Texas Center for Pediatric and Congenital Heart Disease

2022 Outcomes Report

dell children's
Ascension

The University of Texas at Austin
UT Health Austin

The mission of the **Texas Center for Pediatric and Congenital Heart Disease** (TCPCHD) is to improve the care of patients and families with congenital heart disease (CHD) through a model system of health delivery that is integrated, holistic, patient-centered, value-oriented and technology-driven.

Led by **Dr. Charles Fraser Jr.** and in collaboration with some of the finest congenital cardiac physicians in the country, **our multidisciplinary, multispecialty team is capable of treating even the most rare and complex cardiac conditions.** By always surrounding the patient with the highest level of expertise, we ensure the best possible outcome for our patients and their families. Through our robust data program and collaboration with The University of Texas at Austin, we continue to push the envelope by focusing on patient- and family-driven goals, addressing social determinants of health, removing barriers to access, and delivering care in the communities where our patients live. **We really do believe - "What starts here changes the world."**

Charles D. Fraser Jr. MD, FACS, FACC

Professor, Departments of Surgery and Perioperative Care, and Pediatrics

Executive Director, the Institute for Cardiovascular Health

Chief, Pediatric and Congenital Cardiothoracic Surgery

Leading the way

- **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 30-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

> **"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

Carlos M. Mery, MD, MPH

Associate Professor, Departments of Surgery and Perioperative Care, and Pediatrics

Associate Chief, Pediatric and Congenital Cardiothoracic Surgery

Director, Health Transformation and Design

Fast facts

Volumes and outcomes

10,000+
Annual cardiac clinic appointments

107
SDU deliveries

0.75%
Perioperative mortality in the last 12 months*

24
Heart transplants since 2020

63
Publications/ presentations in 2022

1,656
Cardiac operations since August 2018

400
Cardiac operations in 2022

450
Cardiac catheterizations in 2022

People

36
Advanced practice providers

400+
Heart center team members

45
Attending physicians

6
Psychosocial providers

5
Dedicated cardiac perfusionists

134
Full-time cardiac nurses

Capacity

32
NICU beds

30
Cardiac ICU beds

2
Cardiac operating rooms

11
Special delivery rooms

2
Cardiac catheterization labs

*April 2022-April 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 Kyle, College Station, Cedar Park, and Waco

Sabine Barrett

On Jan. 19, Sabine was on a South Austin soccer field wrapping up practice when she collapsed from sudden cardiac arrest. The medical team at Dell Children's identified a heart defect that caused Sabine to collapse.

Scan the QR code for Sabine's full story.

Congenital heart surgery

5 Full-time congenital heart surgeons | 7 Advanced practice providers

- 400 cardiac operations in 2022
- Over 1,500 cardiac operations since program inception in 2018
- Perioperative mortality less than Society of Thoracic Surgeons (STS) benchmark in all age categories
- 800-gram baby successfully underwent an arterial switch operation and was discharged home
- 27 neonates less than 3 kilograms have undergone cardiac surgery

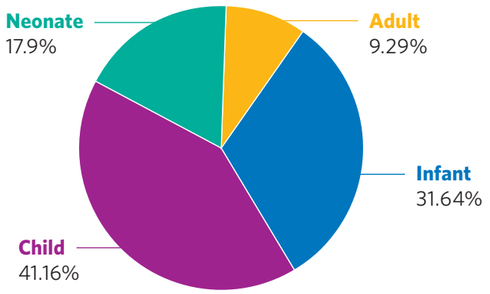
Outcomes by age (Index cases)

