

# 2014

TEXAS CHILDREN'S FETAL CENTER™

OUTCOMES



**Texas Children's  
Hospital®**

**Pavilion  
for Women**



# 2014

## TEXAS CHILDREN'S FETAL CENTER™ OUTCOMES

### TABLE OF CONTENTS

Welcome .....	2
Texas Children's Hospital and Baylor College of Medicine .....	3
Texas Children's Pavilion for Women.....	4
Texas Children's Fetal Center.....	5
Fetal Center Services .....	6
Fetal Center Volumes and Outcomes .....	8
Fetal Cardiology Program .....	12
Congenital Diaphragmatic Hernia .....	16
Neural Tube Defects.....	18
Twin-Twin Transfusion Syndrome .....	20
Meet Our Leaders .....	22
Physicians .....	25
Providers and Staff .....	27
Publications.....	28
Referrals .....	40

For information about Texas Children's Fetal Center, informative videos, physician profiles and more, visit [women.texaschildrens.org/fetalcenter](http://women.texaschildrens.org/fetalcenter).

**Dear colleagues, parents and friends:**

We are very pleased to present the first edition of the Texas Children's Fetal Center Outcomes Book. Here you will find important data about patient volumes and outcomes on the diagnoses we frequently see and treat. As one of the nation's leaders in the diagnosis and treatment of abnormalities in unborn and newborn infants, Texas Children's Fetal Center is committed to providing the best possible care and outcome for each mother, baby and family.

The core staff of Texas Children's Fetal Center includes fetal and pediatric surgeons, maternal fetal medicine specialists, subspecialty consultants and specialized coordinators. The Fetal Center's physicians are recognized leaders in fetal medicine and fetal and neonatal surgery. As one of only a few centers in the United States to provide the full spectrum of fetal therapies, Texas Children's attracts parents from around the world seeking the best care for their unborn child. Currently, Texas Children's Fetal Center provides the broadest scope of procedures, including experimental interventions, of any center in the world.

We perform groundbreaking fetal surgeries and other procedures in the state-of-the-art operating facilities at Texas Children's Pavilion for Women, immediately adjacent to our 173-bed neonatal intensive care unit (76-bed level IV) in Texas Children's Hospital. The Fetal Center is committed to responsiveness and open 24/7 with physicians on call to discuss diagnoses and care plans with referring doctors. We are prepared for surgical or medical intervention around the clock, all year long.

One of the joys of our work is seeing children thrive. As our patients grow, they often continue to receive care through our award-winning hospital and pediatric network. In this publication, we introduce three patients who have become part of our extended family and whose successful outcomes are a reminder of the importance of our work.

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

Sincerely,

Texas Children's OB/GYN-in-Chief

**Michael A. Belfort, M.D., Ph.D.**

and

Texas Children's Fetal Center Co-Directors

**Darrell L. Cass, M.D.**

**Wesley Lee, M.D.**

**Oluyinka O. Olutoye, M.D., Ph.D.**

**Rodrigo Ruano, M.D., Ph.D.**

# Texas Children's Hospital and Baylor College of Medicine

*Texas Children's mission is to create a healthier future for children and women throughout our global community by leading in patient care, education and research. Renowned worldwide for our expertise and breakthrough developments in clinical care and research, Texas Children's Hospital is ranked #4 among top children's hospitals in the nation and is also ranked in all 10 subspecialties in U.S. News & World Report's list of America's Best Children's Hospitals.*

A large, light blue, stylized graphic of the number 4 with a hash symbol (#) to its left, positioned behind the text in the first paragraph.

Texas Children's operates Texas Children's Hospital, Texas Children's Health Plan, the nation's first health maintenance organization (HMO) created just for children, and Texas Children's Pediatrics, the nation's largest primary care pediatric network with more than 50 practices throughout the greater Houston area.

The main campus of Texas Children's Hospital is located near downtown Houston in the Texas Medical Center, the largest medical center in the world. The main campus includes more than 600 inpatient beds, the Clinical Care Center for outpatient visits, the Feigin Center for pediatric research and Texas Children's Pavilion for Women, a comprehensive OB/GYN facility with a focus on high-risk births. Located nearby is the Jan and Dan Duncan Neurological Research Institute at Texas Children's Hospital, a basic research institute dedicated to solving childhood neurological diseases.

To serve the rapidly growing population of Houston, Texas Children's opened its first community hospital in 2011, Texas Children's Hospital West Campus, and will open its second community hospital in 2017, Texas Children's Hospital The Woodlands. Both locations offer an emergency center, ICU beds, inpatient beds, surgical suites and more than 20 subspecialty clinics.

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 more than 60-year partnership, Texas Children's Hospital has served as Baylor's primary pediatric training site and Baylor faculty are the division chiefs and staff physicians of Texas Children's patient care centers. The collaboration between Texas Children's Hospital and Baylor is one of the top 10 such partnerships for pediatric research funding from the National Institutes of Health.

With a staff of more than 11,000 employees and more than 2,000 board-certified physicians (faculty, residents and fellows), Texas Children's offers the highest level of care in more than 40 subspecialties, programs and services.

# Texas Children's Pavilion for Women

Texas Children's Pavilion for Women brings together obstetricians, gynecologists, reproductive endocrinologists, surgeons, maternal fetal medicine specialists, geneticists, fertility specialists and support staff under one roof to provide women and babies the highest quality health care available. OB/GYNs in top private practices, including Baylor OB/GYN, Partners in OB/GYN Care and the Women's Specialists of Houston, provide comprehensive obstetrics and gynecology services at the Pavilion for Women.

With more than 6,000 births annually at the Pavilion, we provide a unique model of care called family-centered maternity care. This evidence-based approach is designed to help a woman achieve her wishes for her birth experience and to provide postpartum care for mother and baby together, rather than apart. Mothers and babies are not separated for care unless medically necessary, promoting enhanced bonding and attachment. For babies who need extra care and monitoring, the Pavilion's blended-care NICU provides state-of-the-art medical care in a family-centered environment. In situations that require more complex care and access to subspecialists, babies are transferred to Texas Children's Level IV NICU through a private, patient-only bridge, where they receive the highest level of care available for newborns.

