



Texas Center for Pediatric and Congenital Heart Disease

2023 Outcomes Report





The Texas Center for Pediatric and Congenital Heart Disease is ranked among the nation's best Pediatric Cardiology & Heart Surgery specialty programs by U.S. News & World Report in 2023-2024.

Texas Center for Pediatric and Congenital Heart Disease Leadership

Congenital Heart Surgery



Charles D. Fraser Jr., MD, FACS, FACC

Professor, Departments of Surgery and Perioperative Care, and Pediatrics
Chief, Pediatric and Congenital Cardiothoracic Surgery
John L. Hern Distinguished Chair, Pediatric Cardiothoracic Surgery
Executive Director, Institute for Cardiovascular Health



Carlos M. Mery, MD, MPH

Professor, Departments of Surgery and Perioperative Care, and Pediatrics
Associate Chief, Pediatric and Congenital Cardiothoracic Surgery
Director, Health Transformation and Design in Congenital Cardiac Care

Pediatric and Congenital Cardiology



D. Byron Holt, MD, FSCAI

Associate Professor, Department of Pediatrics
Chief, Pediatric Cardiology
Director, Cardiac Catheterization Lab



Michael Taylor, MD, PhD

Professor, Department of Pediatrics
Associate Chief, Pediatric Cardiology
Director of Cardiac Non-invasive Imaging

Pediatric Cardiac Critical Care



Daniel Stromberg, MD

Professor, Departments of Surgery and Perioperative Care, and Pediatrics
Director, Cardiac Critical Care



Jeremy Affolter, MD

Associate Professor, Department of Pediatrics
Medical Director, Patient Safety and Quality, TCPCHD
Associate Director, Cardiac Critical Care
Associate Director, Health Transformation and Design

Pediatric Cardiac Anesthesiology



Erin Gottlieb, MD, MHCM

Associate Professor, Department of Surgery and Perioperative Care
Chief, Pediatric Cardiac Anesthesiology

Service Line Leaders



Kimberly Krauklis, MSN, APRN, NP-C, PNP-AC

Director, Advanced Practice Providers



Joel Wise, MBA

Director, Cardiac Service Line

Fast facts

Volumes and outcomes



10,575+

Annual cardiac clinic appointments

180

SDU deliveries

1.29%

Perioperative mortality
in the past 12 months

30

Heart transplants since 2020

88

Publications/presentations
in 2023

1,945

Cardiac operations since August 2018

394

Cardiac operations in 2023

470

Cardiac catheterizations in 2023

Areas of care

- Acute care cardiology
- Adult congenital heart disease
- Advanced cardiac imaging
- Cardiomyopathy
- Chest and neck tumor treatment
- Coronary anomalies
- Electrophysiology
- Enhanced recovery after surgery (ERAS)
- Fetal cardiology
- Fontan optimization
- Heart failure, VAD and transplant
- Health Transformation and Design
- Interventional cardiology
- Neurodevelopmental outcomes
- Neuromuscular disorders
- PDA program for premature infants
- Percutaneous (nonsurgical) valve replacement
- Preventive cardiology
- Pulmonary artery rehabilitation
- Psychosocial team
- Single Ventricle (IMPACT)
- Transition
- Outreach programs in Cedar Park, Georgetown, Kyle, Waco, and College Station

Leading the way

“We have some of the best results in the nation after congenital heart surgery, according to the Society of Thoracic Surgeons. We are constantly working to improve outcomes for patients with congenital heart disease and their families, not only in the short term but throughout their lifelong journey.” -Carlos M. Mery, MD, MPH