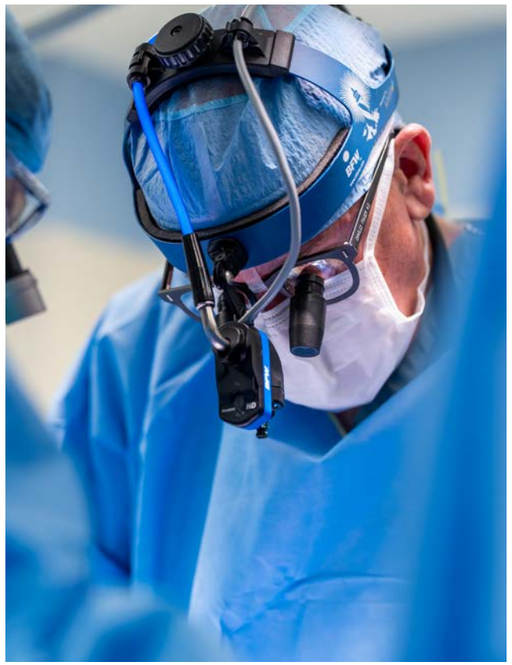
		Perioperative mortality		STS benchmark mortality percent
Age	Volume	N	percent	
Neonate	77	3	3.9	7.4
Infant	123	3	2.4	2.4
Child	137	0	0.0	1.1
Adult	37	0	0.0	2.7
Grand total	374	6	1.6	2.7

Jan. 1, 2022-March 31, 2023

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

Surgery patients by age





Pediatric and congenital cardiology

26 Pediatric cardiologists | **11** Advanced practice providers

- Over **10,000 cardiology clinic visits** per year
- Over **1,300 adult congenital clinic visits** per year
- **24 heart transplants** since heart transplant program inception October 2020
- **4 fetal cardiologists** opened the Special Delivery Unit (SDU) July 2021
- **Telemedicine consults** to support outreach initiatives

Over 450
interventional or diagnostic cardiac catheterizations per year

Our Pediatric and Congenital Cardiology team is dedicated to providing excellent service for our patients and their families. To that end, we staff numerous clinics throughout Central Texas for convenient points of access, and provide all areas of specialization including interventional catheterization, electrophysiology, advanced cardiac imaging, fetal cardiology, adult congenital cardiology, and many others.

D. Byron Holt, MD
Associate Professor, Department of Pediatrics
Chief, Pediatric Cardiology

Pediatric cardiac critical care

11 Dedicated cardiac care intensivists | **23** Advanced practice providers

Compared to the PC4 Aggregate:

- 65% lower surgical in-hospital mortality
- 51% lower post-op ECMO rate
- 50% lower postoperative cardiac arrest rate
- 72% lower postoperative stroke and intracranial hemorrhage rate
- 23% lower postoperative complication rate
- 10% lower CLABSI rate — 20% lower than 2021
- 35% better cardiac arrest rate in 2022

Shorter length of stay compared to STS benchmark:

- > 50% shorter for coarctation of the aorta, ventricular septal defect, complete atrioventricular canal defect and Glenn
- 45% shorter for tetralogy of fallot and arterial switch operation with ventricular septal defect closure
- > 20% shorter for arterial switch operation and Fontan

Our CICU medical mortality rate is nearly 14% better than the national benchmark.

Our Cardiac Critical Care team works seamlessly with the larger multidisciplinary heart center team to manage the most complex patients with CHD, from neonates to adults. Through daily rounds, where the entire heart center team meets to discuss patients, we are able to seamlessly manage these medically fragile patients, whether recovering from cardiac surgery or an acute illness. Understanding how to manage these complex patients and work as a broader team is critical to good outcomes — with this in mind, our team is poised to provide the best care possible.

