing techniques of tomorrow; Children's Medical Center is leading and actively participating in two dozen multi-center therapy trials. Industry groups and research centers actively seek out Children's Medical Center as a research partner not only for our case volume but also our reputation for pioneering advances in pediatric cardiac care.

Highlights for 2014 include:

- Pioneering advancements in the use of biodegradable stents for treating congenital heart disease and tracheal anomalies
- Being first in the nation to develop technologies that facilitate implantation of the advanced technologies available through the adult Impella® transcatheter assist device in small children

- Participating in the Melody® Transcatheter Pulmonary Valve Multicenter Post-Approval Study
- Being one of 30 centers participating in the Pediatric Heart Transplant Study (PHTS) database

In addition, Children's Medical Center ranks higher than any other pediatric hospital in North Texas and among top-tier academic medical centers across the country in terms of published research. Most of our clinicians frequently publish techniques and results in peer reviewed literature.

Volume of publications by department in 2014 include:

- Cardiology: **13** publications
- Cardiothoracic Surgery: **11** publications
- Echocardiography: **8** publications
- Interventional cardiology: **10** publications
- Transplant: **4** publications

The background of the slide is a solid red color. It is decorated with a repeating pattern of white, thin-lined circles of various sizes. These circles are arranged in a dense, overlapping manner, creating a complex, organic texture. The circles are centered horizontally and vertically on the page.

# Patient Stories



## Rylynn Riojas

### Journey to a New Heart

Rylynn Riojas, a typical 5-year-old, loves horsing around at her family's ranch. But her life has been anything but typical.

Like many parents-to-be, Andrea and Gilly Riojas anticipated the day they would find out whether to plan for pink or blue. But what was supposed to be a simple anatomy scan at 20 weeks gestation turned into much more. Unexpected news of a serious heart condition changed their focus to saving their baby girl's life.

### Life-saving Care

Rylynn was born with hypoplastic left heart syndrome, a condition causing the left side of the heart to be severely underdeveloped. As planned, Dr. Joseph Forbess, division director of Cardiothoracic Surgery and co-director of the Heart Center at Children's Medical Center, performed the first of a three-part open-heart surgery series when Rylynn was 4 days old. This allowed the single right ventricle to pump blood to the lungs and body. At 4 ½ months old, Rylynn headed back to the operating room for her second surgery – bidirectional Glenn shunt procedure – which allowed most of the upperbody blood to flow directly into the lungs. At this point, she was closely monitored with the hopes of waiting until age 2 or 3 for a final surgery when her lungs were further developed.

Thirteen months later, an echocardiogram revealed declining heart function, and Andrea and Gilly started the transplant listing process which included moving from their ranch in Lampasas to be closer to the hospital.

“It was heartbreaking to take Rylynn away from our home and her horses and cows,” Andrea said.

### **Worsening Symptoms**

Rylynn’s PRA (panel reactive antibody) levels were high, meaning her chance of receiving a match was very low. Throughout the next couple of months, Rylynn’s worsening heart function caused her to be moved to status 1A on the transplant list. She desperately needed a new heart.

On the brink of liver failure, doctors at Children’s Medical Center knew they had only one option to keep her alive until a donor heart became available – implanting a Berlin Heart Ventricular Assist Device to help pump blood from her heart to her body.

“Sometimes when tiny patients are waiting for a heart, like in Rylynn’s case, medical therapy isn’t enough, and the Berlin Heart is their only option for survival,” said Dr. Kristine Guleserian, surgical director of Pediatric Cardiac Transplantation at Children’s Medical Center.

But the FDA had not yet approved the device at the time of the crisis. Dr. Guleserian contacted the FDA seeking emergency access to it on a compassionate-use basis, a request the agency approved.

“After Berlin Heart implantation, we saw an immediate improvement – her liver had drastically decreased in size, her eyes were less puffy, and the pressures inside her heart and lungs came down, giving her the chance she needed to wait for a donor heart,” Dr. Guleserian said.