- **Novel collaboration** between Dell Children’s Medical Center and UT Health Austin, the clinical practice of Dell Medical School at The University of Texas at Austin to provide the best care for children and adults with CHD
- Integrated multidisciplinary heart center **focused on redesigning the long-term journey** of individuals with congenital heart disease and the people who care about them
- **Health Transformation and Design Program** identifies, measures, and works to improve outcomes through research, innovation, data integration, and health transformation initiatives
- **Psychosocial team integrated into the fabric of the program** to support patients and families
- **Unique partnerships** with the Value Institute for Health and Care, the Oden Institute for Computational Engineering and Sciences, the Cockrell School of Engineering, the College of Fine Arts and McCombs School of Business at The University of Texas at Austin, focused on improving value, increasing access, and mitigating social determinants of health
- Participation in **eight national and international quality registries**
- **World-renowned faculty**, leading efforts to pioneer research and integrate medicine, engineering and physics into the diagnosis and treatment of patients with complex cardiac conditions
- **Integrated care delivery with collaborative teams** including maternal-fetal medicine, fetal cardiology, and neonatology to ensure smooth transition for high-risk deliveries
- **State-of-the-art** and family-centered patient care areas including a 48-bed dedicated cardiac care unit, 11-bed special delivery unit (SDU) and 32-bed neonatal intensive care unit (NICU)
- **Close partnership with Dell Children’s Comprehensive Care Clinic** to provide multidisciplinary care to the most vulnerable patients



Our hospital-based multidisciplinary clinics

This clinic brings cardiologists, cardiac surgeons, cardiac anesthesiologists, cardiac intensivists, pharmacists, dietitians, therapists (physical, occupational and speech), social workers, psychologists, and other subspecialists together to collaborate and coordinate complex patient care in a single visit in a single location decreasing the need for multiple visits and streamlining their care.

- Adult Congenital Heart Disease and Transition program
- Cardiac genetics, including aortopathy
- Cardiac feeding and tube weaning
- Cardiomyopathy, heart failure, VAD and transplant
- Coronary anomalies
- Fontan optimization
- Preventive cardiology
- Single ventricle interstage (IMPACT)



Congenital heart surgery

5 dedicated surgeons | 7 advanced practice providers

Our dedicated team of surgeons, anesthesiologists, perfusionists, advanced practice providers, faculty instructors, Registered Nurse First Assistants (RNFAs), scrub techs and nurses work together every day providing surgical expertise and hope to some of the most complex patients in the country.

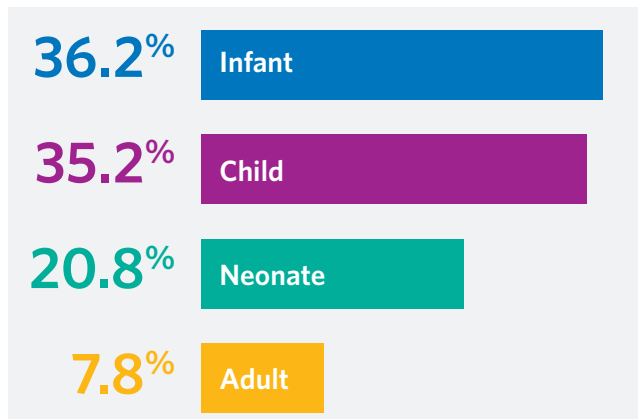
- In 2023, 20 neonates less than 3 kilograms underwent cardiac surgery
- **11 VADs placed** since October 2020, including 4 VADs in Fontan patients and 4 infant Berlins
- **7th reported partial heart transplant** in the United States
- Our **1st Organ Care System (OCS™) Transplant** in July 2023

Our risk-adjusted perioperative mortality rate is **38% better** than the national benchmark.*

*Risk-adjusted perioperative outcomes for the last 4 years as reported by the Society of Thoracic Surgeons



Surgery patients by age



Outcomes by age (Index cases)

Age	Volume	Perioperative mortality		STS benchmark mortality percent
		N	percent	
Neonate	61	4	6.6	7.3
Infant	105	0	0.0	2.5
Child	103	2	0.0	1.6
Adult	23	0	0.0	1.6
Grand total	293	6	2.0	2.7

2023 only

Pediatric and congenital cardiology

27 cardiologists | 13 advanced practice providers | 3 Acute Care Cardiology APPs

Our team of experienced congenital cardiologists and advanced practice providers deliver an unparalleled level of expertise from fetal life through adulthood in central Texas. Our team is comprised of cardiac specialists in genetics, heart failure, fetal cardiology, cardiac cath, electrophysiology, invasive and non-invasive imaging and adult congenital heart disease working together to push the field of study forward in search of a better quality of life for our patients.

