

Texas Center for Pediatric and Congenital Heart Disease Volumes and Outcomes Report: July 2018 - December 2021







Dear Friends,

I am pleased to offer a few opening words for the first Annual Report of the Texas Center for Pediatric and Congenital Heart Disease. Our commitment to patients and families is to offer compassionate, holistic, integrated care in an environment completely focused on optimized outcomes. As such, we offer, for your consideration, our cumulative program experience. We do not claim perfection; we do claim transparency and focused persistence to offer objective measures of performance. We are privileged to help in the journey of care for patients with congenital heart disease.

Yours sincerely,

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

Charley D. S.

Professor, Departments of Surgery and Perioperative Care, and Pediatrics Executive Director, the Institute for Cardiovascular Health Chief, Pediatric and Congenital Cardiothoracic Surgery and Cardiothoracic Surgery Dell Medical School at The University of Texas at Austin

Dell Children's President, Christopher M. Born, MBA, CPA, reflects on the building and continued growth of The Texas Center for Pediatric and Congenital Heart Disease



"There can be no keener revelation of a society's soul than the way in which it treats its children." - Nelson Mandela. This sentiment is realized daily within The Texas Center for Pediatric and Congenital Heart Disease (TCPCHD) at Dell Children's Medical Center. Our patients and families are the center of our world. The drive and determination for excellence by every member of the team, coupled with the commitment to the outcomes patients and families value most, has created unparalleled success for the growing team of professionals within our pediatric and congenital heart program.

Overlaid by a global pandemic, the team has accomplished the near impossible. From managing complex premature infants to adults with congenital heart disease, our interdisciplinary team of nurses, respiratory therapists, pharmacists, operating room staff, child life specialists, physicians, social workers, psychologists, dieticians, chaplains, housekeeping services, supply chain experts, and more have gone above and beyond to ensure that our patients feel safe during these very uncertain times. This team has kept patients at the forefront and relentlessly pursued excellence in a time of chaos and uncertainty. The grit and tenacity as well as commitment and resolve that the team has shown for all of our patients has been nothing short of awe inspiring.

When Dr. Fraser arrived in Austin in 2018, he brought with him an unwavering commitment to build a pediatric heart program on a blank canvas in a new way, a better way. We knew that the brand of excellence he brings to his work and his leadership would transform the entire hospital. The recruitment of the incomparable Dr. Carlos Mery and almost 100 more mission-aligned clinicians secured TCPCHD's success in outcomes and our commitment to achieving a higher standard of care for patients' entire lives. With 1 in 100 children born with congenital heart disease, the need in our region was undeniable. Before Dr. Fraser's arrival in Austin, families had no choice but to seek care in other cities. The imperative existed to build a very different kind of heart program here in Austin to serve the people of this 47-county catchment area and beyond, and that is exactly what has happened. Now, all families can remain here at Dell Children's for even the most complex heart care.

Excellence is the rising tide that lifts all, as evidenced by the growth of complex care at Dell Children's in a very short amount of time. In less than four years, since the inception of TCPCHD, much has been accomplished. Highlights for me include the following achievements:

- A dedicated Cardiac Critical Care Unit that is now expanding to meet the growing demand for care
- The creation of a Special Delivery Unit at Dell Children's, so the most fragile infants in need of heart surgery no longer need to be transported to other hospitals; they can be born right here
- Norwood operation success and other high-acuity neonatal surgical procedures
- Transparency in long-term outcomes to ensure healthy lives long past surgery
- A culture of relationship-centered care that truly leaves no one behind
- Improved access for all who seek excellent congenital and pediatric cardiac care
- A world-class heart transplant program
- Mechanical circulatory support devices
- ECPR 24/7 emergent ECMO initiation capabilities
- Comprehensive adult congenital cardiac care
- IMPACT program, including Single Ventricle Home Monitoring Program

- Cardiac Cath Lab Piccolo[™] devices and transcatheter valve replacement
- Use of Sickbay[™] technology
- Cardiac Neurodevelopmental Program
- Health Transformation and Design Program
- Robust Research Program pushing innovation continually for patients and families

It is vital that Dell Children's along with our partners at Dell Medical School at The University of Texas and the Value Institute at Dell Medical School and McCombs School of Business continue, in unison, to resource and support The Texas Center for Pediatric and Congenital Heart Disease for the children in our region and beyond. A new international destination program for those seeking the very best care for their children, TCPCHD approaches care not with 30-day outcomes in mind for our patients but rather by envisioning an 80-year journey map specifically designed for each patient, their particular diagnosis, and a lifetime ahead of them.

This flagship program, with its determined leaders and truly unique individuals as its strength, serves as a model for all others to push themselves and their ideas forward to continually find improved ways of caring for children and their families. They are revolutionizing the treatment of congenital heart disease for children and adults and prove daily that together, we can ensure access to world-renowned, innovative care while providing the equity our children deserve in healthcare.

With gratitude and pride,

Christopher M. Born, MBA, CPA

President, Dell Children's Medical Center

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The Texas Center for Pediatric and Congenital Heart Disease (TCPCHD) is a clinical partnership between Dell Children's Medical Center (DCMC) and UT Health Austin, the clinical practice of the Dell Medical School at The University of Texas at Austin.

Charles D. Fraser, Jr., MD serves as the director of the Texas Center for Pediatric and Congenital Heart Disease and is supported by the different division leads, including Chief of Anesthesiology Erin Gottlieb, MD, Chief of Cardiology Byron Holt, MD and Medical Director of Cardiac Critical Care, Daniel Stromberg, MD. With a vision that stretches beyond surgical outcomes, TCPCHD brings a focus on redesigning traditional approaches to congenital heart disease and includes optimizing health and well-being throughout all of our disciplines in an interdisciplinary fashion, supported by the Health Transformation and Design team led by Carlos Mery, MD.

Our team of experts includes cardiac surgeons, cardiologists, interventional cardiologists, critical care specialists, cardiac hospitalists, cardiac neonatologists, anesthesiologists, perfusionists, nurses, advanced practice providers, social workers, psychologists, child life specialists, dietitians, cardiac sonographers, physical and occupational therapists, pharmacists, and more, providing unparalleled care for patients and their families in a way that supports their optimal health.

TCPCHD Leadership



Charles D. Fraser, Jr., MD Professor, Departments of Surgery and Perioperative Care, and Pediatrics Executive Director, the Institute for Cardiovascular Health Chief, Pediatric and Congenital Cardiothoracic Surgery and Cardiothoracic Surgery



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



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



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

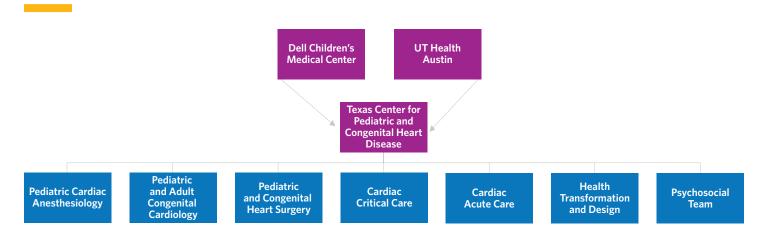


Carlos M. Mery, MD, MPH Associate Professor, Departments of Surgery and Perioperative Care, and Pediatrics Associate Chief, Pediatric and Congenital Cardiothoracic Surgery Director, Health Transformation and Design

Texas Center for Pediatric and Congenital Heart Disease (TCPCHD) timeline

September: Dedicated perfusion team September: Dedicated Cardiac Service Line Director September: Dedicated CCU physician leadership Year-End: 116 surgical cases completed
March: Dedicated cardiac anesthesiology March: Dedicated CCU nursing staff March: Dedicated CCU social worker June: Opening of the dedicated CCU August: Dedicated cardiac pharmacist September: First heart failure, VAD, transplant cardiologist hired Year-End: 305 surgical cases completed
April: Opening of the second dedicated Cardiovascular Operating Room (CVOR) April: Dedicated CCU educator May: Expansion of CCU nursing leadership July: Pediatric Acute Care Cardiology Collaborative initiation September: Dedicated Cardiac Respiratory Therapy Supervisor October: First solid organ transplant, heart December: Pediatric Cardiac Critical Care Consortium initiation Year-End: 341 surgical cases completed
January: First Ventricular Assist Device implant May: Expansion of CCU nursing leadership December: Further expansion of CCU nursing leadership December: Second heart failure, VAD, transplant cardiologist hired Year-End: 360 surgical cases completed

TCPCHD Structure





Texas Center for Pediatric and Congenital Heart Disease 2021

Congenital heart surgery

The Division of Pediatric and Congenital Heart Surgery is led by Charles Fraser, Jr., MD. He brings over 30 years of experience to the program, caring for the most complex cardiac lesions while adapting and innovating cutting-edge surgical techniques aimed at providing patients with the greatest opportunity to fulfill their potential.

Our group includes surgical advanced practice providers, nurse navigators, and scheduling nurses, all of whom focus on supporting our patient families throughout their surgical journeys. Our congenital cardiac surgical program emphasizes not only achieving the best surgical outcomes but simultaneously supporting our patients and families in a holistic way and maximizing the long-term outcomes of our patients. Our team works closely with our psychosocial providers to be able to provide unparalleled patient-centered care.