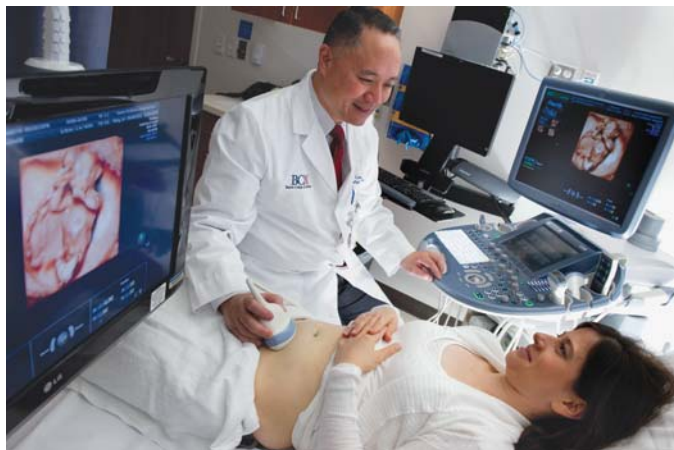
The Pavilion for Women specializes in high-risk pregnancies and births. Because we are part of one of the nation's top pediatric hospitals, we are able to offer seamless, collaborative and comprehensive care before, during and after birth. A cornerstone of this unique model of care is Texas Children's Fetal Center, one of only a few centers worldwide to offer comprehensive fetal diagnostic and intervention therapies.



# Texas Children's Fetal Center

Advances in fetal medicine and fetal surgery mean that early detection of fetal problems and anomalies is often matched by equally sophisticated treatments. Such innovation can help change emotions surrounding a complex pregnancy from fear to hope.

Texas Children's Fetal Center, established in 2001 and located within Texas Children's Pavilion for Women, is one of only a few centers in the United States to offer the full spectrum of fetal therapies. We provide comprehensive care to meet the needs of pregnant women, including advanced diagnostic procedures and consultation to help families understand complex diagnoses and treatment plans.



## **Our approach**

Fetal Center physicians are among the world's leaders in fetal medicine and in perinatal surgery. Our core staff includes fetal and pediatric surgeons, maternal-fetal medicine physicians and specialized coordinators. Depending on the case, the Fetal Center team may call on cardiologists, cardiovascular surgeons, neonatologists, urologists, neurologists, neurosurgeons, anesthesiologists, radiologists or genetics specialists with expertise in fetal conditions. The patient's entire multidisciplinary care team meets on a regular basis to discuss every aspect of care for the fetal patient.

Fetal surgery and other interventions are performed in the state-of-the-art operating facilities at Texas Children's Pavilion for Women, with immediate access to Texas Children's Level IV NICU. Texas Children's Fetal Center is open around the clock with physicians on call to discuss diagnoses and care plans with referring doctors.

## **Dedicated support**

Every family that comes to Texas Children's Fetal Center for treatment is paired with a clinical coordinator highly trained in the needs of patients with fetal anomalies. The coordinator is available to the family from the moment of arrival until treatment is complete. This service provides patients and families with a direct link to medical information, insight and explanation – and equally important – a familiar face and source of support throughout treatment.

# Fetal Center Services

## Advanced diagnostic imaging

Texas Children's Fetal Center offers state-of-the-art fetal imaging services and consultation from a multidisciplinary collaboration of specialties that include maternal-fetal medicine, radiology, and pediatric surgery, urology, neurosurgery and cardiology. We perform routine screening for first and second trimester pregnancies, nuchal translucency assessment, detailed anatomic surveys, fetal growth evaluation, and antenatal assessment for obstetrical complications. The Fetal Center offers advanced expertise in fetal magnetic resonance imaging as a complementary diagnostic imaging technology for the prenatal diagnosis of severe congenital anomalies.



3D ultrasound surface rendering

## Prenatal diagnosis

The Fetal Center also performs standard and advanced diagnostic procedures for genetic and other testing, including chorionic villus sampling, amniocentesis, fetal cord blood sampling (cordocentesis), and fetal skin and muscle biopsy.

## Genetic counseling

Experienced genetic counselors provide education and support to families regarding the risks, causes and tests related to genetic and fetal conditions. We work with families to:

- Discuss the potential cause(s) of fetal conditions
- Make recommendations for further genetic testing
- Offer modern and comprehensive methods for genetic diagnosis, such as chromosomal microarray analysis
- Offer emerging new genetic tests, such as whole exome sequencing, for the most complex fetal conditions
- Explain the purpose of and meaning of results from complex genetic testing

## Fetal therapies

- Catheter-based fetal cardiac intervention (balloon atrial septostomy for HLHS and balloon dilation for critical aortic stenosis with evolving HLHS)
- Maternal hyperoxygenation therapy for borderline left heart (research study)
- Treatment of fetal arrhythmias
- Open fetal surgery for pericardial teratoma
- Open fetal surgery for lung masses/CCAM
- Open fetal surgery for SCT and vascular tumors
- Open and experimental fetoscopic surgery for myelomeningocele (spina bifida)
- Ex-utero intrapartum treatment

- Fetoscopic laser photocoagulation for twin-twin transfusion syndrome
- Experimental fetal endoscopic tracheal occlusion for congenital diaphragmatic hernia
- Fetoscopic amniotic band resection
- Fetal shunt placement for pleural effusion and lower urinary tract obstruction
- Intrauterine transfusion
- Management of complicated monochorionic pregnancies using radiofrequency ablation, bipolar cord coagulation and/or microwave methods

### **Fetal anomalies commonly treated**

Texas Children's Fetal Center evaluates and treats many conditions, including the following:

- Abdominal wall defects (gastroschisis and omphalocele)
- Amniotic band syndrome
- CNS lesions (anencephaly, encephalocele, holoprosencephaly, hydrancephaly and hydrocephalus)
- Congenital airway obstruction
- Congenital diaphragmatic hernia
- Craniofacial anomalies (cleft lip and palate)
- Duodenal and intestinal atresia
- Esophageal atresia with tracheoesophageal fistula
- Congenital heart disease (including hypoplastic left heart syndrome, tetralogy of Fallot, atrioventricular septal defects, other simple and complex anomalies)
- Fetal arrhythmia (including congenital heart block, supraventricular tachycardia, atrial flutter)
- Cardiac masses
- Pericardial effusions
- Fetal chylothorax or hydrothorax
- Giant neck masses
- Lung lesions (congenital cystic adenomatoid malformation, hybrid lesions, pleural effusion, pleuro pulmonary blastoma, and pulmonary sequestration)
- Maternal immune disorders affecting the fetus (congenital heart block, platelet alloimmunization, red cell alloimmunization)
- Myelomeningocele (spina bifida)
- Non-immune hydrops
- Small bowel obstruction
- Sacrococcygeal teratoma
- Skeletal dysplasia
- Twin abnormalities (discordant intrauterine growth restriction, discordant structural anomalies, TRAP sequence (acardiac twin), and twin-twin transfusion syndrome)
- Urinary tract obstruction (bladder outlet obstruction and hydronephrosis)

# Fetal Center Volumes and Outcomes

Since 2001, Texas Children's Fetal Center has been at the forefront of innovations in fetal diagnostics and intervention therapies. The following data represents evaluations, procedures and outcomes through 2014.