- **1,498 adult congenital clinic visits** in 2023
- **13,084 ECHOs** read in 2023 (includes inpatient and outpatient and other facilities)
- **603 acute care** inpatient visits in 2023
- **23 Piccolo devices** for closure of patent ductus arteriosus in 2023
- **5 transcatheter pulmonary valves** in 2023

30
Heart transplants since heart transplant program inception, October 2020

Pediatric cardiac critical care

11 critical care intensivists | 22 advanced practice providers

Our dedicated team of physicians, advanced practice providers, nurses, therapists (respiratory, physical, occupational, speech), pharmacists, social workers, child life specialists and psychologists diligently work to optimize patient recovery while maximizing the patient and family experience in our newly renovated and expanded 48-bed unit. From the tiniest premature infant to the adult, our team is pushing the envelope to provide better care through predictive analytics, AI and quality improvement.

Compared to the PC4 aggregate:

- **46% lower** surgical in-hospital mortality
- **72% lower** post-op ECMO rate
- **56% lower** postoperative cardiac arrest rate
- **64% lower** postoperative stroke and intracranial hemorrhage rate
- **23% lower** postoperative complication rate
- **24% lower** CLABSI rate
- **49% less** surgical site infection per 100 surgical procedures

Shorter length of stay compared to STS benchmark:

- **> 50% shorter** for coarctation of the aorta and Glenn
- **>40% shorter** for off bypass coarctation (47.7%), complete atrioventricular septal defect (42.5%), tetralogy of Fallot (44.9%) and arterial switch operation with ventricular septal defect closure (45.5%)
- **> 20% shorter** for arterial switch operation and Fontan



Pediatric cardiac anesthesiology

6 pediatric cardiac anesthesiologists

Our team of physicians, CRNAs, and anesthesia technicians, work together to ensure that our patients receive the appropriate level of care and supervision in the safest manner possible. By imbedding our Anesthesiology team into daily rounds, we are able to deliver the highest level of individualized, and comprehensive care possible while simultaneously minimizing potential risk experienced during transitions of care. Our meticulous attention to detail allows us to provide safe and effective care to even the tiniest and most complex patients as well as adults with congenital heart disease.

- **44% of our children and adults** underwent cardiac surgery **without blood products**
- **1,281 anesthesia cardiac cases** in 2023 (Includes CVOR, IR, MRI, CT, Cath, EP, ICU cases)
- **96% of patients** had no anesthesia-related adverse events compared to the STS benchmark
- **100% of Fontan patients** extubated in the operating room as defined by the STS

Health Transformation and Design (HTD)

The goal of this program is to improve and redesign the care of patients with congenital heart disease and their families in a comprehensive and patient-centered way — anchored in the principles of value-based healthcare and human-centered design. The program tracks short- and long-term outcomes for patients and families, engages in heart center- and hospital-wide quality improvement initiatives, participates in local and national research projects, and creates initiatives to improve the care of individuals with congenital heart disease. The HTD Program includes a collaboration of research faculty, outcomes specialists, quality specialists, research coordinators, post-doctoral fellows, data architects, and graduate and undergraduate students.





Impact



64
Abstracts
accepted

8
Invited
presentations

8
Registries
supported

16
Manuscripts accepted
for publication

Three valves, one program

Three devices, one team. Our interventional cardiology program is the only program in Central Texas to offer 3 different types of valves for transcatheter pulmonary valve replacement, increasing the likelihood that we have the right valve for each individual patient.

As part of our Valve Program, we have a multidisciplinary team for patient evaluation and treatment, ensuring a thoughtful recommendation based on the best medical evidence.

Our team in the cardiac catheterization lab has years of experience using stent-mounted valves, which are deployed through a catheter inserted into a vein in the leg. Dr. Byron Holt, Medical Director of the Cardiac Catheterization Lab and Chief of Pediatric Cardiology for the Texas Center for Pediatric and Congenital