Through collaboration with the Health Transformation and Design team, which diligently tracks and tallies important metrics about our Heart Center, the team is able to provide reliable transparency of the program. The unique focus of the team on individualized care with patient-driven outcomes and patient-reported experiences make this surgical program different than others.

Texas Center for Pediatric and Congenital Heart Disease

Program Data

Total Overall Cases (7/31/18-12/31/21)	1,136
Eligible Cases (7/31/18-11/30/21) ¹	1,078
Eligible Index Operations (7/31/18-11/30/21) ²	878

¹ Only operations for patients who have been discharged and audited by the program are eligible

Outcomes by Age and Volume by Operation Type (Eligible Index Cases)

July 31, 2018-November 30, 2021

			perative rtality	STS Benchmark	
Age	Volume	N	%	Mortality*	350
Neonate (<31 days)	149	8	5.4%	7.6%	300 250
Infant (31 d-1 year)	267	5	1.9%	2.5%	200
Child (1-18 years)	381	3	0.8%	1.0%	150
Adult (18+ years)	81	0	0.0%	1.4%	100 50
Total	878	16	1.8%	-	0

^{*}Society of Thoracic Surgeons (STS) Benchmark Mortality Harvest Report 11/2021

² Index operations are procedures with a STAT category and included in outcomes analysis by the Society of Thoracic Surgeons (STS)

Surgical Volume by Month and Year

July 31, 2018-December 31, 2021 N=1,136



August 2018—16 total surgeries (7 by other surgeons)

The program continually submits our de-identified case data to the Society of Thoracic Surgeons (STS) clinical registry. STS combines the data for most congenital heart programs in the United States (and some abroad) and calculates the perioperative mortality risk for each type of procedure. Submitting our data allows us to benchmark ourselves with other programs, identify best practices, and find ways to keep improving care.

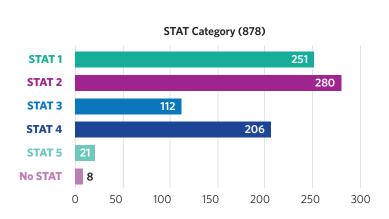
Since the creation of the program in July 2018, we have outperformed the national average for congenital heart surgery outcomes reported to the STS clinical registry (<1.8% mortality in our program compared to a national average of 2.8%). Despite the availability of outcomes, it can still be a difficult decision to find the best program for a child. Families should consider both measured outcomes as well as the many programmatic characteristics of a hospital such as:

- Presence of a dedicated cardiac intensive care unit
- A dedicated neurodevelopmental team
- Dedicated 24/7 staffing of the program
- Expertise of other subspecialties
- Commitment to measure and report outcomes in a transparent way
- Availability of integrated clinical programs

In order to compare the outcomes of surgeries that have different levels of risk and complexity, the STS registry assigns a STAT category (1-5) to most procedures. Procedures with a STAT category of 1 have the lowest risk of perioperative mortality (death), and those with a category of 5 have the highest risk.

Outcomes by Complexity (Eligible Index Cases as defined by the STS)

July 31, 2018-November 30, 2021



STAT		STS Benchmark		
Category	Volume	N	%	Mortality*
STAT 1	251	0	0.0%	0.36%
STAT 2	280	3	1.1%	1.38%
STAT 3	112	1	0.9%	2.02%
STAT 4	206	7	3.4%	6.15%
STAT 5	21	4	19.0%	12.23%
No STAT	8	1	12.5%	-
Total	878	16	1.8%	2.72%

*STS Benchmark Mortality Harvest Report 11/2021





"As key members of the highly specialized team of professionals caring for patients with pediatric and congenital heart disease, registered nurses (RNs) in the CVORs at Dell Children's contribute to optimal patient outcomes. This group of experienced professionals is highly respected by all members of the team, and are active participants in the many academic offerings of the Texas Center for Pediatric and Congenital Heart Disease and Dell Medical School. This collaborative approach ensures the art and science of nursing is inextricably woven into the care each child receives."

- Dave Golder, RN

There are 10 procedures that are considered "benchmark" operations by the STS. The following table outlines the outcomes of these procedures.

Outcomes by STS Benchmark Operation (Eligible Index Cases)

July 31, 2018-November 30, 2021

Procedure Type	Overall Program Volume	Eligible Index Cases	Perioperative Mortality N (%)	STS Benchmark Mortality*	Median Post-Operative Length of Stay (Days)	STS Benchmark Median Post-Operative Length of Stay (Days)
VSD-Patch Repair	75	75	0	0.43%	5	10.12
Tetralogy of Fallot Repair	43	43	0	1.18%	7	12.56
Complete AVSD Repair	33	32	0	1.90%	9	18.16
Arterial Switch Operation	11	11	0	1.87%	11	17.65
Arterial Switch + VSD Repair	10	10	0	5.30%	12	22.06
Glenn/HemiFontan	27	21	1 (4.8%)	2.01%	7	17.80
Fontan Operation	35	35	0	1.06%	10	14.10
Truncus Arteriosus Repair	4	4	0	9.24%	52	32.00
Norwood Procedure	16	14	4 (29%)	12.42%	58	56.93
Coarctation Repair Off Bypass	34	34	1 (2.9%)	0.98%	6.5	14.36

*STS Benchmark Mortality Harvest Report 11/2021

Congenital heart surgery: a patient story

The Texas Center for Pediatric and Congenital Heart Disease celebrates 1,000 open-heart surgeries

On August 13, 2021, the Texas Center for Pediatric and Congenital Heart Disease performed open-heart surgery on its 1,000th patient, five-year-old Mason Willers, who was born with a partial atrioventricular septal defect, or as Mason's dad Paul Willers describes it, "a Swiss cheese heart."

"The children can have problems with growth; they can have problems with their activity levels, but eventually they can have heart failure problems," explains Charles Fraser, Jr., MD.

Mason's parents have been preparing for Mason's surgery since they learned about their son's heart defect when Mason's mother Susan Mims was approximately 18 to 20 weeks pregnant.

"I think any time you think about your kid's chests being opened up, their heart stopped, heart cut into, I mean, these things just are your worst nightmare as a parent, or one of your worst nightmares," says Paul Willers.

Mason and his family are from a small town near Victoria, Texas and traveled over two hours to receive care from the Texas Center for Pediatric and Congenital Heart Disease at Dell Children's.

"We were scheduled [for surgery] the day before and there was some other child that needed more urgent surgery," explains Paul Willers. "Then we ended up in the 1,000th case."

Despite the unique challenges healthcare professionals around the world have faced due to the ongoing COVID-19 pandemic, the Texas Center for Pediatric and Congenital Heart Disease continues to work with patients and families to ensure they are receiving the highest level of specialized care.

"It's been relentless. It's already hard enough to take care of someone's child with heart disease, but to have the overlay of a disease which we're still learning about, and there's a lot that's been demystified in a good sense, but it's been frightening," shares Dr. Fraser.

Since the Texas Center for Pediatric and Congenital Heart Disease was established in July 2018, the Heart Center has achieved several major milestones, including opening the first cardiac care unit in Central Texas in June 2019, successfully implanting the first mechanical heart device in a pediatric patient in Central Texas in September 2019, launching the first pediatric heart transplant program in Central Texas in July 2020, successfully performing the first pediatric heart transplant in Central Texas in October 2020, and more.

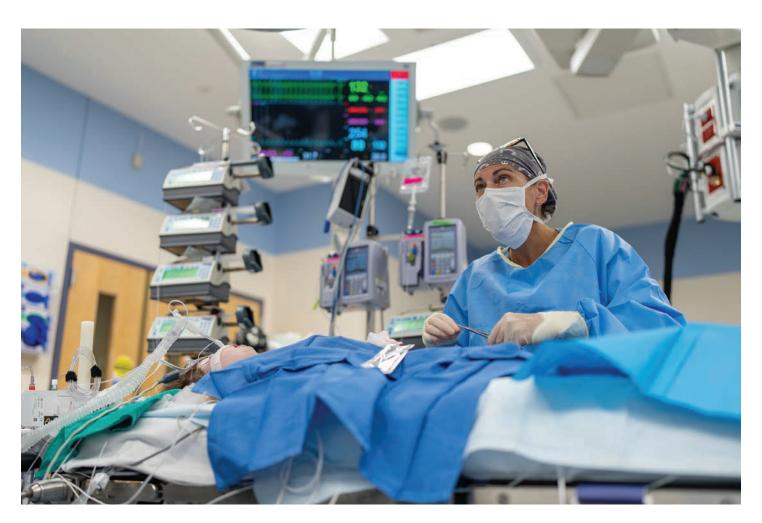


Pediatric cardiac anesthesiology

Our highly skilled, dedicated **pediatric cardiac anesthesiologists**, with the support of our **certified registered nurse** anesthetists, provide safe and compassionate care to patients undergoing procedures and imaging. Optimal airway support, invasive line placement, and hemodynamic management are critical components of a successful procedure. During heart surgery, our team closely monitors the patient. This includes monitoring of the brain with the goals of protecting the brain from potential injury and optimizing neurodevelopmental outcomes.