## Overall totals

2009-2014	Evaluations	3,206
2006-2014	Fetoscopic procedures	447

## Open fetal surgeries

2006-2014	Lung lesions and teratomas	7
2011-2014	Neural tube defects	25
	TOTAL	32

## EXIT (ex-utero intrapartum treatment) procedures

2001-2014	EXIT-to-airway	23
2007-2009	EXIT-to-ECMO (extracorporeal membrane oxygenation)	2
2005-2014	EXIT-to-resection of high risk lung mass	14
	TOTAL	39

## Fetal cardiac conditions/interventions

2005-2014	Total fetal echocardiograms	9,901
2012-2014	Number of catheter-based fetal cardiac interventions	11
2012-2014	Number of fetuses undergoing chronic maternal hyperoxygenation for borderline left heart	9
2005-2014	Number of fetal arrhythmia patients	74

## Fetal lung malformations

2003-2004	Patients evaluated for congenital pulmonary airway malformation/ congenital cystic adenomatoid malformation (CCAM)	162
2006-2014	Open fetal surgeries for CCAM	4
2005-2014	EXIT-to-resection procedures	14
2001-2014	Patients evaluated for high-risk lung malformations*	46

Survival rate for open fetal surgeries for CCAM	75%
Survival rate for EXIT-to-resection procedures	100%
Survival rate for patients with high risk lung masses*	83%
Survival rate for patients with low risk lung masses**	98%

\* Defined as those with hydrops or CCAM volume ratio  $\geq 1.6\%$

\*\* Two deaths due to non-lung related problems

## Fetal tumors and neck masses

2003-2014	Patients evaluated for fetal tumors, including cervical, mediastinal and sacrococcygeal teratomas	33
2001-2014	EXIT-to-airway procedures performed to treat patients with cervical tumors or epignathus	20
2002-2014	Patients evaluated for fetal neck masses	40

## Amniotic band syndrome

2012-2014	Patients evaluated for amniotic band syndrome	8
2012-2014	Fetoscopic interventions for amniotic band release/ shunt complications	5
Survival rate after fetoscopic procedure		100%
Percent of patients who did not need amputation after fetoscopic procedure		80%

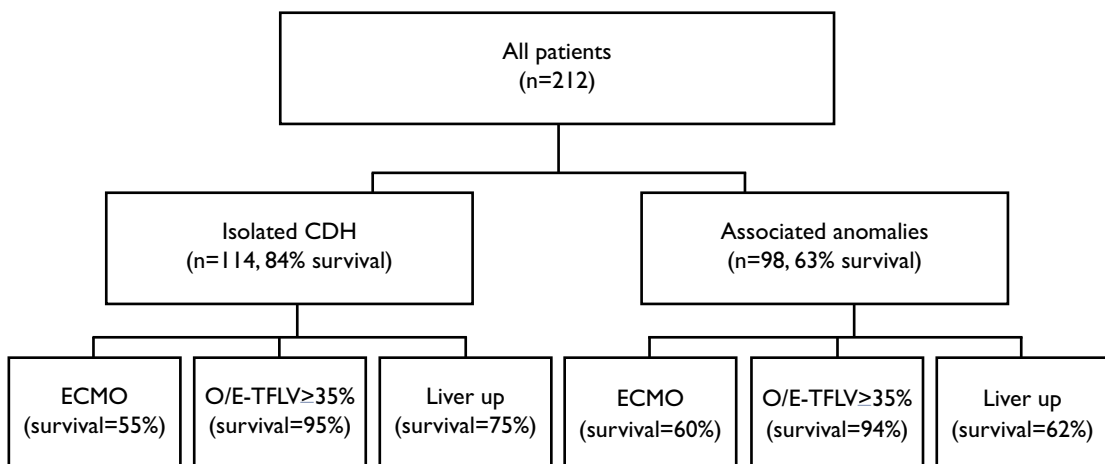
# Fetal Center Volumes and Outcomes

## Congenital diaphragmatic hernia (CDH)

2001-2014	Patients evaluated for CDH	212
2012-2014	Number of fetal endoscopic tracheal occlusion procedures	12
2004-2014	Survival to discharge for isolated CDH*	84%
2004-2014	Survival to discharge for CDH with associated anomalies	63%

\* O/E – TFLV  $\geq$  35%

## Survival to discharge for CDH patients (January 2004 to December 2014)



## Lower urinary tract obstruction (LUTO)

2004-2014	Patients evaluated for LUTO	43
2006-2014	Fetal bladder shunts	22
	Survival for patients with fetal bladder shunts	86%
	Normal renal function at 6 months after fetal bladder shunts	67%

## Neural tube defects (NTD)

2011-2014	Patients evaluated for NTD	106
2011-2014	Open fetal procedures	25
2014	Fetoscopic procedures*	1

Mean gestational age at delivery (in weeks) for those who underwent surgery	34.5
Total shunt rate with follow up	3/27 (2 weeks)
Shunt rate for those > 1 year of age**	3/21

\* 14 fetoscopic NTD repairs completed in 2015

\*\* Includes endoscopic third ventriculostomy (ETV) or shunt

## Omphalocele

2002-2014	Patients evaluated for omphalocele	77
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Survival for isolated omphalocele in live-born infants	100%
Survival for minor omphalocele with associated anomalies	83%
Survival for major omphalocele with associated anomalies	59%