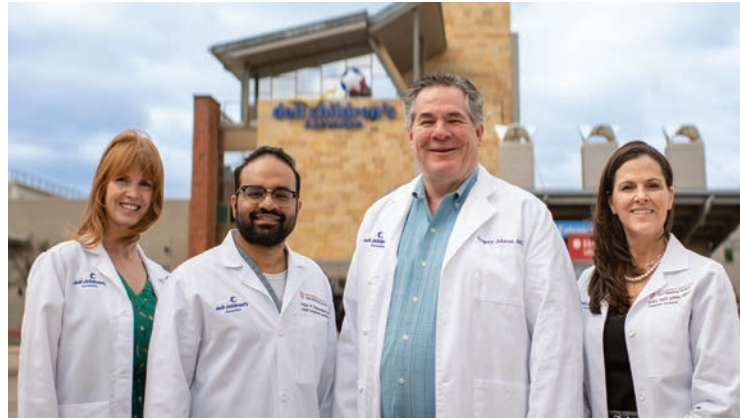
Heart Disease (TCPCHD), says “Our field has made many advances in recent years with structural heart interventions via minimally invasive procedures in the cath lab. This allows the patient to return home the following day and return to regular activity within several days. It is truly remarkable to watch this medical advancement accelerate, and nonsurgical valve replacement is just one example.” Our team is dedicated to making sure that all patients who can benefit from a transcatheter pulmonary valve have the opportunity to receive one.



ACHD program Accreditation

Today there are over 1.4 million adults living in the US with congenital heart disease, yet finding dedicated, comprehensive, multidisciplinary care remains a challenge. The Adult Congenital Heart Association (ACHA) has created a rigorous accreditation process to determine which adult congenital heart disease (ACHD) programs are functioning as multidisciplinary, comprehensive care sites. Accreditation means that the center has been able to demonstrate that they are readily able to care for even the most complex issues facing ACHD patients, 100% of the time.

In 2023, the TCPCHD underwent accreditation and



became the first ACHD center in Central Texas to successfully gain designation as a Comprehensive Care Center with the ACHA. There are only

approximately 50 centers with this honor throughout the country. Led by Dr. Greg Johnson and Dr. Arjun Mahendran, our team currently consists of two full-time dedicated attending physicians and two full-time dedicated nurse practitioners.

The ACHD team continues to grow as

we keep pace with the growing ACHD population in Central Texas and surrounding areas.

Piccolo device for premature infants: 23 placed this year

The Piccolo Program was founded in 2019 after FDA approval of this device for use in premature infants as small as 700 grams. Babies born prematurely often have a blood vessel called a patent ductus arteriosus (PDA) which remains open instead of closing spontaneously shortly after birth as it does in the vast majority of infants. When this occurs, too much blood flows to the lungs and may lead to symptoms such

as fast breathing, slow weight gain, need for supplemental oxygen, or need for mechanical ventilation. This very delicate procedure involves accessing the vein in the patient's leg with a small plastic catheter, then navigating up to the heart and delivering this tiny device to occlude that blood vessel. This has now been performed over 100 times at Dell Children's Medical Center by our TCPCHD team.

Partial heart transplant and 30 full heart transplants

On June 23, 2023, the TCPCHD successfully performed the seventh recorded partial heart transplant on an 11-month-old boy with complex transposition of the great arteries with left ventricular outflow tract obstruction (LVOTO). The baby had undergone two prior operations but had persistent LVOTO despite our best efforts. In a partial heart transplant, the valves are procured from a donor heart that is otherwise unsuitable for full transplantation, but because they are implanted freshly, they are expected to grow with the patient over time, potentially increasing their life expectancy and reducing the number of operations they will face in the future. This is our hope.

“Our team is excited about this procedure, as it has the potential to change the paradigm of valve surgery in pediatric heart disease,” said congenital heart surgeon Carlos Mery, MD, MPH, Associate Chief of

Pediatric and Congenital Cardiothoracic Surgery for the Texas Center for Pediatric and Congenital Heart Disease.

“This is a milestone procedure, as a partial transplant allows surgeons to tap into a supply of donor hearts that go unused due to deficiencies,” said pediatric cardiologist Chesney Castleberry, MD, Medical Director for the Heart Failure, VAD, and Transplant Program within the Texas Center for Pediatric and Congenital Heart Disease. “We are thrilled with his progress, and we are hopeful this will eliminate the need for future surgeries.”

“Our ability to perform this surgery is a major step in Dell Children’s effort to provide innovative, life-changing care for the most complex cardiac cases in the region,” said UT Health Austin congenital heart surgeon Charles Fraser, Jr., MD, Chief of Pediatric and Congenital Heart Surgery for the Texas Center for Pediatric and Congenital Heart Disease. “This groundbreaking surgery provides hope for thousands of babies with congenital heart defects and amplifies the way we can use the gift of organ donation to save more lives.”