### **New Lease on Life**

Rylynn remained in the intensive care unit on the Berlin Heart for 77 days, until Dr. Guleserian informed the family of the news they had anxiously waited to hear – a donor heart was available. The 2-year-old became the first single ventricle patient supported with a Berlin Heart to receive a heart transplant at Children’s Medical Center.

“We couldn’t wait to see her pink cheeks,” Andrea said. “Most beautiful was the growth of her personality and her chattiness. How we had missed the sound of her voice and giggles.”

Two months after the transplant, Andrea and Gilly loaded Rylynn into their car and drove her back home to Lampasas. It had been more than a year since she had seen her horses and cows.

### **A Thriving Kindergartener**

In October 2014, Andrea and Gilly celebrated a special milestone with Rylynn – her third heart “transplanniversary.”

“Three years later, it is wonderfully typical in our world,” Andrea said. “Gilly and I are busy working while Rylynn is attending kindergarten in a class full of new friends. We could not ask for more. Her belly and chest bear the unique and perfect scars of such a painful journey, and we do our best to explain how special she is because of what she has been through.”

“Today, like every day, we are just happy to be with our sweet girl.”



## Ella Burk

### Beating All Odds

After overcoming multiple serious complications related to pregnancy, Amy Burk will never forget the moment when she found out the grim prognosis of her “Sunshine.”

“I was 26 weeks pregnant when we were told that Ella not only had hypoplastic left heart syndrome, but she also suffered from a highly restrictive atrial septum defect,” Amy said. “If she made it through the remainder of pregnancy and birth, she would have a 20 percent chance of living.”

### Finding the Right Place

Ella’s diagnosis was extremely high risk, and she would need immediate specialized care. Doctors in their hometown of Oklahoma referred Amy and her husband, Jon, to Children’s Medical Center Dallas to give Ella the best chance at life.

“We couldn’t bear the thought of losing her,” Amy said. “Our baby Ella, whose name means light, was already so very loved and wanted. There aren’t words to describe the heartbreak we felt.”

When the couple met with the team at Children’s Medical Center, for the first time since Ella’s diagnosis they were hopeful.

“We just felt like we were at the right place,” Amy said.

Children’s Medical Center, the only pediatric hospital in the country that received disease specific certification in fetal heart monitoring from The Joint Commission, provided Amy and Jon with comprehensive care. Amy received a fetal heart echocardiogram, and the couple met with Ella’s cardiologist,

cardiothoracic surgeon and fetal heart coordinator. Ella's heart was monitored for the remainder of the pregnancy, and the team coordinated treatment with Ella's other caregivers to develop a birth plan.

The goal would be to deliver Ella and transport her to the operating room in 20 minutes.

### Highly Specialized Care

Ella was born at 39 weeks gestation, and Amy and Jon were able to touch her hands before she was rushed to the Children's Medical Center Pogue Catheterization Lab. Dr. Alan Nugent, director of cardiac catheterization at Children's Medical Center, performed a highly specialized advanced transcatheter procedure to open her atrial septum. After the successful procedure, Ella spent her first week of life on a ventilator before being wheeled to the operating room for open heart surgery.

But as Ella was prepped for surgery, she became unstable and Dr. Joseph Forbess, division director of Cardiothoracic Surgery and co-director of the Heart Center at Children's Medical Center, knew that she would not make it through the planned procedure. Instead he placed bands around her pulmonary arteries to drive more blood to the body and less to the lungs. This allowed her lungs and kidneys to improve and stabilize for one week before the Norwood procedure which allows the single right ventricle to pump blood to the lungs and body.

"We put the flag in the ground and showed the rest of the world how to treat this diagnosis with placement of pulmonary

artery bands after transcatheter septostomy," Dr. Forbess said. "Now we use this approach with every patient who comes to us with Ella's condition."

Ella's next open heart surgery was at 5 months old. Dr. Forbess performed the Glenn shunt procedure to allow most of the upper-body blood to flow directly into her lungs. Ella underwent the final surgery of the three-part series, the Fontan, when she was 2 ½ years old. This improved her blood's oxygenation.

