



Phoenix Children's Heart Center  
At the very heart of family-centered care.





# President's Message



## Dear Colleagues and Community Friends,

Phoenix Children's Heart Center is the premier regional referral center in the Southwest and the fifth largest program of its kind in the U.S. It offers the most comprehensive inpatient and outpatient pediatric cardiac care services to infants, children, teens and adults with congenital heart defects, rhythm disturbances, heart failure and other cardiac-related problems. The Phoenix Children's Heart Center is comprised of a multidisciplinary team, which includes subspecialty-trained physicians and cardiac nurses who provide advanced family-centered care for simple and complex heart conditions.

Under the leadership of Dr. John Nigro and Dr. Mitchell Cohen, the Phoenix Children's Heart Center has grown into one of the largest and most experienced heart centers in the nation. With the help of our entire Heart Center team of highly dedicated cardiac intensivists, cardiothoracic surgeons, cardiologists, cardiac nurse practitioners, nurses, respiratory therapists, pharmacists, nutritionists, child life specialists and social workers, this was another phenomenal year for the Phoenix Children's Heart Center with many noteworthy accomplishments. Most notably, once again the U.S. News & World Report ranked Phoenix Children's Heart Center among the best in the nation for Cardiology and Cardiovascular Surgery. Also, the Children's Heart Center recently earned the top three-star rating from The Society of Thoracic Surgeons, signifying that Phoenix Children's congenital cardiothoracic surgery outcomes are among the best in the country.

It's very gratifying to see these accomplishments. I am proud of the entire staff and physicians for their role in achieving these milestones, as it shows their commitment to providing the highest quality and most advanced pediatric care. You will not find this quality, experience, or breadth of services anywhere else in Arizona.

In this report, you will read about how the Phoenix Children's Heart Center team is developing new protocols, tools, research and education. You will see how we are addressing complex cardiac medical issues in novel ways. I am excited to share with you the exceptional accomplishments of the Phoenix Children's Heart Center.

Sincerely,

Robert L. Meyer  
President and Chief Executive Officer  
Phoenix Children's Hospital





# Welcome

## Welcome to Our Heart Center!

Phoenix Children's Hospital is ranked 16th in the nation for Cardiology and Heart Surgery by the U.S. News & World Report's 2015-16 Best Children's Hospitals report. We are the only Arizona pediatric hospital to make this highly coveted list.



This past year has witnessed significant national change in how patients are cared for, how patients are insured and the evolving public engagement in determining quality and transparency of care. With these changes, Phoenix Children's Heart Center has committed to the evolution of comprehensive family-centered care and to provide a network of regional care for children in the Southwest. Phoenix Children's Hospital is home to the largest multidisciplinary heart center in the Southwest, combining excellence across cardiac surgery, cardiology, critical care, anesthesia and nursing.

Notable achievements and developments over the past year include the initiation of public reporting of post-cardiac surgical outcomes by Phoenix Children's Hospital through the Society for Thoracic Surgery (STS) Congenital Heart Surgery Database. Phoenix Children's Hospital was awarded a coveted 3-star rating by the STS, which is the highest possible rating given by the STS. Only five other programs out of the 120 national participating programs share this distinction.

Other notable accomplishments in 2014-15 include the expansion of the Heart Transplant Program in number and complexity of transplants performed. Our Heart Failure Program continues to grow now with subspecialty clinics for children with cardiomyopathies, neuromuscular disorders and failing single ventricles. There have been parallel developments and advancements in our critical care, fetal cardiology and advanced cardiac imaging programs, along with expansion of our EP outreach program. Our Adult Congenital Heart Disease Program has witnessed tremendous clinical and academic growth in collaboration with the Mayo Clinic Scottsdale and an unprecedented number of regional congenital heart programs. With all of these achievements, the U.S. News & World Report's 2015-16 Best Children's Hospitals report increased the Phoenix Children's Heart Center ranking from 40th to 16th in the nation.

Our physicians, advanced nurse practitioners and nurses remain committed to building, growing and sustaining a world class heart center through excellent clinical outcomes, innovative research, education and a dedication to continue quality improvement in a family-centered environment.

We are proud to be transparent in our programs and outcomes. We look forward to working with you to provide the best and safest care.

*Thank you for your interest in our Heart Center.*

Mitchell Cohen, MD, FACC, FHRS  
Co-Director, Heart Center  
Chief, Pediatric Cardiology

John Nigro, MD  
Co-Director, Heart Center  
Chief, Cardiothoracic Surgery



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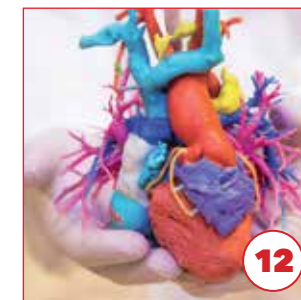
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Cardiothoracic Surgery



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# Cardiothoracic Surgery

★★★ The Society of Thoracic Surgeons (STS) designated the Cardiothoracic Surgical Program at Phoenix Children's Heart Center a 3-star program; the highest designation a program can receive based on patient risk adjusted surgical survival. Patient survival following cardiothoracic surgery is statistically greater than the overall survival rate reported by the STS database.