The Heart Failure, VAD and Transplant Program has performed 30 heart transplants, 93% of our transplants have been in patients with congenital heart disease, 4 transplants were ABO incompatible transplants, 4 VADs were placed in patients with a Fontan, 4 Berlins were placed in infants, and the program’s first OCS transplant.



Endowed Clinical Professorship in Cardiac Advanced Practice and Nursing

Nurses and advanced practice providers (APP) are critical to the mission and success of our cardiac program, so in 2023, through a generous philanthropic gift from Mary Abell and The Favrot Fund, a first of its kind clinical professorship was endowed at the Dell Foundation. The endowment, once funded, will provide funds to be used at the discretion of the named recipient to provide ongoing

clinical education and support for nurses and APPs in our heart center. While an endowed professorship in nursing or advanced practice is not unique, it is unique to have the professorship sit at the clinical site for the benefit of clinicians. This gift will benefit nurses and APPs at Dell Children's in perpetuity for the benefit of future generations of clinicians.



Enhanced Recovery After Surgery

Enhanced Recovery After Surgery (ERAS®) is an evidence-based approach to care that encompasses the entire perioperative period, meaning before, during, and after surgery. Research has shown that the time to recovery for individuals undergoing congenital heart surgery can be shortened by standardizing their care and implementing a few easy, cost-effective interventions.

We share our approach with patients and their families to help them know what to anticipate during their surgical journey, and we have created order sets to help our care team consistently use best practices. After implementation of our ERAS protocol, we have been able to achieve some of the best patient outcomes and shortest hospital lengths of stay in the country.

Before surgery, our team helps patients modify their diet in a way that will decrease the time to return of bowel function, and we target their activity in a way that

shortens recovery and reduces the need for narcotics. Shorter fasting times before surgery and the encouraged drinking of carbohydrate-rich liquids (like Gatorade or juice) can improve patient well-being during the operation. Our patients get back to eating, drinking and moving around quickly after surgery and, as a result, they need less medication for constipation and pain, and they get out of the hospital faster.

Our ERAS program has improved patient engagement, patient satisfaction and most importantly, patient outcomes.

Enhanced Recovery After Surgery (ERAS)

Enhanced recovery after surgery (ERAS) is an evidence-based approach to care before, during, and after surgery. ERAS plans have been proven to help patients recover faster and with fewer complications.

Research shows that certain measures can be taken to speed up the recovery process for individuals undergoing congenital heart surgery. This approach to patient care is known as enhanced recovery after surgery (ERAS). Below are guidelines that can help optimize the recovery process so that patients can get back to the things they enjoy most.

During the Weeks Leading Up to Surgery*

- Eat a healthy diet* that includes:
 - Protein-rich foods (e.g., lean meats, fish, beans, dairy products, protein drinks)
 - Fruit (e.g., citrus fruits, tomatoes)
 - Vegetables (e.g., leafy greens, sweet potatoes, peas, string beans)
 - Whole grains (e.g., brown rice, oatmeal, quinoa, whole wheat pasta)
- Avoid:
 - Fried, greasy foods (e.g., fried chicken, French fries, doughnuts)
 - High-calorie foods (e.g., cakes, cookies, waffles)
 - High-fat foods (e.g., pizza, ice cream, foods with cream sauce)
- Drink at least 8-9 glasses of fluids each day
- Stay active (continue any regular exercise or begin walking short distances as tolerated)

* If you are already on a specific diet for medical reasons, do not modify your diet for surgery.

During the Days Leading Up to Surgery*

- Eat light, healthy meals (e.g., fruit, juices, non-starchy vegetables)
- Avoid heavy and fatty foods (e.g., fried foods, foods with heavy cream, fatty meats)
- Drink at least 8-9 glasses of fluids each day
- Stay active (as tolerated)
- Use the antibacterial wipes and ointment as prescribed (if appropriate)
- Practice using your incentive spirometer at least 10 times a day

* If you have a bowel regimen that you use to treat constipation (e.g., fruit juices, Colace, MiralAX), begin it 3 days before surgery.