### 'Ella is our miracle'

Amy recounted many moments she will never forget when the Children's Medical Center staff went above and beyond to help Ella and her family through the ups and downs of her journey. As for now, Ella is back home in Oklahoma and makes trips to Dallas to be monitored regularly by Dr. Matthew Lemler, pediatric cardiologist at Children's Medical Center. Amy said they are taking it one day at a time.

"Our sweet sunshine is 4 years old and every day we are reminded that she is a miracle," Amy said. "She is a little performer and loves ballet and tap dance classes. She tells us she loves us all the time. We are completely in love."

Just like most parents, Amy and Jon have hopes and dreams for their daughter as she grows older.

"We hope Ella will inspire those who come after her and bring awareness to the Congenital Heart Disease world, and we hope that she gets to live a full life."



## Teddy Mays

### Mending a Tiny Heart

Deborah Mays found herself at a crossroads near the end of her pregnancy. She could stay at the hospital she knew so well with the obstetrician who delivered her other children or follow the pediatrician's advice and consider Children's Medical Center, the flagship hospital of Children's Health<sup>SM</sup>.

"As parents, Erik and I knew the greatest gift we could give Teddy, aside from all our love, was the best possible medical care," Deborah said. "Given the precarious circumstances of his arrival, we knew it could possibly be the only gift we would ever give him."

Deborah found out at her routine 20-week appointment that Teddy would be born with complex heart conditions requiring specialized care.

"What was meant to be a 30-minute appointment became four hours that left me feeling as though the weight of the world was on my shoulders and praying that I would make it to my car without crying uncontrollably," Deborah said. "I will never be able to accurately portray the magnitude, depth and breadth of the despair and heartache that consumed me. It was a despair I had never known and pray I will never know again."

### Searching for the Best

Deborah and Erik began the search to find the best doctors and hospital for Teddy.

The couple did not take the decision lightly. They researched hospitals across the country and would go to the ends of

the earth if it meant their baby boy would live. The moment Deborah will never forget was when she asked a doctor in Boston if he could perform the surgery Teddy needed better than Dr. Joseph Forbess, division director of Cardiothoracic Surgery and co-director of the Heart Center at Children's Medical Center.

"He said 'no' and that Dr. Forbess has an incredible reputation as a pediatric cardiothoracic surgeon with outcomes right up there with the best of the best. That was a huge moment for us."

### Last-Minute Change in Plans

During the first appointment at Children's Medical Center, Deborah and Erik were given answers to questions they did not even know to ask. After meeting Dr. Forbess, they knew Children's Medical Center was the place for Teddy.

"Faith is a big part of our lives, and after doing extensive research and seeing multiple doctors, we approached the decision prayerfully," Deborah said. "We liked that Children's Medical Center was an academic hospital and every specialty that Teddy could possibly need was there. We also really connected with our doctors."

With the due date approaching, Deborah made phone calls to her cardiologist and obstetrician to let them know the change in plans.

Dr. Catherine Ikemba, a pediatric cardiologist and director of the Fetal Heart Program at Children's Medical Center, performed fetal echocardiograms when Teddy was 30 weeks and 36 weeks gestation.

"I am very honest with my patients," Dr. Ikemba said. "There is a lot we cannot predict in life, so I try to prepare families for best and worst case scenarios. Caring for a child with complex single ventricle congenital heart disease is quite an endeavor that affects the entire family."

Deborah appreciated Dr. Ikemba's honesty even when it was not what she wanted to hear.

"Dr. Ikemba was my rock and didn't sugarcoat anything," Deborah said. "The night before Teddy's surgery, she came to visit me after what I am sure was a very long day for her. Over the course of this heartbreaking journey, we found real beauty in so many people."

### Home Sweet Home

At 39 weeks gestation, Teddy was born with dextrocardia and complex single ventricle with pulmonary atresia. He underwent his first procedure in the Children's Medical Center Pogue Catheterization Lab at a couple of days old. After another procedure in the catheterization lab at 2 ½ months old and open heart surgery at 4 months old, Teddy is home and visits Children's Medical Center every three months for checkups.