Daniel Stromberg, MD
Associate Professor, Departments of Surgery and Perioperative Care, and Pediatrics
Medical Director, Cardiac Critical Care

Pediatric cardiac anesthesiology

6 Pediatric cardiac anesthesiologists

- **Over 1,440 anesthetics administered** to patients with heart disease
- **Patient blood management** strategies utilized

42% of our children and adults underwent cardiac surgery **without blood products** including:

- **VAD placement without blood products**
- **VAD explant and heart transplant without blood products**

- **Less than 2.5%** of patients extubated in the operating room required reintubation
- Implementation of **uniform ERAS strategies**
- Participation in the **Naso-VISI study** with over 60 patients enrolled, making TCPCHD the **second-largest contributor of study participants**

97%
of Fontan patients extubated in the operating room

Our multidisciplinary Anesthesiology team works to deliver the highest level of individualized, and comprehensive care while simultaneously minimizing potential risk experienced during transitions of care. Our meticulous attention to detail and individualized care plans allow us to provide safe and effective anesthetic care from the tiniest and most complex patients to adults with congenital heart disease.

Erin Gottlieb, MD, MHCM
Associate Professor, Department of Surgery and Perioperative Care
Chief, Pediatric Cardiac Anesthesiology

Le'Lani Bryant

Jasmine Matthews remembers that ultrasound when she was four months pregnant. "They keep scanning (the baby's) heart," she said, but the doctors were having trouble making a definitive diagnosis.

Scan the QR code for Le'Lani's full story.

Programs

Psychosocial Team

The impact of congenital heart disease on the emotional well-being of patients and their families is undeniable. Wanting to lessen that impact, our integrated psychosocial team meets with all of our patients admitted to the CCU, as well as every patient undergoing evaluation for heart surgery. Early identification allows us to provide the necessary support needed to help our patients and their families navigate the stressful waters of heart disease. The team helps patients and their families identify any developmental or psychosocial concerns as early as possible and manage the implementation of appropriate interventions to maximize their lifetime potential. Our team serves as a source of strength and guidance for our patients and their families throughout their time at Dell Children's and even once they have returned home if necessary.

Our integrated psychosocial team includes clinical psychologists, child life specialists and social workers, all who support the patient and family during their journey with heart disease.

Cardiac Hospitalist Program

Our cardiac hospitalists are a select group of pediatric hospitalists at Dell Children's Medical Center who provide care to children with congenital heart disease who are hospitalized. These can be children with feeding concerns or the need for medication optimization, or patients with heart disease who are admitted to the hospital for non-cardiac reasons. The team works in conjunction with the cardiology, cardiothoracic surgery, anesthesia, cardiac ICU teams, as well as associates in nursing, respiratory therapy, therapies (physical, occupational, and speech), pharmacy, social work, case management, and child life. The team is responsible for patient care, patient education, and ensuring that all patients being discharged from the hospital are equipped to make a successful transition to home. Our multidisciplinary team ensures that families are adequately trained and armed to take on the task of often complicated and overwhelming care of a child with congenital heart disease.

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.