The Day of Surgery

- Adults should drink 24-36 ounces of a clear carbohydrate drink (e.g., Pedialyte, apple juice, white grape juice, Gatorade) at midnight and 2 hours before surgery.
- Children should drink a regular serving size (6-18 ounces) of a clear carbohydrate drink (e.g., Pedialyte, apple juice, white grape juice, Gatorade) at midnight and 2 hours before surgery.

dell children's
Association

The University of Texas at Austin
UT Health Austin

After Surgery

- Begin drinking sips of clear liquids as soon as you are awake enough to drink safely and advance to a regular diet as you can.
- Take 10 breaths with your incentive spirometer every hour you are awake.
- Patients with breast tissue may feel more comfortable wearing a soft, gentle binder to provide support and prevent the weight of the breast tissue from pulling on the chest. If you have a support device that closes in front, this is usually easier to put on and take off. Be sure to bring this to the hospital with you, as you will want to wear it the first day after surgery for walking.
- Your care team will help get out of bed and into a chair as soon as possible (at least sit in a chair rather than lying in bed).
- Your care team will help you walk the first day after surgery and work to increase the distance 3-4 times 10 out of 10, so you can try medicines without narcotics first.
- Control your nausea and pain (ask for medicine if needed; medicine for pain should be requested when the pain is a 5-6 out of 10 rather than a 10 out of 10).
- Stay active (as tolerated). Keep busy (e.g., listen to music, watch movies, play games, practice mindfulness (e.g., listen to music, muscle relaxation, journaling, expressing gratitude), and focus on the positive).
- After surgery, you will be given a medication to help make your bowel movements softer and easier, please let us know when you are having daily bowel movements or if you are still unable to have one after two days and we can adjust the medication.

When You Return Home

- Eat a healthy diet that includes:
 - Protein-rich foods
 - Fruit
 - Vegetables
 - Whole grains
- Stay active (gradually progressing until you are back to pre-surgical activities).
- Keep busy, practice mindfulness, and focus on the positive.
- Take 10 breaths with your incentive spirometer every hour you are awake.
- Treat your pain with your incentive spirometer every hour you are awake (Mobic), as approved by your provider (e.g., Tylenol and Ibuprofen (e.g., Advil, Motrin), as approved by your provider).
- Be sure to return for follow-up appointments with all of your providers and let them know if you are not continuing to make progress at home.