## Twin-twin transfusion syndrome (TTTS)

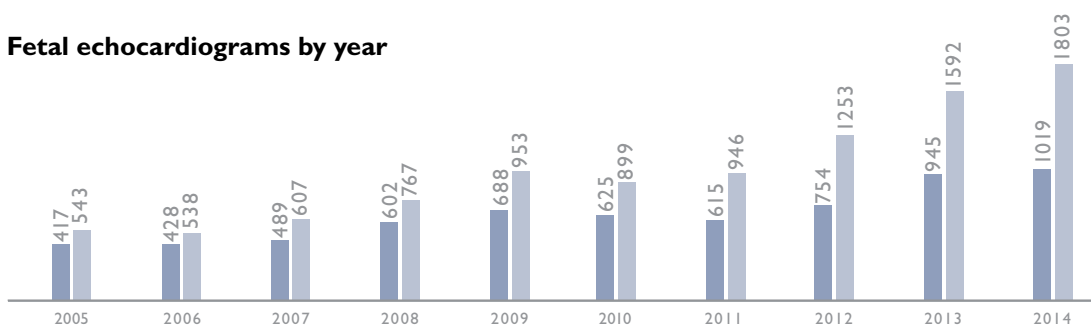
2006-2014	Total evaluations for TTTS	626
2006-2014	Fetal surgical interventions to treat TTTS (SFLP – selective fetoscopic laser photocoagulation)	412
2001-2014	Procedures for TTTS with triplet gestation	18

Survival of at least one twin after SFLP	88%
Survival of both twins after SFLP	63%

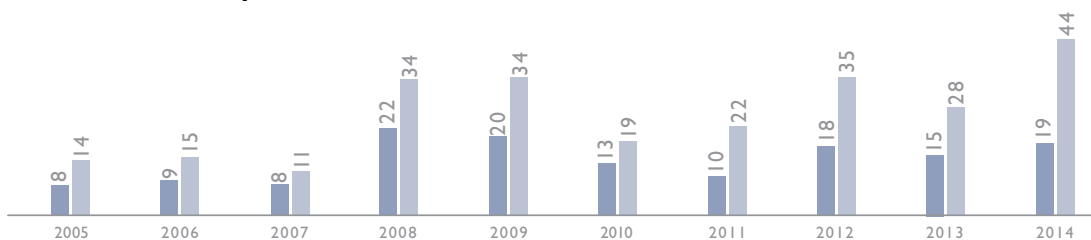
# Fetal Cardiology Program

Prenatal diagnosis can improve outcomes for babies with cardiac conditions. Patients who seek treatment at Texas Children's Fetal Center are cared for by a multidisciplinary team of experts, in collaboration with Texas Children's Heart Center, one of the top two pediatric heart centers in the country. This collaboration between the Fetal and Heart Centers, the Fetal Cardiology Program, has provided new hope for children with congenital heart issues. To learn more about Heart Center outcomes, please visit [texaschildrens.org/heartoutcomes](http://texaschildrens.org/heartoutcomes).