Health Transformation and Design 2022

Staff

1
Health transformation/ research faculty (MD/MSHCT/MPH)

3
Research specialists (MPH/MS)

6
Outcomes specialists (RN, MSN, MSN-NI, PhD)

2
Post-doctoral fellows

1
Research fellow (MD)

1
Data analyst (MPH)

1
Health transformation fellow

1
Quality improvement specialist (PhD)

Impact

47
Abstracts accepted

27
Poster presentations at nationally recognized meetings

16
Manuscripts accepted for publication (20% increase from 2021)

20
Presentations given at nationally recognized meetings

8
Registries supported

Hospital-Based Clinic

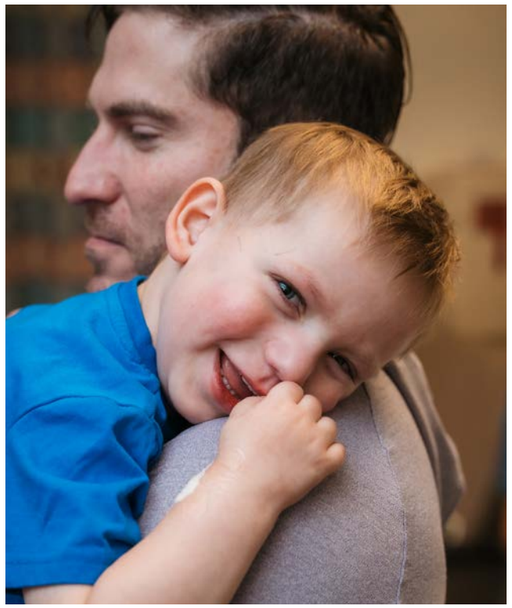
We have a centralized multidisciplinary clinic that brings the necessary team members to the patient so our patients do not have to schedule multiple appointments with each member of their care team. Our hospital-based multidisciplinary clinic brings cardiologists, cardiac surgeons, cardiac anesthesiologists, pharmacists, dietitians, therapists (physical, occupational, and speech), social workers, psychologists and other sub-specialty services as needed together to collaborate and coordinate complex patient care in a single visit. This clinic is home to our IMPACT/ single ventricle patients, heart failure/ VAD/transplant and coronary anomalies program patients, as well as select ACHD patients. One of the goals of the clinic is to bring services to the patients who need them most and minimize the number of days parents and patients miss work or school by minimizing their trips to the clinic. This clinic is just another way that our team is rethinking how we approach CHD.

Single Ventricle Program

The Single Ventricle Program diagnoses, treats, and manages the care of children with single ventricle heart defects from prenatal life through adulthood. We have a dedicated Interdisciplinary Monitoring Program for Ambulatory Cardiac Care of Central Texas (IMPACT), a home monitoring program for high-risk infants who are between the early stages of single ventricle palliation. Our unique collaboration with Dell Children's Comprehensive Care Clinic provides seamless outpatient pediatric care to these fragile children following discharge during the interstage period. We utilize a robust electronic surveillance program, allowing our clinicians to follow our patients at home, in real time. This type of consistent collaboration ensures that wherever the patient is, the entire care team (inpatient and outpatient) is involved and up to date.

Extracorporeal Cardiopulmonary Resuscitation (E-CPR)

This program provides patients who have cardiac arrest with ongoing resuscitation (CPR) the opportunity to be supported and cared for while their bodies try to recover from the arrest.



Our multidisciplinary, multi-specialty IMPACT team closely follows and monitors daily all of our patients who have a single ventricle physiology and are between their first and second stages of palliation to ensure optimal outcomes.

Heart Failure, VAD, and Transplant Program

Our Heart Failure, VAD, and Transplant Program is the first pediatric heart transplant program in Central Texas. The team focuses on diagnosing, treating, and managing the care of children and adults with congenital heart disease, who either have a heart muscle problem or are experiencing heart failure. Our multidisciplinary team is composed of nationally recognized and highly specialized individuals across different disciplines and sub-specialties who are all housed in a single cardiac care unit at Dell Children's Medical Center. With access to expert staff and advanced technology, we provide a wide range of services, from evaluation, testing, and diagnosis to medical management, rehabilitation, surgery, heart transplantation, and more, to give patients and their families the best quality of life.

Mechanical Circulatory Support (MCS)

Our program at Dell Children's provides patients with failing circulatory systems a means of either temporary or durable circulatory support through the utilization of a variety of machines. The MCS team consists of physicians, advanced practice providers, perfusionists, nurses and respiratory therapists who provide care for patients being supported. Our program includes the use of central and peripheral mechanical circulatory support and a variety of ventricular assist devices, including the Heart Mate III and Berlin Heart. We are committed to matching each individual patient with the best type of support for their particular disease to maximize their potential for recovery. Through our intimate relationship with the engineering program at The University of Texas at Austin, we aspire to contribute to the armamentarium of available devices.