For certain cardiac operations, the anesthesiology team is often able to extubate early, that is remove the breathing tube in the operating room at the conclusion of surgery or within four hours of admission to the Cardiac Care Unit. By removing the breathing tube early, patients may benefit from improved hemodynamics and the need for fewer sedative medications. In addition, early extubation may shorten the time that the patient is in the intensive care unit.

Through preoperative consultations with the psychosocial team and child-life specialists, many of our patients and families are armed with the necessary anticipatory guidance to allow for an easy transition from parent to operating room. Prior to surgery, our anesthesiology team makes every effort to separate children from their parents in a way that is comfortable, compassionate, and reassuring for all.



In the operating room, we create an environment that supports optimal communication and collaboration among the cardiac anesthesiologist, the cardiac surgeon, and the cardiac perfusionist. This concept begins with mutual trust and respect, acknowledges the unique qualities that each one brings to the table, and serves to ensure patient safety and excellent outcomes. The operating room is quiet and controlled, and communication is clear, concise, and unambiguous. Additionally, the fact that our team works together consistently creates a level of familiarity that promotes effective teamwork.

Our commitment to patient blood management begins preoperatively, and the anesthesiology, surgery, and perfusion teams collaborate throughout the operation to minimize the use of blood and blood products. Throughout the operation, blood from the operation is collected and prepared in a way that allows it to be given back to the patient after bypass (cell saver). Our bypass strategy is designed to ensure that patients only get the blood that they absolutely need to keep them safe.



"The importance of the cardiac anesthesia program at Dell Children's cannot be summed up in a few sentences. Having the love and compassion from the anesthesia team is something I will never take for granted. The day my daughter had her third open-heart surgery, she wasn't transported in a bed, or a wheelchair, she was carried in the arms of a member of the anesthesia team. As a parent, handing your child over is never easy. You are giving them your whole world. In that moment when I watched my daughter go through those doors to the operating room in the arms of Dr. Gottlieb, smiling and singing as they walked, I felt like I was watching a member of my family carry her back and I knew that this is our medical home, this is why we picked Dell Children's Medical Center. Our daughter is not a number, she is family."

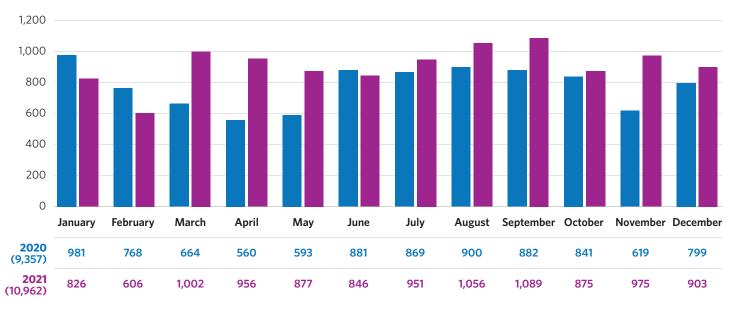
— Courtney Greger, mother of Eva Ann, patient at TCPCHD

Pediatric cardiology

The **pediatric cardiology** team is comprised of a multidisciplinary team that includes cardiologists, advanced practice providers, nurses, and sonographers, all of whom are dedicated to the care of patients with pediatric and congenital heart disease. With clinics spread throughout the central Texas region, our team is committed to improving access to quality cardiac care for all patients.

Cardiology Outpatient Visit Volume (2020–2021)

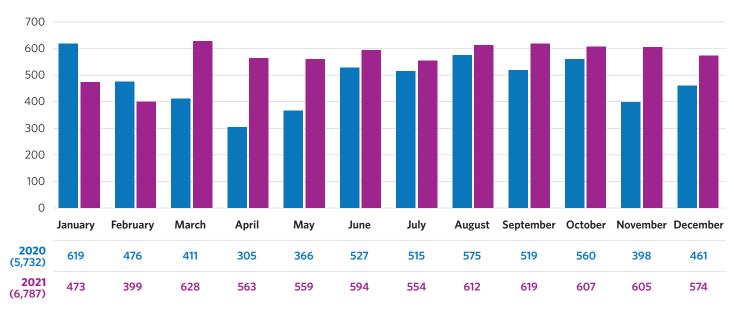
2020 = 9,357; 2021 = 10,962



Data provided by Pediatrix Cardiology.

Total Outpatient Echo Volume

2020-2021



Data provided by Pediatrix Cardiology.

Cardiac catheterization laboratory

The cardiac catheterization (cath) laboratory is used by two different subspecialty groups, the Interventional Pediatric Cardiology team and the Electrophysiology team. The laboratory allows these two teams specialized cath lab equipment to care for patients with a variety of different cardiac conditions. Many of the procedures performed in the cardiac cath lab were previously performed in the operating room, but through the advanced technology of the cath lab equipment, these same procedures are able to be performed in a minimally invasive fashion.

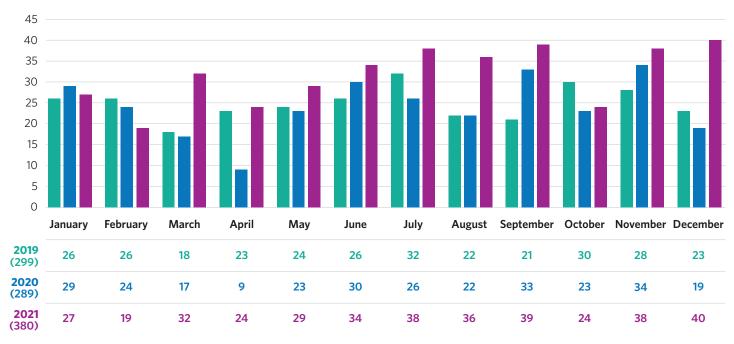
Interventional Pediatric Cardiology is a subspecialty of Pediatric Cardiology and allows physicians to alter a patient's anatomy through the utilization of catheters with various accessories without surgery. Our team of highly trained and skilled interventional doctors has over 45 years' experience in treating structural heart disease through tiny blood vessels.

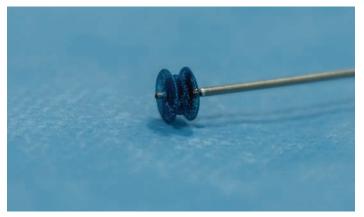
Electrophysiology is a subspecialty of Pediatric Cardiology and focuses on the heart's electrical system and the multitude of things within the body that impact the rhythm of the heart. Our electrophysiology service works with patients of all ages to ensure that they have a stable or safe rhythm through the use of implantable devices like pacemakers and defibrillators.

With advances in modern medicine, babies that are born severely prematurely now survive and often grow to be healthy children with the help of numerous specialists. One of the most common problems in these fragile patients is a blood vessel, called a Patents Ductus Arteriosus or PDA, which remains open and can lead to excessive blood flow to the lungs. Normally, the PDA would spontaneously close within 48 hours after birth. The excessive blood flow to the lungs can lead to the need for a ventilator or supplemental oxygen, delayed lung development, and poor growth.

Total Cath/EP Volume, Monthly

2019-2021





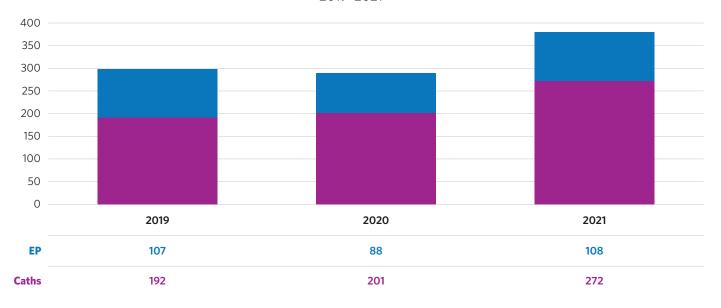


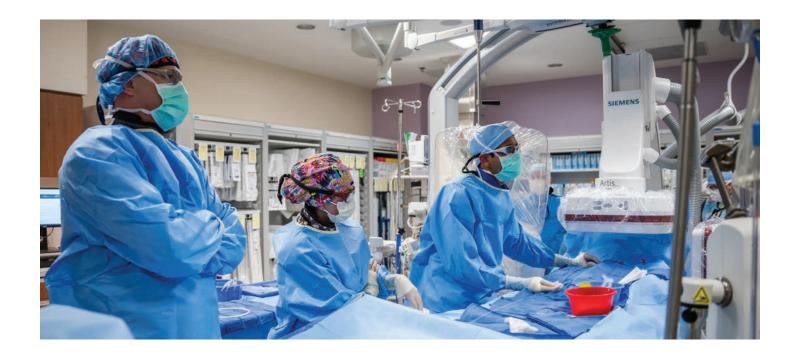
The Piccolo[™] device

The Piccolo device is a new tool developed to close the PDA without the need for surgery. Our Piccolo program allows premature infants as small as 700 grams (~ 1.5 pounds) to undergo PDA closure in the cardiac catheterization laboratory rather than with traditional surgery. Cardiology specialists in cardiac catheterization use a vein in the leg and pass a long plastic tube called a catheter up to the heart and deploy the Piccolo device to occlude the PDA. The procedure takes approximately one hour to complete, is well tolerated by the patients, and has a low rate of complications. At Dell Children's, the Piccolo device is placed by our highly trained and skilled Interventional Cardiology team with the assistance of the Pediatric Cardiac Anesthesiology team.