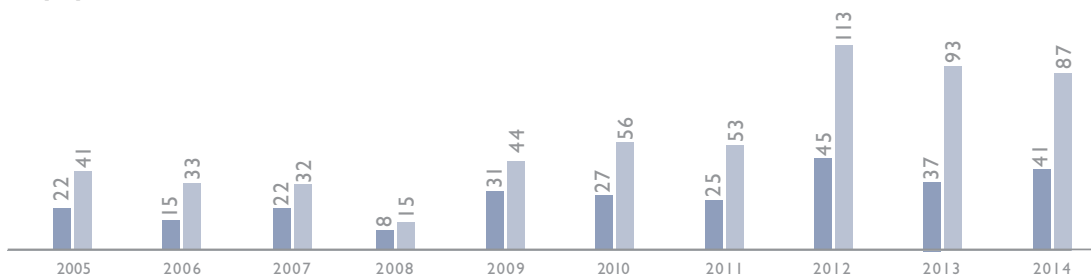
## Fetal echocardiograms by year



## Atrioventricular septal defect/atrioventricular canal defect

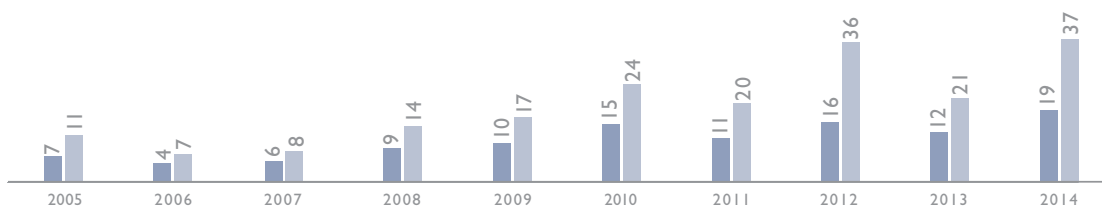


## Hypoplastic left heart syndrome and associated conditions

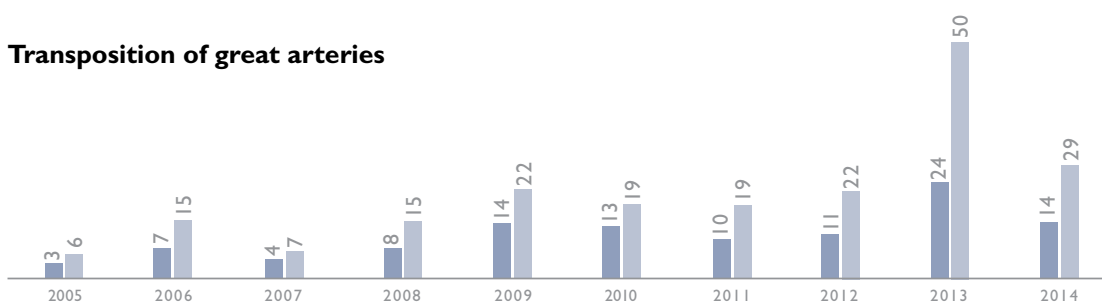


■ Total number of patients ■ Total number of visits

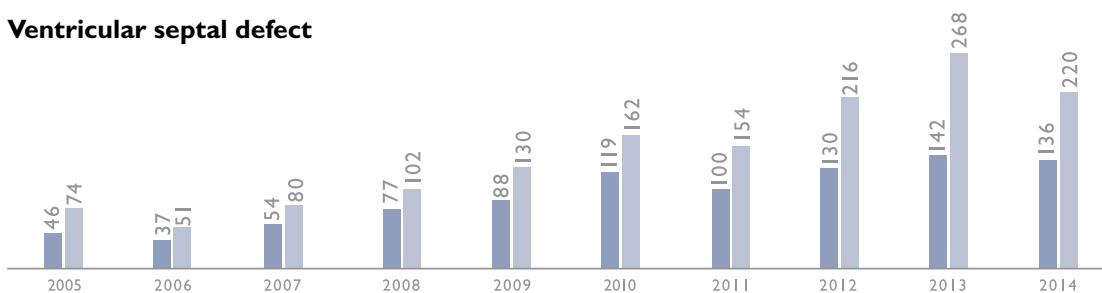
## Tetralogy of Fallot and Tetralogy of Fallot with pulmonary atresia



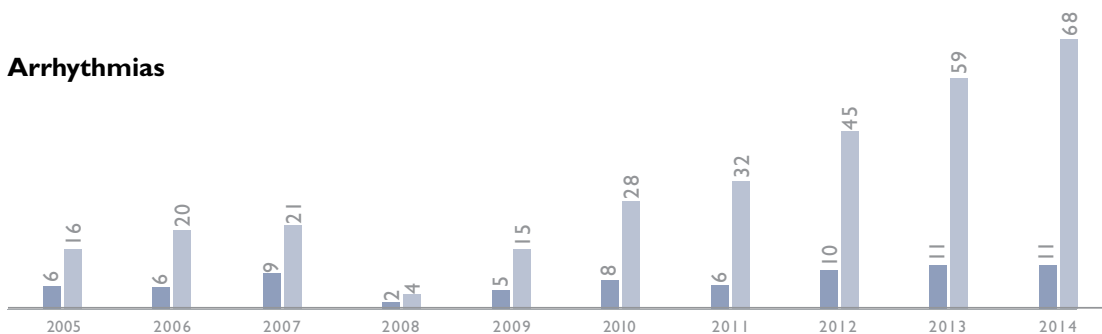
## Transposition of great arteries



## Ventricular septal defect



## Arrhythmias



Total number of patients



Total number of visits

# Fetal Cardiology Program

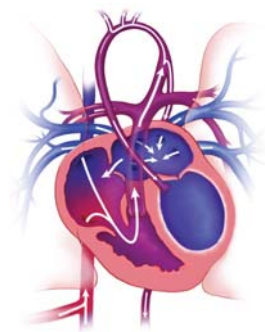
## Fetal cardiac interventions for HLHS and associated conditions

Hypoplastic left heart syndrome (HLHS) is a complex congenital heart defect that occurs when the left side of the heart does not form properly. The mitral valve, the left ventricle and the aortic valve are too small, and there is not enough blood pumping through the left side of the heart to support the rest of the body. Related conditions include evolving HLHS, where the valve is beginning to narrow and there is concern that the baby will have HLHS by the time of birth, and borderline left heart, where multiple left-sided structures are smaller than they should be.

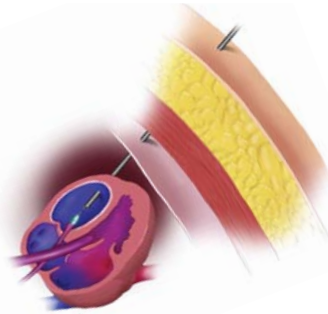
Texas Children's Hospital has successfully completed in-utero fetal cardiac interventions for all three conditions. A coordinated effort among a large, multidisciplinary team of fetal cardiologists, obstetricians and gynecologists, interventional cardiologists, congenital heart surgeons, fetal imaging experts, maternal and fetal anesthesiologists and other clinical specialists, Texas Children's Hospital is the first in the southwestern U.S. to create a program to treat these defects in utero.

## Catheter-based fetal aortic valvuloplasty for fetal aortic stenosis (evolving HLHS)

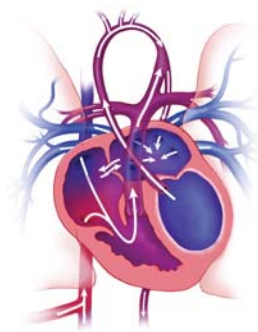
We perform this catheter-based procedure for babies with severe aortic stenosis in utero (evolving HLHS). A tiny balloon is inflated inside the aortic valve to open up the leaflets, and removed. This allows blood to flow more easily through the left side of the baby's heart and potentially improve growth of left-sided structures.



**Fetal AS  
baseline**



**Fetal valvuloplasty for  
AS intervention**



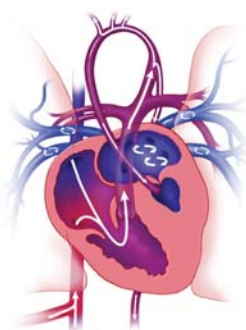
**Fetal AS  
post-intervention**

*Illustrations by Beth Sumner*

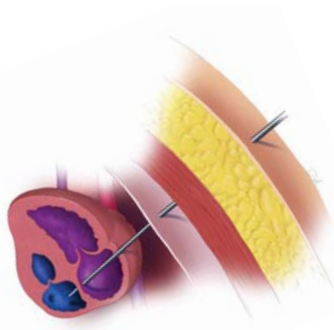
### **Catheter-based atrial septal interventions for HLHS with intact or restrictive atrial septum (RAS)**

Babies who already have HLHS in utero with no potential for growth of the left-sided structure depend on a hole in the atrial septum to keep blood circulating throughout their body. In some babies, this hole either does not exist or it is too small, and they have a high risk of complications and death.

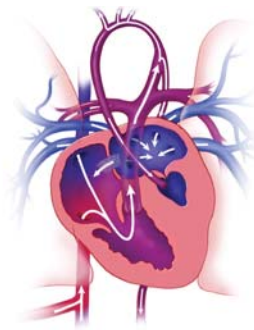
In a catheter-based procedure, we use a balloon or stent to create an atrial septal defect (a hole between the top chambers of the heart) to keep blood flowing through the baby's heart.