Fetal Cardiac Program

The Cardiac Fetal Program diagnoses, monitors, and manages the care of babies diagnosed with heart problems in utero. Heart problems can include congenital heart disease, heart rhythm problems, or other problems that affect the fetal heart. Advances in prenatal care, such as advanced imaging and testing, have allowed for many heart problems to be detected as early as 12 weeks of gestation. The Cardiac Perinatal Team works to ensure that parents have access to the most up-to-date data and treatment options to ensure that everyone is prepared for the baby's arrival. We understand the importance of keeping mothers close to their children after delivery and have recently opened our new Specialized Delivery Unit (SDU) at Dell Children's. When the perinatal team determines that the baby will likely need an urgent cardiac procedure or intense monitoring after delivery, arrangements are made allowing the mother to deliver in the same facility where their child will receive cardiac care, thus allowing them time to bond right after the baby is born.

Transition Program

In order to ensure that children and young adults with congenital heart disease are supported psychologically, socially and medically as they transition into adulthood, our transition program works to bridge the gap by preparing them to become knowledgeable about and take ownership of their disease and the care it requires. Our comprehensive and longitudinal approach assesses readiness for transition and uses a staged process with integrated redundancy to ensure seamless and uninterrupted transition of care from parent to child and pediatric cardiologist to ACHD cardiologist. Our goal is to provide continuous care starting in fetal life and extending throughout all stages of life.

Adult Congenital Heart Disease Program (ACHD)

Our ACHD Program diagnoses, treats, and manages the care of adults with congenital heart disease. Our team is composed of internationally recognized and highly specialized physicians, advanced practice providers, nurses, dietitians, and therapists who provide compassionate, comprehensive, patient-driven care. Most patients with CHD are not 'cured' of their disease and require life-long follow-up. The ACHD Program was developed with all the necessary support systems integrated into our team to maximize the quality of life experienced by adults with congenital heart disease. Our care team is dedicated to helping adults with congenital heart disease navigate their lifelong journey while mitigating disability and optimizing their health.

Cardiac Neonatology

Neonatology is at the cornerstone of every perinatal program. Our neonatology program includes a Level IV Neonatal Intensive Care Unit (NICU) that provides the most specialized and comprehensive care to both premature and critically ill babies. Dell Children's has more pediatric specialists and specialty programs than any other hospital network in Central Texas. The NICU is staffed 24/7 with a dedicated team of specialists trained in caring for critically ill newborns and includes physicians, nurse practitioners, nurses, and respiratory therapists. Our dedicated neonatal transport team ensures that critically ill babies are transported either by land or air to our hospital where they can receive the highest level of care available in Central Texas.

Our dedicated cardiac neonatology team provides the necessary comprehensive care to our tiniest patients so that even a baby weighing 800 grams can undergo and recover from an arterial switch operation safely.

Coronary Anomalies Program

Our Coronary Anomalies Program diagnoses, treats, and manages the care of children, adolescents, and adults with anomalous coronary arteries. Our multidisciplinary program includes cardiologists, cardiac surgeons, radiologists, and psychologists. We utilize a unique shared decision-making model to individualize each patient's plan of care. Our management strategy uses a standardized approach to diagnose and risk-stratify patients in an effort to ensure that our decisions are both reliable and consistent. Our Coronary Anomalies Program surrounds the patient and their family with the highest level of expertise available to ensure that the plan of care reflects patient-driven goal setting and that the patient is supported in their decision making by our dedicated clinical psychologist who helps the patient and their family navigate the journey.

Preventive Cardiology

There are conditions, some hereditary, that put children and adults at risk for the development of cardiovascular disease, including things like high blood pressure, obesity, hyperlipidemia, hypercholesterolemia, liver disease, and metabolic syndromes. Our Preventive Cardiology team includes physicians, nurses, advanced practice providers, pharmacists and dietitians who work together to evaluate and treat children who are considered to be at risk for the development of heart disease. Our goal is to identify those at risk and then to work with them to mitigate those risks and optimize their health.

Cardiovascular genetic conditions are thought to occur in 1 out of every 200 people and the impact of that condition stays with them throughout their lifetime. Our team helps these individuals identify, understand and live with their condition while optimizing their health.