The unique relationships that our team has with regional neonatal intensive care units (NICUs) affords babies the opportunity to have this specialized procedure without losing continuity of care provided by the referring team. Babies can stay in their current NICU until the team is ready for occlusion. They can then transfer the baby to Dell Children's Medical Center several days before the scheduled procedure, monitor for stability, complete the procedure, and then transfer the baby to their home NICU after several days of stability following the procedure. We have demonstrated great success in safely transferring patients to Dell Children's specifically for the Piccolo procedure utilizing a standard protocol and algorithm.







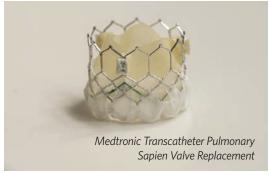
Advanced procedure to replace a heart valve without the need for surgery

Numerous children are born each year with congenital heart problems that specifically affect the pulmonary valve, and this becomes a lifelong issue with the need for periodic valve replacements due to progressive narrowing or leakage. Due to advances in biomedical engineering, it is now possible to replace some heart valves without the need for open-heart surgery. This is accomplished by sewing a new valve, typically made of tissue from a cow or pig, inside of a metal stent. The stent is then mounted on a specialized catheter that is inserted into a vein in the leg and advanced up to the heart where it can be expanded and deployed in the intended location.

Patients must be carefully screened based on their size, anatomy, and severity of valve dysfunction before proceeding with this advanced intervention. There are currently three FDA approved valves for transcatheter pulmonary valve replacement, all of which are available to our team. Once a patient is deemed a suitable candidate, our highly trained team of interventional cardiologists, cardiac anesthesiologists, cardiac nurses, and cath lab staff organize this procedure to include full surgical backup with a surgery team and operating room on standby as a safety precaution.

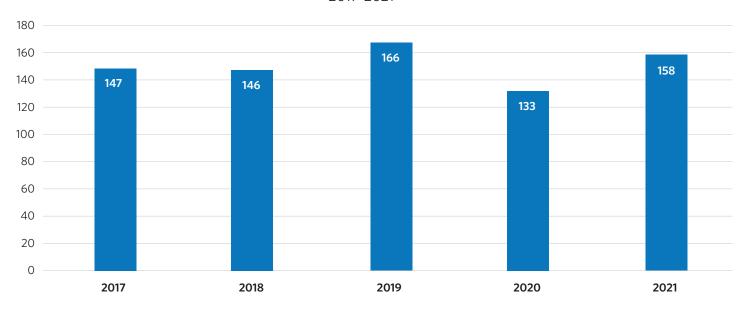
Our Advanced Interventional Catheterization team at Dell Children's has had great success in Transcatheter Pulmonary Valve Replacement (TPVR), which has resulted in fewer open-heart surgeries for these patients over a lifetime. With further advances in medical technology, this procedure will almost certainly be available to a larger portion of our congenital heart patients and result in improved quality of life.





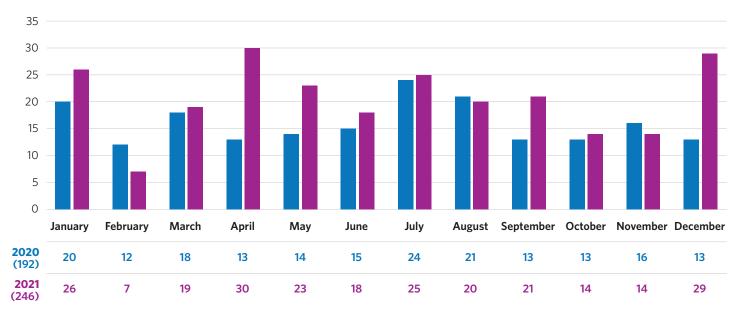
Cardiac MRI Volume by Center

2017-2021



Cardiac Computed Tomography Angiography (CTA) and Magnetic Resonance Imaging (MRI) Volume at DCMC, Monthly

2020-2021



Cardiac Care Unit (CCU)

The Cardiac Care Unit (CCU) is a 24-bed variable acuity unit with a dedicated multidisciplinary team consisting of physicians (both critical care and cardiac hospitalists), advanced practice providers, nurses, respiratory therapists, pharmacists, psychologists, social workers, child-life specialists, therapists (occupational, physical, and speech), and dieticians who round together daily and provide comprehensive care for patients with pediatric and congenital heart disease regardless of age or acuity. Our patients benefit from on-site, cardiac-focused physicians 24 hours a day, seven days a week for both our intensive care and our acute care cardiac patients. Additionally, our commitment to providing the highest quality of care available today through continuous quality improvement includes our partnerships with internationally recognized groups like the Pediatric Cardiac Critical Care Consortium (PC4) and Pediatric Acute Care Cardiology Collaborative (PAC3), and keeps patient outcomes at the core of what we do.

The Cardiac Care Unit is staffed by a dedicated group of registered nurses, many of whom have a Bachelor of Science in nursing degree or higher, as well as many who hold national certification in pediatrics and critical care. The CCU nursing team is committed to providing the highest level of care with compassion and understanding that comes from being dedicated to the TCPCHD program and the families that it serves. Through ongoing continuing education provided by our dedicated cardiac education team, the nursing staff continues to evolve and excel to meet the constantly changing needs of the most fragile patients in our medical center. Blending neonatology, cardiology, pediatrics, and adult care allows the CCU nursing team to provide the highest level of care to all of our patients.

The dedicated Cardiac Respiratory Therapy care team is an integral part of the patient care team and ensures that patients in the CCU have a customized respiratory treatment plan that takes into consideration their cardiac disease and complex cardiac physiology as it relates to various types of respiratory support. The respiratory therapy team, in conjunction with the nursing, advanced practice, and physician teams, uses goal-directed therapy to help patients progress through their hospital stay as quickly and as safely as possible. Through a collaborative effort, the team was able to create a tracheostomy teaching plan that successfully decreased the time patients stayed in the hospital following tracheostomy placement (see story on next page).





Total Dell Children's Medical Center

January 1, 2021 to December 31, 2021

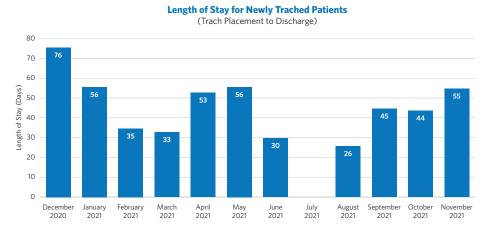
	Patients
Admissions	437
Surgical Admissions	290
Nonsurgical Admissions	147

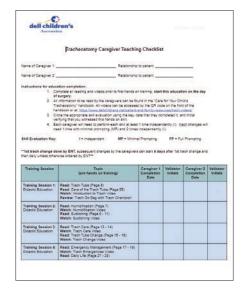
Cardiac Care Unit: a story of quality improvement

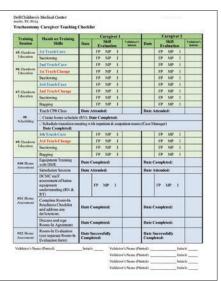
In late 2020, Dell Children's Medical Center began experiencing a rapid increase in the number of patients who had undergone placement of a tracheostomy (a tube placed into the windpipe to help some children breathe better). At the time, the team was relying on an outdated education platform and under-utilizing resources in order to prepare the caregivers for their child's new medical needs at home. This, along with a crippling home nursing shortage, led to increased length of stay and under-prepared caregivers. These issues prompted us to improve our education process for these caregivers to safely care for their newly trached child often without the security of home nursing.

Led by Dr. Daniel Stromberg, we brought together a multidisciplinary team to create a platform that would better educate and prepare these families while simultaneously decreasing length of stay. This new platform includes pre-trach care conferences with all stakeholders to identify any barriers, education for the caregiver that begins on post-op day one, didactic as well as hands-on education sessions, repetitive skills demonstrations, and a thorough room-in readiness and evaluation process to simulate a home environment to ensure all caregivers can successfully execute 24 hours of care for their child while having the medical team nearby.

This new process has led to a 44% decrease in length of stay, which ultimately provided patients with obtaining their home setting an average of 35 days sooner than previous years. After successful trials in the CCU, we expanded this platform to all units at Dell Children's Medical Center and continue to see tremendous progress. Many thanks to Jennifer Simpson, Shaina Weitz, Katherine Dillon, Marty Barnes, Dr. Daniel Stromberg, Dr. Joseph Tayar, Victoria Klabunde, and Rachel Westervelt for their leadership and execution of this ambitious and successful education platform.