**HLHS with RAS  
baseline**



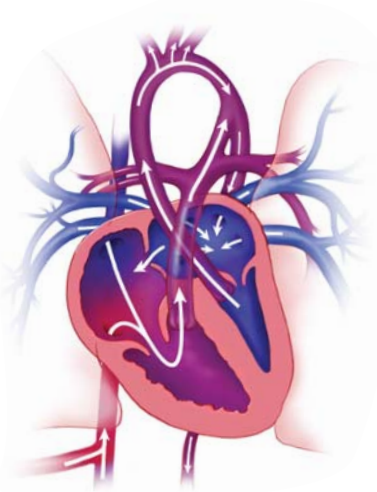
**HLHS with RAS  
intervention**



**HLHS with RAS  
after stent placement**

### **Chronic hyperoxygenation for borderline left heart**

For babies with borderline left heart, Texas Children's Fetal Center is the first in the country to offer a brand new research protocol in which mothers receive daily oxygen therapy throughout their third trimester. By delivering extra oxygen to the mother through face mask or cannula, we hope to increase the amount of oxygen in her blood, the amount of oxygen going to the placenta and fetus, and ultimately the amount of oxygen flowing into the baby's lungs and into the left side of the baby's heart. By improving flow to the left side of the heart, growth should improve as well. Nine mothers have participated in the trial so far.



**Borderline  
left heart**

# Congenital Diaphragmatic Hernia

## Glenn Family finds hope far from home



John Glenn

During a sonogram at 15 weeks, Jeanie and Shaun Glenn of Seward, Alaska, found out their baby's heart was off center. Additional tests eventually revealed congenital diaphragmatic hernia (CDH) with the liver, spleen, stomach and a portion of intestines all squeezed above the diaphragm into the chest cavity.

"Our doctor told us, if you want this baby to live, you need to seek care at an expert center," recalled Jeanie.

The Glenns searched to try to find the best center to treat their unborn baby with CDH.

"Our thinking was that if we had to leave home anyway, we might as well pick a hospital which is known to have the best outcomes and extensive experience in treating CDH," Jeanie said.

They chose Texas Children's Fetal Center, and Jeanie's doctor began coordinating care with Dr. Oluyinka Olutoye and Dr. Darrell Cass, co-directors of the Fetal Center.

Jeanie underwent extensive prenatal evaluation which included ultrasound and echocardiography studies which revealed severe left-sided CDH. Mother and fetus were followed closely until 37 ½ weeks, at which time labor was induced due to concerns about fetal distress and poor growth.

Shaun, still working in Alaska, made it to Houston with just three hours to spare before baby John was delivered by emergency cesarean section due to a decrease in his heart rate. Weighing just 4 pounds, 9 ounces, John immediately went on a ventilator to support his severely underdeveloped lungs. John was treated with what is known as a "gentle ventilation" approach and a number of medicines to optimize the heart and lung function. His condition stabilized and then slowly started to improve. Remarkably, extra corporeal membrane oxygenation, a treatment for the most serious cases of heart/lung failure, was avoided.

At just five days old, Dr. Cass performed surgery on John in the NICU, a strategy pioneered at Texas Children's Hospital. The liver, spleen, stomach and intestines were carefully removed from the chest and placed into their normal spots. John was born with almost no diaphragm muscle on the left side, and thus the repair required the use of a large patch to close the hole.

John slowly recovered. After 100 days in Texas Children's NICU, the Glenns flew back to Seward with John on oxygen. He has had a couple of scares since moving back to Alaska, but overall John is progressing remarkably well given the severity of his initial diagnosis.

"We are incredibly lucky," said Jeanie. "We picked Texas Children's because they said that they would give our baby every chance, and that's exactly what they did. All along the way, they never gave up. I don't think John would be alive if we had not found the excellent care that we received at the Texas Children's Fetal Center and Texas Children's Hospital."

## Fetal endoscopic tracheal occlusion

In addition to the excellent care John received, Texas Children's Hospital is also able to provide treatment for the most severe cases of CDH under a research protocol approved by the Food and Drug Administration.

Fetal endoscopic tracheal occlusion places a tiny balloon in the trachea of the fetus in mid gestation to improve lung growth. The balloon is then removed later in the pregnancy to allow the baby be delivered normally.



Illustration by Beth Sumner

The physicians and team at Texas Children's Hospital have the most experience with this treatment modality in the United States and are currently evaluating and treating patients in this study.

## **Canezaro Family first to undergo successful two-port fetoscopic spina bifida repair in U.S.**



*Grayson Canezaro*

When Althea Canezaro found out she was pregnant, she was thrilled to give her son, Blaine, a sibling. But, her 22-week ultrasound revealed something she didn't expect – spina bifida.

In 2014, Althea and her son, Grayson, became the first in the United States to successfully undergo a minimally invasive two-port, fetoscopic procedure to repair spina bifida in utero.

After being diagnosed, Althea's physicians in Baton Rouge immediately referred her to Texas Children's Fetal Center, where she met with OB/GYN-in-Chief Dr. Michael Belfort, pediatric neurosurgeon Dr. William Whitehead and their team, who explained the delicate surgery and how it could change the course of their son's life.

"Each doctor took their time answering all of my questions, which put my nerves at ease," Althea said. "Even though this was the first experimental procedure, I had no fear in me."

Texas Children's team of fetal surgeons proposed a new, experimental approach that builds upon the success of the open fetal surgery technique to treat spina bifida, but with a focus on reducing risks to the mother. While open fetal surgery improves motor function in spina bifida patients treated in utero – as proven in a landmark trial known as the Management of Myelomeningocele Study – the procedure requires a six-centimeter opening in the uterus, which increases the risk of uterine rupture and other pregnancy complications.

To counter these risks, Drs. Belfort and Whitehead collaborated with physicians from Vall d'Hebron University Hospital in Barcelona to develop a fetoscopic method using two 4 mm uterine incisions.

"By navigating two small ports with the aid of a fetoscope, our goal is to minimize complications to the mother's uterus," Dr. Whitehead said. "The potential risks that occur after open fetal surgery – like preterm delivery, the need for cesarean section for every delivery, and placenta accreta – make the fetoscopic approach more attractive."