Cardiovascular Genetics

Our multidisciplinary, multi-specialty program brings physicians, advanced practice providers, genetic counselors, psychologists, and nurses together to help families with known or unknown cardiovascular genetic conditions receive a thorough evaluation as well as comprehensive longitudinal care focused on early intervention and risk mitigation. Since some conditions are shared between multiple family members, we offer care across all age groups. We also know that some conditions impact other organ systems, so when needed, our team can help to integrate those other sub-specialties into your clinic experience thus minimizing days missed from work and school and trips made to the hospital.

Pulmonary Artery Rehabilitation Program

There are a variety of congenital cardiac conditions in which the pulmonary arteries do not develop normally, and the treatment of these conditions requires a multidisciplinary team approach with specialists in cardiology, cardiac catheterization, cardiac imaging, cardiac surgery, and cardiac anesthesiology. Our team works together to create an individualized comprehensive longitudinal road map of rehabilitation to optimize the pulmonary blood flow in each individual patient. Whether the pulmonary arteries are isolated or there are major aortopulmonary collateral arteries (MAPCAs) in need of unifocalization, our team works in collaboration with referring cardiologists around the country to ensure that the patient's journey is mapped and their time away from home is minimized.

Fontan Optimization

Understanding the longitudinal journey of single ventricle patients is essential to the physical and psychosocial well-being of patients living with a Fontan circulation. Understanding the unique physiology as well as the predictably unpredictable impact that the Fontan physiology has on other organ systems makes it imperative that patients be thoroughly evaluated at regular intervals in order to optimize health and mitigate disability. Our team is adept at collaborating with outside cardiology groups to ensure that best practice interventions are being considered by the primary cardiologist. Patients can be seen in our Optimization Clinic for comprehensive testing and then recommendations will be made in collaboration with the referring cardiologist and their patient to ensure that patient-centered goals remain at the forefront.

Cardiac Neurodevelopmental Outcomes Program

Our program tracks, monitors, and manages the development of children with congenital heart disease who undergo surgical intervention as infants as well as those with genetic syndromes as they are at higher risk for neurodevelopmental disabilities. These disabilities might include mild cognitive impairment, oral-motor discoordination, expressive speech and language differences, impaired visual-spatial and visual motor skills, attention-deficit/hyperactivity disorder (ADHD), and learning disabilities, among others. Through an integrated approach, we provide expert evaluation and diagnosis as well as integration of caregiver assessment in which families record and share their own observations related to their child's development. We utilize advanced imaging and neurological and neuropsychological testing to help implement the latest evidenced-based therapies to monitor and treat patients.

The Cardiac Neurodevelopmental care team uses advanced imaging, neurological and neuropsychological testing, and the latest evidence-based therapies to monitor and treat any developmental delays.

Dell Children's Transport Team

Our transport team, started in 1996, is a multidisciplinary team consisting of a crew that are all BLS-, PALS-, ACLS-, NRP- and TNCC-certified, routinely transports more than 600 critically ill neonates, infants, children and ACHD patients per year. Accredited by the Commission on Accreditation of Medical Transport Systems, our team is ready to transport the most fragile and complex patients, regardless of diagnosis or acuity via ambulance, rotor wing, or fixed wing. Utilizing stabilizing strategies such as high-frequency ventilation, inhaled nitric oxide or Heliox, our transport team provides medical control via our PICU/CCU staff and in collaboration with the referring hospital physicians to ensure that patients arrive safely at their destination. While our team services a 46-county area, we have also provided transport to patients from northern California, Philadelphia, Florida, Mexico and the Bahamas, who were seeking care at Dell Children's Medical Center.

dell children's Ascension

The University of Texas at Austin
UT Health Austin

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 non-profit 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

Contact us

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Dell Children's Medical Center
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Dell Children's Specialty Pavilion
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Photo credit: UT Health Austin

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