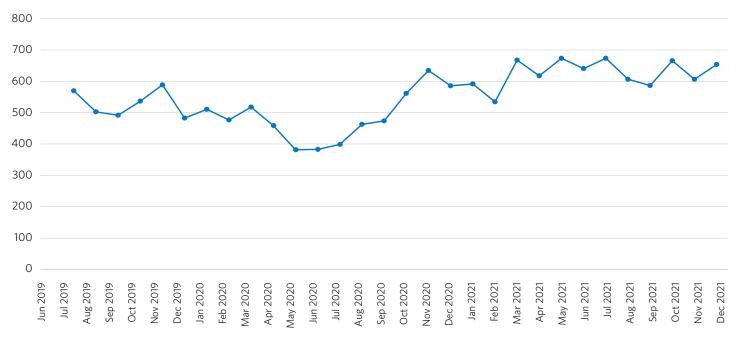


2021 PC4 Quality Metrics

Metric	DCMC Adjusted	PC4 Adjusted
Surgical In-Hospital Mortality	1.38	2.13
Post-operative ECMO Rate	1.65	2.9
Post-operative Cardiac Arrest Rate	3.18	2.92
Post-operative Stroke/Intracranial Hemorrhage	1.29	1.39
Post-operative CICU LOS	10.1	8.69
Post-operative Hospital LOS	13.7	14.5
Post-operative Duration of Mechanical Ventilation	2.26	2.38
CICU Medical Mortality	1.64	4.18
Medical Cardiac Arrest Rate	2.21	2.22

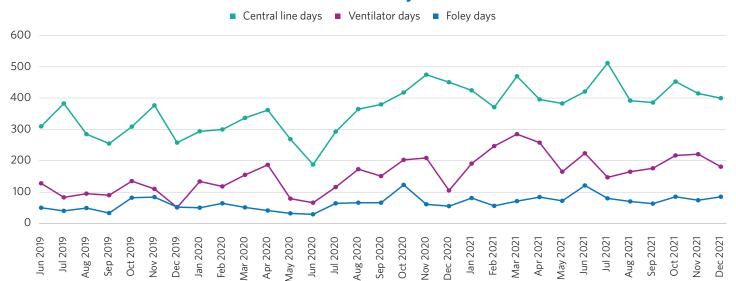
Pediatric Cardiac Critical Care Consortium (PC4) is a multi-institutional collaboration committed to providing transparency of outcomes as a basis for programmatic quality improvement. PC4 focuses on these nine key benchmark metrics as a means to assessing a program's performance when compared to similar cardiac units. The data above reflect a better than expected outcome in 8 of the 9 benchmark areas.

CCU Patient Days





CCU Device Days





CCU in the time of COVID-19

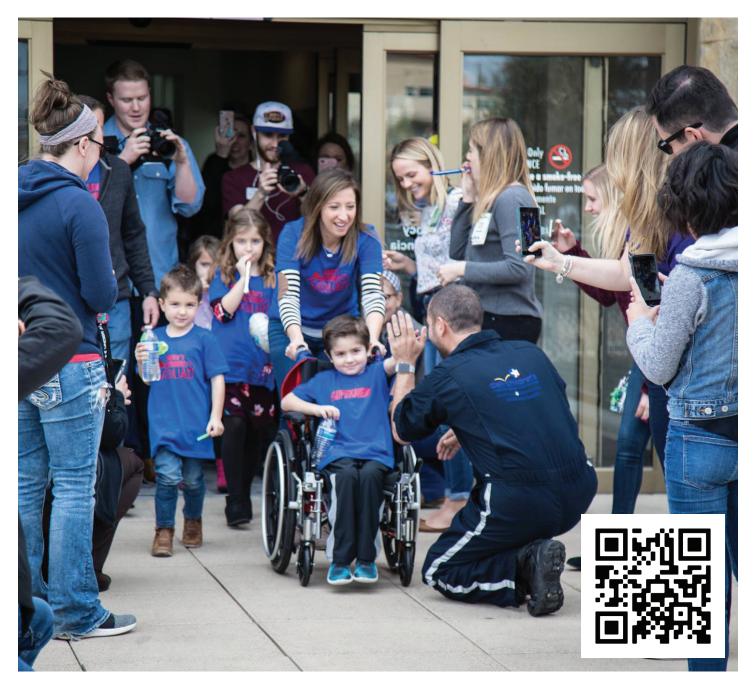
In the early spring of 2020, the COVID-19 pandemic crept into Central Texas and began to change our entire lives, including the way we cared for patients with pediatric and congenital heart disease. With many pediatric hospitals experiencing low volumes as the governor restricted elective surgeries, our CCU maintained high occupancy and acuity as cardiac patients continued to be born and require surgical intervention. The CCU staff eloquently pivoted and adjusted to all of the new restrictions according to each new mandate. The CCU launched into 2021 with an unparalleled sense of team and unity.

Cardiac Care Unit: a patient story

Checking in with Owen Coulter three years after his heart stopped at Dell Children's Medical Center

On December 13, 2018, five-year-old Owen Coulter's heart stopped beating in the emergency room at Dell Children's Medical Center. He underwent 90 minutes of CPR and other critical interventions before his heart began beating again thanks to the interdisciplinary efforts of the TCPCHD team. This now eight-year-old is enjoying a happy life filled with activities any second grader is prone to love, such as riding his bike, fishing, hiking, and building Legos.

"Dell Children's is not just a medical facility," shares Owen's mother Kristin Coulter. "Dell Children's is our family because, even post-discharge, they haven't left our side. We know we can call on them at any time and they'll be there for us, which is why Owen is doing great."



Recovery and the long return to health

Regaining his heartbeat was just the beginning of a long road back to health for Owen. In the Pediatric Intensive Care Unit (PICU), Owen stayed connected to the ECMO machine and a dialysis machine while his breathing was supported by a respirator. "There were five days where he fought for his life," remembers Kristin. "He went into kidney failure. He had multiple strokes. He had blood pools in his brain. It seemed like everything that could go wrong went wrong."

But Owen held on, making incremental improvements with each passing day. After five days, his heart and blood oxygen levels fared well enough that the ECMO machine could be turned off. Later, he came off dialysis. On Christmas Eve, three weeks after "The Incident," Owen was removed from the ventilator and allowed to wake up. "That was the moment when the whole team wondered if he would recognize me and Darin due to the brain damage we feared may have been caused," says Kristin. "The first thing he said was, 'Where's mama?' The whole unit was clapping and cheering."

After a month in the PICU, Owen was moved to the rehabilitation unit where his body and mind were retrained for normal functioning. "He had to learn everything again," explains Kristin. "He had to learn how to eat and talk and crawl and walk. We sort of went back to the infant stage." With 30 days of rehab under his belt, two months following his cardiac arrest, Owen was discharged from Dell Children's to return home with his family. With the assistance of a walker, Owen was able to walk a few steps on his way out of the hospital.

Continuing collaborative "whole-person" care

For the first year following "The Incident," Owen received intensive, ongoing therapy across a range of specialties and disciplines at Dell Children's. "We basically lived at the Dell Children's outpatient center in Cedar Park, where Owen had physical therapy and occupational therapy multiple times a week," says Kristin. "He went in not being able to walk and now has what we call his 'Owen Run.'"

The damage done to Owen's kidneys continues to be monitored by nephrologists. Owen also continues to receive annual checkups in other areas, including his vision and hearing. He receives routine neurological testing to chart his progress as he's recovered from the strokes he experienced, as well as neuropsychological support.

"The fact that we don't have to worry about trying to get to other hospitals in big cities for Owen's care, the fact that the city is growing to the point that we have the technology and the expertise and we're recruiting top physicians, that's real peace of mind," shares Kristin.

"We're still healing, but it's a very positive healing journey that we're going through. We know there may be a point in the future when we have to intervene again for Owen, but we find some relief in knowing the whole Dell Children's team is with us."

Read Owen's story, including a full account of his encounter at Dell Children's by scanning the QR code on the previous page.

Cardiac hospitalists

The cardiac hospitalists are a select group of pediatric hospitalists at Dell Children's Medical Center that take care of children with congenital heart disease who are non-ICU status. These can be children who have not had surgery yet and have been admitted for feeding issues, medication management, or illness, or children who have had heart surgery and are at the tail-end of their recovery period in the hospital. The team works in conjunction with the cardiology, cardiothoracic surgery, anesthesia, and cardiac ICU teams, as well as associates in nursing, respiratory therapy, therapies, pharmacy, social work, case management, and child life. These physicians are responsible for a large part of the care coordination of these patients, particularly in the planning for discharge home. 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. Ensuring that families have all of the supplies and skills that they need to provide care at home is often complicated and overwhelming, but our multidisciplinary team ensures that families are adequately trained and armed to take on the task.

Cardiac advanced practice provider team

The TCPCHD multidisciplinary team includes over 30 advanced practice providers (APPs). APPs, including both nurse practitioners and physician's assistants, are incorporated into every aspect of care within the program. APPs care for patients in both the inpatient and outpatient care setting, providing comprehensive cardiac care to patients and functioning in a variety of roles, including assisting in the operating room, managing patients in the Cardiac Care Unit, and following patients in the clinic. The APPs are actively engaged in ongoing research initiatives as well education and quality improvement. Throughout our program, APPs ensure that patients receive the highest level of integrated compassionate care based on the things that patients and families value most.

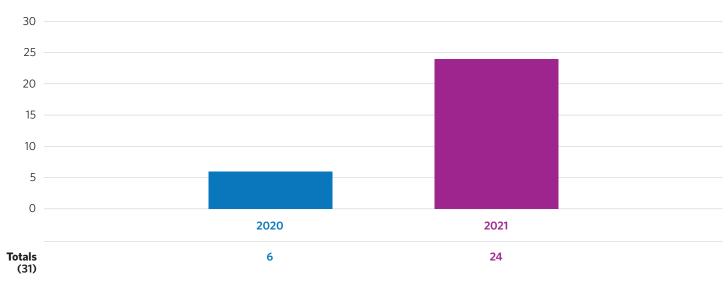


Heart failure and transplantation

Our Heart Failure, VAD (Ventricular Assist Device), 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. Led by Chesney Castleberry, MD and Carlos Mery, MD, the Heart Failure, VAD, and Transplant Program has been caring for patients with advanced heart failure since 2019 and performed its first transplant in October of 2020. Since then, the program has performed a total of 11 cardiac transplants on children and adults with no other treatment options.