Years of preparation and training went into developing this surgical innovation. It began with Dr. Belfort and Dr. Whitehead practicing the technique in an animal model before creating their own unique inanimate experimental prototype. They performed more than 30 simulated procedures.

After receiving Institutional Review Board approval for this experimental procedure, Texas Children's multidisciplinary team of fetal experts performed the in-utero spina bifida fetoscopic closure for the first time on July 29, 2014. At 25 weeks gestation, they successfully closed the opening in Grayson's spine.

Seven weeks later, Grayson was born. Today he is doing remarkably well. "He never developed hydrocephalus and has full movement of his legs," Althea said. "We are grateful to Dr. Belfort, Dr. Whitehead and their team for helping our son achieve this, which would not have been possible without the exceptional care we received at Texas Children's Hospital."

While the fetoscopic procedure is in the early stages of experimentation and refinement, Belfort said, "I'm excited to see what the future holds when it comes to repairing anomalies fetoscopically. With advanced technology and imaging capabilities, our hope is that this innovation will lead us to a new era of fetal medicine and surgery."

## Fetoscopic repair of MMC

Spina bifida is a type of neural tube defect with a wide range of severity. For the most serious cases of myelomeningocele (MMC), where the baby's spinal column is exposed and leaking cerebral spinal fluid, Texas Children's Fetal Center offers a research protocol for fetoscopic MMC repair. The mother receives general anesthesia, a small incision is made using a two-port or three-port fetoscopic procedure, the MMC is repaired by a neurosurgeon, and then the incision is closed.

After a five day recovery at the hospital, the pregnancy is closely monitored with once or twice weekly ultrasounds until birth. While there are risks associated with this invasive procedure, trials have shown potential benefits that are being evaluated, including a smaller uterine scar, the ability to deliver vaginally, and less risk of long-term placenta-related complications while maintaining the same benefit for the fetus.



# Twin-Twin Transfusion Syndrome

## Burroughs Family evens the odds with TTTS treatment



Avery and Brynn Burroughs

When Julie Burroughs went in for an ultrasound of her twins at 16 weeks, she was shocked to learn that they were not growing properly due to twin-twin transfusion syndrome (TTTS).

TTTS occurs in approximately 10 to 15 percent of pregnancies in which identical twins share one placenta.

Abnormal blood vessel connections cause the fetuses to share a blood supply, and the smaller (donor) twin pumps blood to the larger (recipient) twin.

It's a condition that causes a host of problems for both babies, and without treatment, many may die.

Julie's obstetrician in Des Moines, Dr. Karen Drake, contacted Dr. Michael Belfort, OB/GYN-in-chief of Texas Children's Hospital, and sent Julie's ultrasound results to Dr. Belfort who confirmed TTTS.

Julie and her husband Tony flew to Houston the next day and underwent a comprehensive evaluation by the Fetal Center team. Dr. Belfort and the team explained the procedure they would need to perform.

Fetoscopic laser photocoagulation uses a small camera and lasers to locate and seal the abnormal blood vessels on the surface of the placenta. It stops the transfer of blood between twins and gives the babies time to develop normally in the womb before birth.

The Texas Children's Fetal Center team monitored Julie closely for two and a half weeks before the time was right to perform the surgery. In Julie's case, because of the position of her placenta, a laparoscope-assisted procedure was required. This is more complex than the routine fetoscopic laser surgery. The procedure was a success, and the Burroughs were back in Iowa a few days later.

Dr. Drake and Dr. Belfort continued to coordinate care and monitor Julie closely. At 23 weeks, she was put on hospital bed rest. Six weeks later, at 29 weeks, daughters Avery and Brynn were born.

Weighing 3 pounds 5 ounces and 3 pounds 4 ounces, the girls were larger and healthier than expected and spent just six weeks in the NICU before going home.

“Looking back at our journey, it seemed like such a very dark time, but now we see it as an inspiring, strengthening time in our lives,” said Julie.

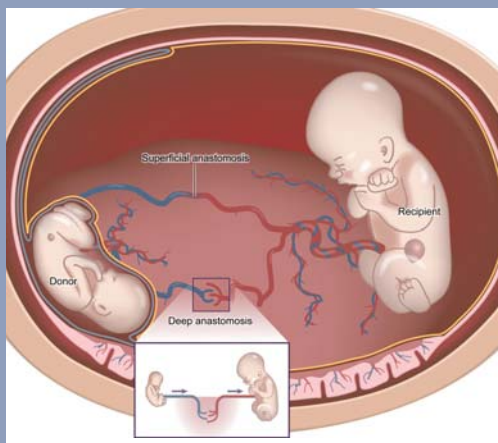
“Because of what we experienced, we have so much gratitude for our healthy and happy little girls – as well as for the doctors and nurses at Texas Children’s Fetal Center who cared for us and our babies.”

## Fetoscopic laser photocoagulation for TTTS

At Texas Children’s Fetal Center, our experts have refined the use of a delicate in-utero laser ablation to stop the uneven blood exchange when it occurs between monochorionic diamniotic twins. Fetoscopic laser photocoagulation is a minimally invasive surgical procedure that should be performed between 16-26 weeks gestation.

Using ultrasound to continuously monitor the procedure and a small camera (fetoscope) to locate abnormal blood vessel connections in the placenta, a laser seals the abnormal blood vessels and disconnects them permanently. After sealing the blood vessels between the twins, our surgeons laser a line between the connections in order to coagulate even smaller vessels from one side to the other.

A Texas Children’s Fetal Center study published in the journal *Ultrasound in Obstetrics & Gynecology* showed that this procedure is responsible for a better survival rate of both twins. It is the preferred method of treatment for certain severe cases of TTTS, stopping the transfer of blood between fetuses, and often halting the progression of TTTS.



## Meet Our Leaders



**Michael A. Belfort, M.B.B.C.H., M.D., Ph.D.**, is obstetrician and gynecologist-in-chief of Texas Children's Pavilion for Women and the Ernst W. Bertner chairman and professor in the Department of Obstetrics and Gynecology at Baylor College of Medicine. A nationally and internationally renowned specialist in maternal fetal medicine and fetal intervention, Dr. Belfort is board certified in Obstetrics and Gynecology and in Maternal Fetal Medicine by the American Board of Obstetrics and Gynecology. He is also co-director of the Perinatal Surgery Fellowship at Baylor College of Medicine.