Enhanced Recovery After Surgery (ERAS) postoperative protocol

POD	0	1	2	3
CV Meds	<ul style="list-style-type: none"> No Inotropes Heparin 10 U/kg/hr (max 500units/hr start 4hrs post op if CT < 3ml/kg/hr or <60ml/hr) 	<ul style="list-style-type: none"> Heparin 10U/kg/hr (max 500units/hr) - Dc when central line removed. 	<ul style="list-style-type: none"> None 	<ul style="list-style-type: none"> None
Fluids	<ul style="list-style-type: none"> Based on ideal body weight - 50% maintenance, wean IVF when taking PO to maintain intake to 50% maintenance 	<ul style="list-style-type: none"> Based on Ideal body weight - 60% maintenance, wean with increase PO intake 	<ul style="list-style-type: none"> None 	<ul style="list-style-type: none"> None
Respiratory	<ul style="list-style-type: none"> OR extubations or goal < 6hr in ICU. CPTq 6 	<ul style="list-style-type: none"> DC O2 if sats > 92% CPT q 6 IS q 1 hr WA 	<ul style="list-style-type: none"> DC O2 if sats > 92% CPT q 6 IS q 1 hr WA 	<ul style="list-style-type: none"> DC O2 if sats > 92% CPT q 6 IS q 1 hr WA
Lines/tubes	<ul style="list-style-type: none"> Pleural chest tubes, central line, arterial line Remove foley 	<ul style="list-style-type: none"> Remove arterial and central line once hemodynamically stable CT removal per CHS algorithm 	<ul style="list-style-type: none"> CT removal per CHS algorithm 	<ul style="list-style-type: none"> CT removal per CHS algorithm
Nutrition/ GI Meds	<ul style="list-style-type: none"> NPO until 4hrs after extubation Can drink once they are awake and able to protect their airway, usually 2-4 hours after extubation Advance diet as tolerated. IV Pepcid change to PO when taking oral medications Colace PO BID Prn: Zofran 	<ul style="list-style-type: none"> Limit PO intake to keep within fluid balance goal Continue Pepcid while on schedule Toradol/Ibuprofen Colace PO BID Prn: Zofran 	<ul style="list-style-type: none"> Full PO Dc Pepcid unless home medication 	<ul style="list-style-type: none"> Full PO
Mobilization	<ul style="list-style-type: none"> Bedrest w/ HOB 30 degrees Dc bedrest if hemodynamically stable OOB to chair within 4hrs of extubation 	<ul style="list-style-type: none"> Ambulate 3-4 times/day with nursing and/or PT Walk halls twice/day. 	<ul style="list-style-type: none"> Ambulate 4 times a day Walk halls twice a day Should be in a chair more than in the bed each day 	<ul style="list-style-type: none"> Full mobilization as at home (min 4/day)
Pain Meds	<ul style="list-style-type: none"> If intubate - Precedex gtt 0.1-1mcg/kg/hr- Dc when extubated Tylenol IV 15mg/kg IV q 6 x 4 doses (Max 1Gm/dose) Toradol (unless contraindicated) 0.5mg/kg IV q 6 x 4 doses (Max dose 15gm) - not to be used if Cr above 50% of baseline, chest tube output sanguineous, > 3ml/kg/hr or > 60ml/hr Gabapentin (Optional)- 5mg/kg (Max 300mg) PO q 8 Prn: morphine 0.05mg/kg/dose (max 2mg) for moderate to severe pain; oxycodone initial 0.05-0.1mg/kg (max 5mg) when taking PO 	<ul style="list-style-type: none"> Tylenol PO While CT in place Dc Toradol and start Ibuprofen (unless contraindicated) 10mg/kg (max 600mg) q 6 alternating with Tylenol. Gabapentin (Optional) 	<ul style="list-style-type: none"> Tylenol PO While CT in place. Change Ibuprofen to PRN Dc Gabapentin if started Prn morphine for moderate to severe breakthrough pain. 	<ul style="list-style-type: none"> Tylenol PO while CT in place. Prn: Ibuprofen
Adjunct Therapies	<ul style="list-style-type: none"> Music or any distractors identified during preop visit to avoid Narcotics. Involve Child Life for any procedures. Age appropriate games/movies 	<ul style="list-style-type: none"> Music or any distractors identified during preop visit to avoid Narcotics. Involve Child Life for any procedures. Age appropriate games or movies 	<ul style="list-style-type: none"> Music or any distractors identified during preop visit to avoid Narcotics. Involve Child Life for any procedures. Age appropriate games or movies 	<ul style="list-style-type: none"> Music or any distractors identified during preop visit to avoid Narcotics. Involve Child Life for any procedures. Age appropriate games or movies
Disposition	<ul style="list-style-type: none"> ICU 	<ul style="list-style-type: none"> Transfer to PCRS 	<ul style="list-style-type: none"> PCRS 	<ul style="list-style-type: none"> PCRS DC criteria met?

Specialized cardiac feeding program

The literature suggests that across the United States, between 30% and 50% of children who undergo neonatal heart surgery are not able to consume adequate nutrition by mouth before going home and therefore require a feeding tube at the time of discharge. Feeding difficulties have been reported in the literature as a source of extreme family stress and have even been said to overshadow the stress of the cardiac problem. In response to all of this, the cardiac feeding program at Dell Children's Medical Center was established in 2023 to provide multidisciplinary comprehensive feeding and nutrition support to congenital heart disease patients who rely on a feeding tube for their nutrition. The feeding team is made up of cardiologists, advanced practice providers, cardiac dietitians, speech therapists, social workers, and nurses who work together to support our congenital heart disease families who are living with a feeding tube.

When patients are ready, the tube weaning clinic provides individualized and robust weaning plans. Our team provides intensive support and careful monitoring to ensure a safe, effective, and rapid wean from tube feeds. While the initial assessment is done in person, subsequent feeding program clinic appointments can be performed via telemedicine. We are a hunger-led feeding program with growth and feeding monitored via Locus remote monitoring.

Our inpatient portion of the program includes implementation of a preoperative feeding protocol

with a feeding intolerance algorithm, a standardized somatic growth measurement process, weekly feeding rounds, and rounding for influence, that included nursing education with hands-on feeding



In 2023, we created a dedicated multidisciplinary feeding team committed to creating a family-friendly program that could provide the support and education needed to families in search of a tube-free life, regardless of whether their child had a gastric tube or a nasogastric tube.

simulation. We developed and implemented a feeding readiness assessment tool to be utilized by nursing staff and parents to determine appropriate implementation of different strategies to foster oral skills without increasing stress. Babies are offered a pacifier, expressed breast milk drops, colostrum swabs and skin-to-skin care during feeds until they are able to demonstrate consistent readiness to feed, at which time they are allowed to begin oral feeds.