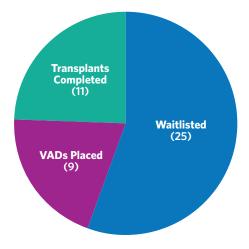
Transplant Evaluation Volume

2020-2021 (YTD)



DCMC Patients—Waitlisted, VADs, Transplants

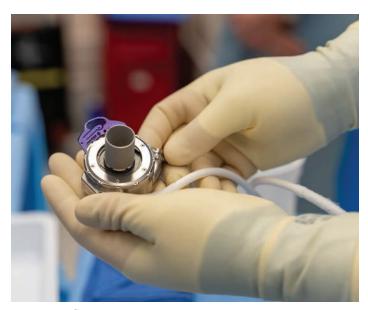
2019-2021



Mechanical Circulatory Support Program

The Mechanical Circulatory Support (MCS) Program at Dell Children's Medical Center 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 is a multidisciplinary team of physicians, perfusionists, nurses, and respiratory therapists who provide care for patients being supported. The Extracorporeal Cardiopulmonary Resuscitation or E-CPR 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 cause of the arrest. Our MCS Program includes the use of peripheral extracorporeal membrane oxygenation (ECMO) and a variety of ventricular assist devices such as the Heart Mate 3™ and Berlin Heart® among others. The MCS Program is committed to matching each individual patient with the best type of support for their particular problem, and through our relationship with the engineering program at The University of Texas at Austin, we hope to contribute to the body of available devices.





Berlin Heart®

Heart Mate $3^{\scriptscriptstyle\mathsf{TM}}$

Mechanical Support

July 31, 2018-December 31, 2021

Perioperative Mortality

Type of Support	Volume	N	%
Temporary (ECMO)	29	15	51.7%
ECMO post-cardiotomy during same hospitalization	15	10	66.7%
Durable (VAD)	8	0	0.0%
Heart transplant	10	1	10.0%

Single Ventricle Program

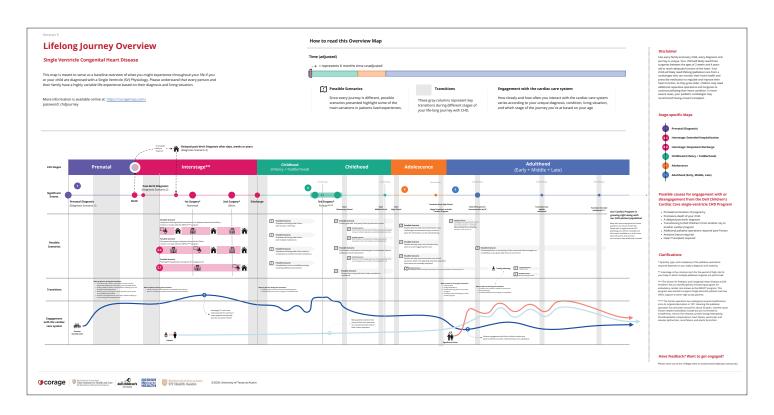
IMPACT: Interdisciplinary Monitoring Program for Ambulatory Cardiac Care of Central Texas

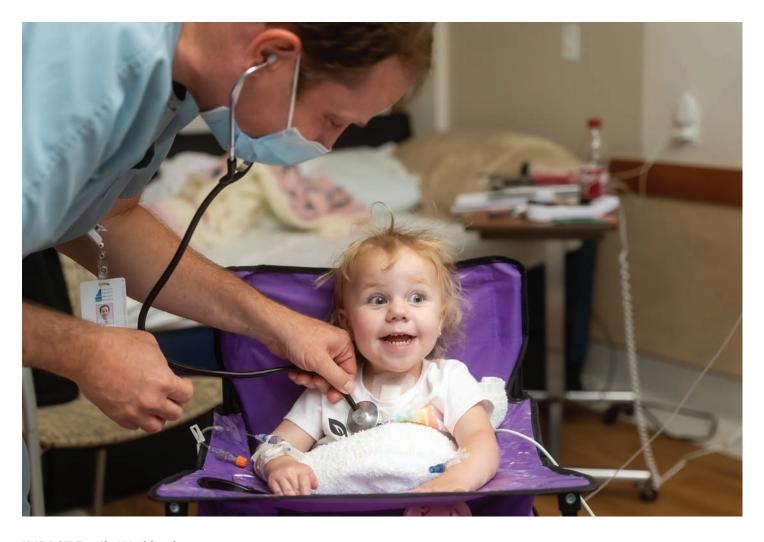
The Single Ventricle Program, led by Eileen Stewart, MD, diagnoses, treats, and manages the care of children with single ventricle heart defects from prenatal life through adulthood. We have a dedicated Interdisciplinary Monitoring Program for Ambulatory Cardiac Care of Central Texas known as the IMPACT Program, which is a home monitoring program for highrisk infants who are between the stages of their single ventricle palliation. Our unique collaboration with Rahel Berhane, MD and the Comprehensive Care Clinic provides seamless outpatient pediatric care to these fragile children following discharge, during the interstage period. The entire IMPACT team rounds together regularly to discuss current status and overall goals. We have implemented a robust electronic surveillance program that allows our clinicians to follow in real time how our patients are doing at home. This type of consistent collaboration ensures that regardless of where the patient is at that time, the entire team, inpatient and outpatient, is involved and up to date.

Journey maps

Our program is focused on improving the lifetime journey of patients with congenital heart disease. Through our **Health** Transformation and Design Program, our team embarked on an ambitious initiative with the Value Institute for Health and Care and the Design Institute for Health at Dell Medical School to better understand the lifetime journey for these, our most vulnerable patients.

After interviewing more than 150 patients and families, we were able to create a series of journey maps that depict the incredible complexity of single ventricle palliation and the impact that the journey has on the patient and the entire family unit. It is this unique focus on patients and their families and our desire to alleviate the burden of care by providing accurate and insightful anticipatory guidance that sets our program apart.

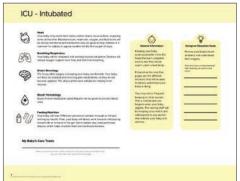


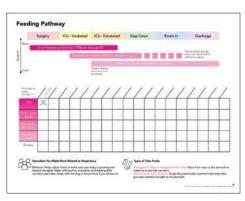


IMPACT Family Workbook

In an effort to help our families navigate the complex time during their child's first six months of life, we created the IMPACT Family Workbook as a resource for families. Through a human-centered design approach, the workbook was developed by a team of UT Design in Health graduate students. The goal was to create design interventions that would provide information to help families transition from hospital to home after their child's first surgery. Recognizing that each family and baby's journey is unique, the workbook, available in English and Spanish, is customizable.









Physical and occupational therapists work with Zaria after her Berlin Heart placement surgery.

Psychosocial team

The impact of congenital heart disease on the emotional well-being of patients and their families is undeniable. Wanting to ameliorate that impact, our integrated psychosocial team consisting of clinical psychologists, social workers, and certified child life specialists (CCLS) meets with all of our patients admitted to the CCU as well as every patient undergoing evaluation for heart surgery. We administer the **Ages and Stages Questionnaire-3 (ASQ-3)**, the **Pediatric Quality of Life Inventory (PedsQL)**, the **Depression and Anxiety and Stress Scales (DASS-21)**, and the **Psychosocial Assessment Tool (PAT)** as a way of screening our patients and families. 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 implement appropriate interventions to maximize their lifetime potential.

Additionally, our social workers and clinical psychologists hold academic appointments at Dell Medical School at The University of Texas at Austin. 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 as necessary.



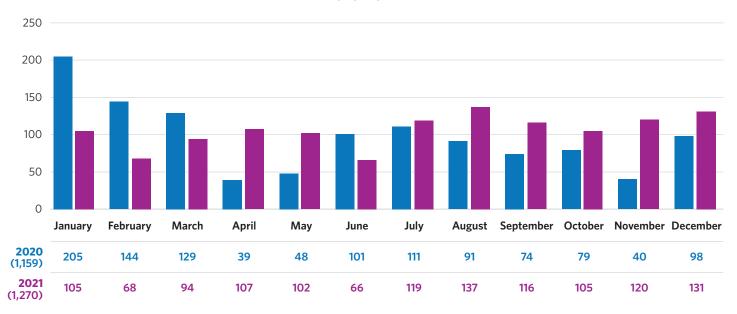
Alyssa Geis, CCLS (right) with her patient Grace Jennings before a major surgery.