The thriving 14-month-old spends the majority of his time keeping Deborah on her toes. Teddy's four older siblings adore him.

"Teddy rules the roost," Deborah said. "Nobody messes with Teddy. If he isn't happy, no one is."

With the toddler's constant hugs and endless laughter, the Mays family is happy – and complete.



## Keely Henry

### Keeping a Steady Pace

Keely Henry plans to be a veterinarian or animal caretaker when she grows up. The teen from Mount Pleasant, Texas, has been around animals her entire life and feels most at home when competing at the rodeo.

“When I’m out there on my horse, I feel free,” Keely said. “There is no other feeling in the world.”

### Abnormal Rhythms

Five years ago, Melody Henry, Keely’s mom, thought the days of Keely pursuing her passion were over. At a youth rodeo in Lufkin, Melody watched as Keely rode into the arena and passed out in the middle of the competition. Keely had developed a serious abnormal heart rhythm called polymorphic ventricular tachycardia. To prevent her from experiencing a more serious abnormal rhythm in the future, doctors implanted an Internal Cardiac Defibrillator (ICD) at Children’s Medical Center. This device can detect the abnormal rhythm and shock her heart to a normal rhythm.

### A Rough Start

This was not the first time Keely experienced problems with her heart. When Keely was 4 weeks old, Melody took her to a routine checkup where the pediatrician noticed she looked pale and detected low oxygen levels. In a matter of hours, Keely was flown to Children’s Medical Center for treatment.

“We were packed for a Labor Day trip and planned for a quick stop at the doctor before leaving town,” Melody said. “The next thing I knew Keely was being loaded onto the plane headed to Dallas. I was in shock.”

At Children’s Medical Center, doctors discovered that Keely was born with Transposition of the Great Arteries and a ventricular septal defect (VSD). Within hours of her arrival, Keely underwent a balloon atrial septostomy using a catheter placed in her leg vein and maneuvered into her heart. It ultimately gave more oxygenated blood to her brain and body.

### Mending Keely’s Heart

Five days later, Dr. Thomas Zellers, interventional pediatric cardiologist at Children’s Medical Center, performed open heart surgery to allow the deoxygenated blood to come to the right ventricle and to be pumped to the lungs to pick up oxygen and the oxygenated blood to be pumped to the body. He also closed the VSD to prevent blood from being pumped across the hole and adding too much blood to the lungs.

“Keely developed heart block, a condition in which the electrical impulses could not be transmitted from the upper to the lower chambers to keep her heart rate normal,” Dr. Zellers said. “At that time, she required a pacemaker to regulate her heart rate.”

Melody remembers the overwhelming feeling of being a new parent on top of Keely’s heart problems and credits the staff at Children’s Medical Center with helping her through a challenging time.

“We hardly knew about having a child, much less one with heart problems,” Melody said. “But the caregivers at Children’s Medical Center have such a wonderful bedside manner and made me feel at ease even though it was a stressful situation.”

### Back in Action

With a mended heart, Keely thrived as an infant and grew to love the rodeo just like her parents.

“My husband and I attended college on rodeo scholarships, so it’s a family affair,” Melody said.

After passing out at the rodeo, Keely’s involvement came to a quick halt, and she began showing lambs instead. But her love for training, riding and competing stayed strong.

“I’ll never forget at our appointment two years ago when Dr. Zellers asked Keely if she wanted to compete again,” Melody said. “I was nervous to let her dive back into it, but she was ready and hasn’t looked back.”

Today the eighth grader spends 45 minutes each day training a 6-month-old filly named Harley and rides Coyote, her competing horse, regularly. She is fourth in the region in the Youth Rodeo Association.

Keely prefers to steer clear of doctor’s offices, but Melody says she does not mind visiting Children’s Medical Center.

“It feels like a second home to me,” Keely said.





We believe there is no better affirmation of our mission than seeing happy, healthy patients leave the hospital.



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