We encourage positive early feeding exposure/ experiences with nutrition being at the forefront of our daily medical plans. We have implemented a tube weaning exit plan at the time of tube insertion, and we ensure that outpatient feeding support (OT/ Speech Therapy) is ordered and in place at the time of discharge.

Most importantly, we work with the family to establish realistic goals for tube removal as it involves heavy parent engagement and commitment to being tube free. While our feeding program initially focused on children in our single ventricle program, we have recently expanded services to other patients in our heart center. Our team's commitment to helping eligible children eat independently through our standardized approach, in combination with our home monitoring and telehealth services, has allowed patients previously thought to be tube dependent to become independent eaters, regardless of their physical proximity to our program.

We were recently able to wean a patient from their feeding tube from 275 miles (6 hours) away.

Neurodevelopmental multidisciplinary inpatient rounds

Helping people with pediatric and congenital heart disease achieve their greatest potential is at the forefront of everything we do. We anticipate that roughly 85% of children with congenital heart disease born today will survive into adulthood, however, many of them are at risk for developmental delay. We understand that there are certain risks that we are able to modify through early detection and intervention. We know that by providing hospitalized newborns, infants and children with a nurturing environment in the Cardiac Care Unit, we can mitigate some delays and help optimize their development, despite being in the hospital.

In 2023, we developed a multidisciplinary neurodevelopmental team to help patients, parents, nurses and providers optimize our patients'

development. One of our cornerstone interventions was the elimination of traditional sternal precautions. By eliminating sternal precautions, we are better able to help infants and children engage with their parents and their care team in ways that stimulate their development in a safe and effective way.

We evaluate every patient in our CCU to determine if there are any strategies that we can implement to help prevent or close the gap on delays. Following evaluation and discussion with the Neurodevelopmental team, we post therapeutic info graphics to help nurses, therapists, and parents to engage the children in developmentally stimulating activities. Our interventions help parents to bond with and engage with their children, which ultimately translates to better outcomes.





Collaboration with UT Health Austin

UT Health Austin is the clinical practice of the Dell Medical School at The University of Texas at Austin. The collaboration between UT Health Austin and Dell Children's brings together a team of highly specialized providers who are at the forefront of the latest research and technological developments in this field of medicine to build an integrated system of care that is a collaborative resource for clinicians and their patients.

Ascension Texas

In Texas, Ascension operates Ascension Providence in Waco and Ascension Seton, which includes Dell Children's Medical Center, the region's only comprehensive children's hospital and pediatric Level I Trauma Center, and Dell Seton Medical Center at The University of Texas, the region's only Level I Trauma Center for adults. Ascension Seton partners with Dell Medical School at The University of Texas at Austin and shares a common vision of transforming healthcare through a focus on quality and value. Serving Texas for more than 120 years, Ascension is a faith-based healthcare organization committed to delivering compassionate, personalized care to all, with special attention to persons living in poverty and those most vulnerable. Ascension is one of the leading nonprofit and Catholic health systems in the U.S., operating 2,600 sites of care — including 139 hospitals and more than 40 senior living facilities — in 19 states and the District of Columbia.

Visit ascension.org and ascension.org/DellChildrens

UT Health Austin

UT Health Austin is the clinical practice of the Dell Medical School at The University of Texas at Austin. UT Health Austin clinicians collaborate with colleagues at the Dell Medical School, The University of Texas at Austin, and in the community to utilize the latest research, diagnostic, and treatment techniques in every clinical encounter. Our experienced healthcare professionals deliver personalized, whole-person care of uncompromising quality and treat each patient as an individual with unique circumstances, priorities, and beliefs. Working directly with patients and their families, we create individualized care plans designed to help our patients reach the goals that matter most to them — in the care room and beyond.

Visit UtHealthAustin.org



**The multidisciplinary team at Texas Center
for Pediatric and Congenital Heart Disease**





**Texas Center for Pediatric and Congenital Heart Disease
Dell Children's Medical Center**

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Dell Children's Specialty Pavilion

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