Adult Congenital Heart Disease Program (ACHD)

The Adult Congenital Heart Disease (ACHD) Program diagnoses, treats, and manages the care of adults with congenital heart disease. Our team is comprised of internationally recognized and highly specialized physicians across different disciplines who provide a wide range of services, from evaluation, testing, and diagnosis to medical management, home monitoring, rehabilitation, heart surgery, and more. 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 improve the efficiency and effectiveness of the care provided to adults with congenital heart disease. Through our collaboration with Dell Medical School at The University of Texas at Austin and UT Health Austin, the clinical practice of Dell Med, and Ascension Seton, we can provide full-service care to our adult patients in a thoughtful and comprehensive way. We are dedicated to helping adults with congenital heart disease navigate their lifelong journeys while mitigating disability and optimizing their health.

Adult Congenital Outpatient Visit Volume

2020-2021



Data provided by Pediatrix Cardiology.

ACHD and Cardiac Cath Lab: a patient story

Lessons in persistence, and the amazing healing journey that started with a child's next footstep

"It was December 13th, just 12 days until Christmas, and I was 13 years old," she says, remembering the days after her first surgery, quite a long time ago. "I had been so sure that, after they fixed my heart, I was going to get right up and just feel better. That I was going to go out and run, and play, and do everything I wanted to do. But instead, it felt like someone was sitting on my chest. My mother, and my father, my brother and my sister, they all stayed with me in the hospital, all day, and all night, they rotated so someone was always there to hug me. They did everything they could possibly do for me. But if I wanted to be home for Christmas, which is all I wanted, I knew I had to get up and walk, every day. And I had to do it for myself.

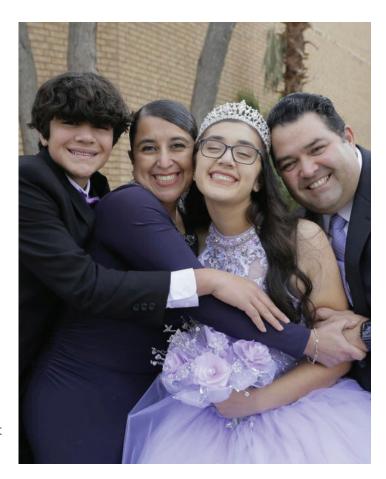
"I can still remember that long hallway, where I set my goals: the banister, the wall, the third tile. It seemed so far away. Three times a day, out in that hallway. Get to the third tile, maybe the fourth tile. One more step. One more. Three times a day. Four times a day. Every day. Until I finally got home, on Christmas."

Her name is Patty, and she's 45 years old. She's the mother of two, a native of El Paso, Texas, and a resident of Austin for the last 10 years. She's a dyslexia therapist, and one of the 1,071 teachers in Texas who are National Board Certified. National Board Certified teachers are recognized as meeting and maintaining the highest, most rigorous standards for their profession, which is certainly a description that fits Patty, in any number of ways. She's a motivated, committed, loving woman of faith who has also just completed her educational diagnostician certificate, which means that she's trained to use academic records, information obtained from parents and teachers, and a range of cognitive and achievement tests to assess and diagnose learning problems in students.

And, because of a congenital heart defect that her doctors and her parents originally and optimistically hoped was a "murmur that would fix itself in time," she had her first open-heart surgery when she was 13 years old. She had her second surgery when she was 19; her third at the age of 24; and her most recent surgery, which was a minimally invasive procedure during which she received a new bovine heart valve, on July 28th of 2021, to replace the porcine heart valve that was supposed to have lasted 15 years, but actually

gave her 20. Her doctor is D. Byron Holt, MD, FSCAI, Chief of Pediatric Cardiology, and an Interventional Cardiologist at TCPCHD. While her journey has not always been easy, it has given her a unique and valuable perspective on how a serious heart condition can affect a person over the course of a lifetime. And she knows, and can describe, what it's like to be a patient who experiences heart care as a child, an adolescent, a young adult, and as a mother with children of her own which, she recalls, was a weighty concern for a young woman looking forward to a family.

"At first, naturally," she says, "I didn't know if I would ever be able to have kids. But after my valve repair, when I was 24, just six months after I got married, my doctor assured me that I would be fine. But still, you know, each time I was pregnant, I would ask, 'Can you check? Okay. Now, can you check again?' I even had Dr. Holt double-check my daughter, who is 15, and my son, who is 12, last fall, because they're both involved in sports and all the other school and outside school activities."



The time came for the pulmonary valve she received 20 years ago to be replaced. In April, 2021, she told Dr. Holt that she was having a little trouble finishing her whole hour of an online Zumba class. After a cardiac MRI, it was time to make a plan because, as a teacher, even though her procedure would be conducted in a minimally invasive way, through an artery in her leg, which would substantially reduce her recovery time, scheduling was a concern. Ideally, she was hoping to get things done during the summer break. Even with all the preparation that was required, she went into Dell Children's Medical Center on July 28th, and it was, she says, the best hospital experience of her life.

"Everyone was so amazing," she says, "so attentive and compassionate. My husband was able to stay with me overnight. Everyone knew me, and was genuinely concerned about me. You can feel it in the way they talk to you, and the way they do their work, especially Dr. Holt, who is such a remarkable doctor. He communicates so well, which is probably the most important thing. It's the relationship we have, the connection. I know he's there for me, for whatever I need, whenever I need it. He'll take the time to answer all my questions, and I know I can ask questions until I really understand the answers. And, in two days, I was home."

After a lifetime experiencing health issues most of us would find difficult to imagine, when asked what she would say to a young boy or girl facing their own heart surgery, Patty is clear and focused in her advice. "I would be honest, and reassuring," she says. "I would let them know that right after their procedure, they are going to have some things to do that might seem like they are pretty hard. But I would tell them that I know they can do those things, because I did them. I would tell them to listen to the doctors, and to do their breathing exercises, to get up when the time comes, and walk, step by step, day by day, even it if feels really far at first. I would encourage them to set their own goals, but also to know it's okay to stop, it's okay to take a breath. But then, they should keep going. They should have faith, most importantly, in themselves."

For parents who might be helping their own children recover and thrive, her advice is equally concise.

"There will be times when your child will be sad," she says. "It's natural, and it's understandable. They will have just experienced something so big that it will probably be a long time before they can really comprehend it. But what they need to know, what they need to believe, is that you, their mother, their father, you are on this journey with them. When

I was sad, my mom would hold me, she would hug me. She comforted me, and she assured me that everything was going to be okay. She made sure that I knew that she was going to be there with me. And then, when the time came for a walk, she made sure I knew that she was going to be there, with me, every step of the way."





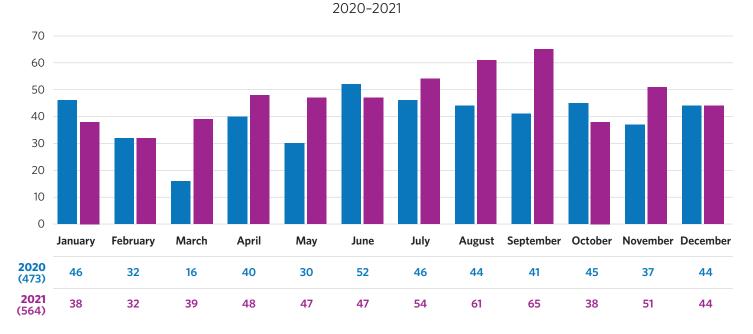
Perinatal care team

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 at 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 make sure 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.

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.

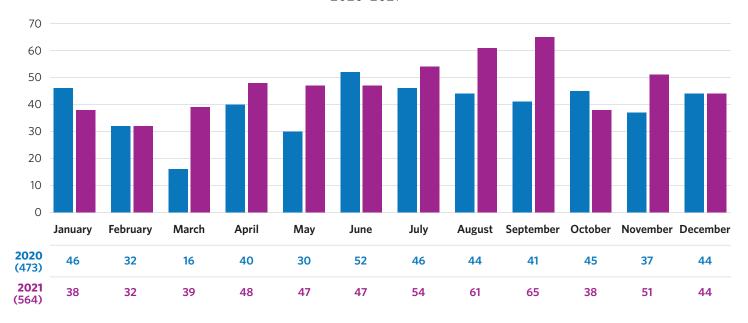
Fetal Cardiology Outpatient Visit Volume



Data provided by Pediatrix Cardiology.

Total Outpatient Fetal Echo Volume

2020-2021



Specialized delivery unit at Dell Children's Medical Center

The unit is an 11-bed, state-of-the-art delivery unit that is staffed 24 hours a day by an experienced obstetric trained nursing care team, anesthesiologists, and obstetricians. The unit includes two operating rooms, five labor and delivery suites, and six antepartum/postpartum suites. All suites include private bathrooms, sleeping accommodations for partners, and regular inroom meals. Mothers that require early admission stays before delivery will be admitted and receive care until their delivery.



Neurodevelopmental Outcomes Program

Children with complex congenital heart disease are at higher risk for neurodevelopmental disabilities than other children. Babies born with congenital heart disease have brains that develop and mature at slower rates in utero. Additionally, babies with congenital heart disease and lower oxygen levels may also experience developmental delays.

The Cardiac Neurodevelopmental Outcomes Program tracks, monitors, and manages the development of children with congenital heart disease who undergo surgical intervention as infants as well as those with accompanying genetic syndromes.

This program detects and treats developmental delays with the goal of optimizing each child's development. Developmental delays 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), learning disabilities, and more.