A native of South Africa, Dr. Belfort received his medical degree (M.B.B.C.H.) from the University of the Witwatersrand in Johannesburg, South Africa. He received a Doctorate in Medicine (M.D.) from the University of Cape Town, South Africa, and a Ph.D. from the Karolinska Institute in Stockholm, Sweden. Dr. Belfort is the author/editor of several textbooks notably, *Hypertension in Pregnancy*, *Obstetric Clinical Algorithms: Management and Evidence*, *Preeclampsia: Etiology & Clinical Practice* and *Critical Care Obstetrics* and has more than 219 peer reviewed papers.





**Darrell Cass, M.D.**, is co-director of Texas Children's Fetal Center and associate professor of Surgery, Pediatrics and OB/GYN at Baylor College of Medicine. He is co-founder of the fetal surgery team and a general pediatric and thoracic surgeon. After receiving his M.D. in 1991 from the University of California Los Angeles School of Medicine (with AOA honors), Dr. Cass pursued residency in general surgery at the University of California San Francisco. Dr. Cass studied as a postdoctoral research fellow at the Fetal Treatment Center at the University of California San Francisco and at the Center for Fetal Diagnosis and Treatment at The Children's

Hospital of Philadelphia. He completed training in pediatric surgery at Texas Children's Hospital and Baylor College of Medicine in 2001.

Dr. Cass has expertise and clinical interest in fetal and neonatal surgery for a range of problems, including fetal lung malformations, congenital diaphragmatic hernia, omphalocele and esophageal atresia. He is also experienced in laparoscopic and minimally invasive surgery, chest and lung surgery, the Nuss repair of chest wall deformities and endocrine surgery. His basic research interests center on the mechanisms of fetal tissue healing. His research goal is to understand the mechanisms involved in these unique reparative processes in order to develop new strategies to surgically treat problems that affect the developing fetus. Dr. Cass's clinical research focuses on treatment advances of fetal and neonatal surgical conditions.



**Wesley Lee, M.D.**, is co-director of Texas Children's Fetal Center and professor of Obstetrics and Gynecology at Baylor College of Medicine. He also serves as division director for Women's and Fetal Imaging at Texas Children's Pavilion for Women. His medical degree was from Oregon Health Sciences University in Portland, and his OB/GYN residency was completed at Parkland Memorial Hospital in Dallas. Additional training included a maternal-fetal medicine fellowship at Baylor College of Medicine.

Dr. Lee has authored more than 149 peer-reviewed articles and 20 book chapters pertaining to perinatal medicine, prenatal detection of congenital anomalies, fetal growth, 3D/4D fetal ultrasonography, and fetal magnetic resonance imaging. He is an associate investigator with the Perinatology Research Branch of the Eunice Kennedy Shriver National Institute of Child Health and Human Development and served as a scientific advisor to the World Health Organization for fetal growth studies. He has chaired task force committees regarding the development of practice guidelines for prenatal ultrasonography; chaired the Clinical Standards Committee at the International Society of Ultrasound in Obstetrics and Gynecology; served as deputy editor of the *Journal of Ultrasound Medicine*; and co-edited the textbook *Sonography in Obstetrics and Gynecology, Principles and Practice*, McGraw-Hill, 2011. In 2015, Dr. Lee received the William J. Fry Memorial Lecture Award for his significant contributions in fetal imaging.

# Meet Our Leaders



**Oluyinka Olutoye, M.D., Ph.D.**, is co-director of Texas Children's Fetal Center and professor of Surgery, Pediatrics and OB/GYN at Baylor College of Medicine. He is co-founder of the fetal surgery team and a general pediatric and thoracic surgeon. Dr. Olutoye received his M.D. from Obafemi Awolowo University in Ile-Ife, Nigeria, and his Ph.D. in anatomy from Virginia Commonwealth University. He completed his residency in general surgery at the Medical College of Virginia Hospitals, Virginia Commonwealth University, and his fellowship in pediatric surgery at The Children's Hospital of Philadelphia and the University of Pennsylvania School

of Medicine. Dr. Olutoye is the 2016 co-president of the International Fetal Medicine and Surgery Society, a Fellow of the Surgical Section of the American Academy of Pediatrics, the American College of Surgeons, and the West African College of Surgeons and the American Surgical Association. He is certified by the American Board of Surgery both in general surgery and pediatric surgery.

Dr. Olutoye has specialized clinical expertise in fetal and neonatal surgery, with specific interest in congenital diaphragmatic hernia, necrotizing enterocolitis and complex wounds. Dr. Olutoye's research interests include understanding the role of the fetal inflammatory response in scarless fetal wound healing, development of animal models of congenital anomalies, in-utero correction of severe congenital malformations, deformation of early indications of necrotizing enterocolitis and effects of anesthesia on fetal brain development.



**Rodrigo Ruano, M.D., Ph.D.**, is co-director of Texas Children's Fetal Center and professor of Obstetrics and Gynecology at Baylor College of Medicine. He is also an adjunct professor in the Department of Bioengineering at Rice University. Dr. Ruano received his medical degree from the Medical School of University of São Paulo in Brazil in 1997. He completed his residency at Hospital das Clinicas Medical School of University of São Paulo in 2001. Additional training included a maternal-fetal medicine fellowship at Hôpital Necker-Enfants Malades at the University of Paris in 2003 and fetal surgery fellowship at Centre Hospitalier Intercommunal

Saint-Germain-en-Laye in Versailles in 2004. He concluded his Ph.D. thesis "Evaluation of lung volumes by 3D-ultrasonography in fetuses with diaphragmatic hernia congenital isolation" at Medical School of University of São Paulo in 2005.

Dr. Ruano has authored more than 160 peer-reviewed articles (PUBMED) and 50 book chapters pertaining to maternal-fetal medicine, prenatal detection of congenital anomalies, 3D/4D fetal ultrasonography, and fetal surgery. Dr. Ruano focuses his clinical efforts on developing and investigating new minimally invasive fetal therapies such as fetal endoscopic tracheal occlusion for congenital diaphragmatic hernia, fetal cystoscopy for fetal bladder obstruction and fetoscopic laser ablation for twin-twin transfusion syndrome.

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## CHAOS

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## **EXIT Procedures**

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## Fetal Cardiology

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