Through an integrated approach, our Cardiac Neurodevelopmental Outcomes Program:

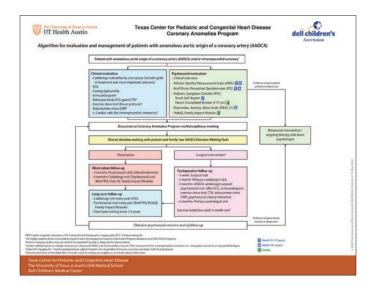
- Provides expert evaluation and diagnosis
- Integrates caregivers in the assessment process, facilitating care coordination between caregivers and experts across specialties
- Utilizes advanced imaging, neurological, and neuropsychological testing
- Implements latest evidenced-based therapies to monitor and treat patients

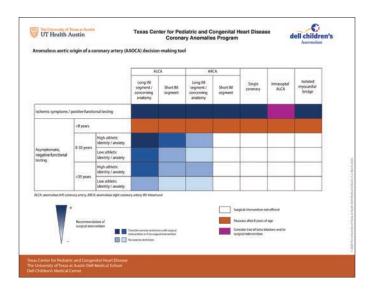
The team conducts weekly screening of all patients admitted to the Cardiac Care Unit, rounds weekly on all at-risk patients with therapists and child-life specialists, provides weekly documentation in the electronic health record regarding assessment and plan for inpatients as appropriate, and conducts weekly clinics for continued outpatient assessment and management following an established risk assessment timeline with specified domains, including cognitive, motor, language, adaptive, social-emotional, and executive functioning as appropriate based on age.



Coronary Anomalies Program

The Coronary Anomalies Program diagnoses, treats, and manages the care of children, adolescents, and adults with anomalous coronary arteries. The program includes cardiologists, cardiac surgeons, radiologists, and psychologists. What makes this program unique is the shared decision-making model that the team utilizes in creating the patient's plan of care. Our management strategy includes a standardized approach to diagnosis and treatment ensuring that the data we use to make decisions is 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 goalsetting, and that the patient is supported in their decision-making by our dedicated clinical psychologist who helps the patient and their family navigate the process.





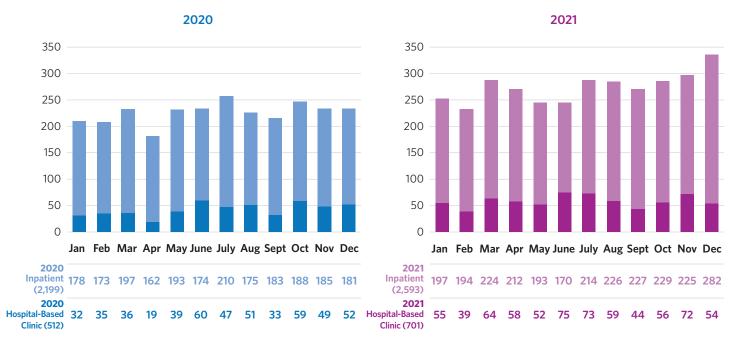
Anomalous Aortic Origin of a Coronary Artery, or AAOCA, is associated with an increased risk of sudden cardiac death (SCD). It tends to happen unexpectedly to young athletes (children, teenagers, and young adults) while exercising. Unfortunately, the actual risk for each individual patient and the effectiveness of different therapies are still unknown. This can lead to significant anxiety in patients and families, especially as most patients are diagnosed incidentally while undergoing workup for unrelated issues. Our program not only offers world-class surgical intervention; we support the whole family system from the time of diagnosis, and beyond. One of the unique ways we support families is by integrating psychological support from the time of diagnosis through the AAOCA journey. This allows us to promote and focus on each patient's and family's goals and provide guidance as they negotiate this unexpected terrain. Our program is also involved in multiple research initiatives to advance our understanding of this important disease.

Hospital-based multidisciplinary cardiac clinic

Some of our cardiac patients have very complex care needs and require a focused team approach in the outpatient setting. Rather than have patients schedule multiple appointments with different members of their care team, we have a centralized multidisciplinary clinic that brings all of the necessary team members to the patient. Our hospital-based multidisciplinary clinic brings together cardiologists, cardiac surgeons, cardiac anesthesiologists, pharmacists, dieticians, therapists (physical, occupational, and speech), social workers, psychologists, and other subspecialty services as needed 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 patients, and 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 and children miss school by minimizing their trips to the clinic. This clinic is just another way that our team is rethinking how we approach congenital heart disease.



Dell Children's Medical Center Total Echo Volume



Data provided by Pediatrix Cardiology.

Health Transformation and Design Program

The goal of the **Health Transformation and Design (HTD) 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 valuebased 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 program includes research faculty, outcomes specialists, quality specialists, research coordinators, post-doctoral fellows, data architects, and graduate and undergraduate students working together to improve the care of patients through outcomes measurement, quality improvement, research, and innovation.

The HTD Program collaborates intimately with different entities within The University of Texas at Austin and beyond to achieve our goal of improving care. Some of our main collaborators include:

- The Value Institute for Health and Care (VIHC) at Dell Medical School and McCombs School of Business. The goal of the VIHC is to accelerate the transformation to high-value healthcare delivery. In healthcare, value is created by improving the health outcomes that matter most to individuals and families, while at the same time decreasing the expense and time required to achieve this improvement. Through education, research, and thought leadership, the institute serves as a resource for those seeking to catalyze change in how healthcare is delivered.
- The Design Institute for Health (DIH) at Dell Medical School and the College of Fine Arts. Design is acknowledged as a creative, human-centered method to identify and solve problems, yet has been noticeably absent in healthcare. The DIH is a first-of-its-kind institute that aims to bridge that gap by incorporating human-centered design in solving the most challenging problems in healthcare.
- Cockrell School of Engineering. As part of our relentless pursuit to transforming healthcare and making it better for the patients that we serve, we have created a unique partnership with the Division of Biomedical Engineering to train medical students and graduate biomedical engineering students in the process of medical technology innovation. Through the Clinical Innovation and Design (CID) Program, students engage in a hands-on nine-month fellowship to identify problems affecting patients with congenital heart disease and develop technological solutions to address these problems. Our program is also collaborating with the James Willerson Center for Cardiovascular Modeling and Simulation to better understand the nuances of heart disease through computational biomechanical models in order to find ways to improve the way care is provided.

Academics by the Numbers

	2019	2020	2021
Manuscripts	14	18	8
Abstract - Posters	1	9	28
Abstract - Presentations	3	8	10

In addition to many in process

Unique fellowship

The Health Transformation and Design Program and the Value Institute for Health and Care (VIHC), a collaboration between Dell Medical School and the McCombs School of Business, came together to design a unique fellowship for physicians-intraining to study and research valued-based healthcare delivery for children with heart disease and their families.

The Health Transformation Fellowship recruits emerging leaders with a unique interest in cardiac care and high-value healthcare. This a new program for physicians-in-training launched in 2019 and focuses primarily on the congenital heart disease (CHD) population. The fellow earns a Master of Science in Health Care Transformation (MSHCT) while also learning to design and lead services that achieve better health and value for the people they serve. The degree equips leaders and emerging leaders across the healthcare sector with the knowledge and skills to design and lead healthcare services that achieve better health and better value for individuals and families. Our inaugural fellow Andrew Well, MD decided to join our faculty at the end of his fellowship as the inaugural Assistant Director of Health Transformation and Patient Experience.

The Assistant Director for Health Transformation and Patient Experience role bridges the gap between clinical research and clinical implementation. Through traditional and novel research methodologies, the goal is to identify opportunities to rethink and redesign congenital heart care in a more value-based, empathic, and patient- and family-centered way. By understanding the outcomes that matter most to patients and families as well as the gaps in care that they perceive, innovation in care delivery can be targeted to these gaps to improve those outcomes that matter most. Leveraging technology and design, findings from research can then be rapidly applied to clinical care to improve care and the care experience.







"As the inaugural Health Transformation Fellow in Congenital Heart Surgery at the Texas Center for Pediatric and Congenital Heart Disease, I was able to hone my skills in value-based health transformation and implementation. The unique opportunity to work with and learn from the cardiac specialists in TCPCHD and health transformation experts at the Value Institute for Health and Care at The University of Texas at Austin allowed me to grow as a clinician and researcher as well as improve my skill and understanding of healthcare delivery implementation. My experiences as a fellow drove a shift in my career focus to value-based, patientcentered care design and delivery. In my new role, I am leveraging these skills to truly rethink and redesign congenital heart care around the outcomes that matter most to patients and families. This will not only continue to improve the care provided but will improve the lived experience of patients, their families, and other loved ones in a meaningful way."

- Andrew Well, MD

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About Ascension Texas

In Texas, Ascension operates Ascension Providence 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 115 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 150 hospitals and more than 50 senior living facilities—in 20 states and the District of Columbia. Visit www.dellchildrens.net

About 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 to designed to help our patients reach the goals that matter most to them — in the care room and beyond. Visit www.uthealthaustin.org

About the Partnership between Dell Children's Medical Center and UT Health Austin

UT Health Austin is the clinical practice of the Dell Medical School at The University of Texas at Austin. The partnership 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 the field of pediatric and congenital heart disease to build an integrated system of care that is a collaborative resource for clinicians and their patients.



Contact us



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