The Cardiothoracic Surgical Program at Phoenix Children's Heart Center provides comprehensive surgical care for patients from birth through adulthood with congenital heart disease in a family-centered environment.

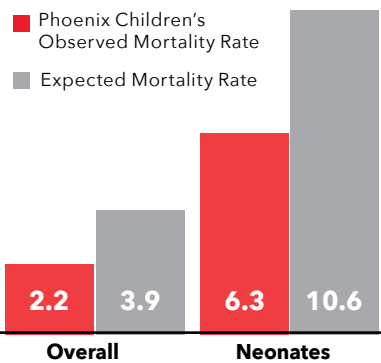
The Heart Center's comprehensive surgical program is the largest in the Southwest and performed 550 cardiothoracic surgical procedures in 2014.

The program continues to report data and outcomes to the Society of Thoracic Surgeon's (STS) Congenital Heart Surgery Database and is a strong advocate for public reporting and transparency of outcomes. In early 2015, the STS initiated public reporting of surgical outcomes and the Cardiothoracic Surgery Program at Phoenix Children's Heart Center became one of the first participating programs.



## STS Risk Adjusted Mortality Rate 2011 – 14

Survival after congenital heart surgery at Phoenix Children's Hospital is statistically greater than expected when adjusted for patient complexity.



The Phoenix Children's Heart Transplant Program continues to grow in scope and depth. The team serves as the only pediatric heart transplant program in Arizona and has a growing experience with ventricular assist systems. In 2014, ten children underwent heart transplantation at Phoenix Children's Hospital with 100% operative survival, making it the 16th busiest pediatric transplant program in the country by volume.

The Cardiothoracic Surgical Program continues to collaborate with Dignity Health St. Joseph's Hospital and Medical Center and Mayo Clinic in Arizona, while performing 32 adult congenital heart surgeries in 2014.

## Survival Rate in Percent

OPERATION	VOLUME	PHOENIX CHILDREN'S	STS
Ventricular Septal Defect Repair	145	99.3	99.3
Tetralogy of Fallot Repair	59	100.0	99.0
Arterial Switch Operation	31	100.0	97.3
Norwood Procedure	35	97.1	84.4

## 2014 Highlights

**550**  
Cardiothoracic operations

**95.1%**  
Neonatal survival rate  
(STS rate 90.8%)

**98%**  
Overall survival rate  
(STS rate 96.7%)





# Cardiac Anesthesiology



**This group of 20 specially trained and experienced Anesthesiologists provides state-of-the-art care for patients undergoing cardiovascular surgery.**

The Pediatric Cardiovascular Anesthesia Program at Phoenix Children's Heart Center is supported by Valley Anesthesiology Consultants. They provide services for the Heart Center patients with congenital and acquired heart disease.

This group of 20 specially trained and experienced anesthesiologists provides state-of-the-art care for patients undergoing cardiovascular surgery with and without cardiopulmonary bypass. They also provide services for patients who require diagnostic, interventional and hybrid procedures in the cardiac catheterization laboratories.

The physicians also care for children needing anesthesia or sedation for echocardiography and computed tomography (CT) or magnetic resonance imaging (MRI) cardiac imaging studies. As part of long-term continuity of cardiac care, cardiac anesthesia services are utilized for inpatient and outpatient non-cardiac procedures in various surgical specialties, interventional radiology, endoscopy and pediatric dentistry.

The group provides consultation and support for cardiac patients undergoing procedures in the intensive care units, as well as assistance with pain control and airway management for other care areas of the Hospital. The teaching activities for the Cardiac Anesthesia Section include instruction for anesthesia residents from the University of Arizona, Mayo Clinic Scottsdale, the Pediatric Intensive Care Unit and Emergency Medicine Fellows. The anesthesiology group is actively involved in clinical data collection through the Anesthesia Module of the Society of Thoracic Surgeons National Database.





# Fetal Heart Program

Our fetal cardiac program has greater than 98% concordance with postnatal diagnosis.



The mission of the Arizona Pediatric Cardiology Fetal Heart Program at Phoenix Children's Hospital is to provide state-of-the-art, comprehensive perinatal cardiac care to the mother and fetus with compassion and coordination from multidisciplinary specialists. The Fetal Heart Program has the fundamental building blocks to accomplish our mission and goals.

**Our advanced trained fetal cardiologists performed more than 1,550 fetal echocardiograms and cardiac consultations in 2014 - both in the outpatient and inpatient settings.** Alongside our fetal cardiologists, highly experienced fetal cardiac sonographers perform thorough fetal cardiovascular evaluations using advanced ultrasound diagnostic imaging. During and even well after the fetal consultation, our fetal cardiac nurse coordinators provide emotional, educational and logistical support for our families. The results from the comprehensive fetal cardiac evaluation becomes part of the integrated care plan in conjunction with obstetricians, maternal-fetal medicine specialists, neonatologists, surgeons and other healthcare professionals.

Our fetal cardiac program has greater than 98% concordance with postnatal diagnosis.

Sponsored by Phoenix Children's Hospital, the Phoenix Fetal Cardiology Symposium has become one of the premiere fetal cardiology conferences, attracting an international audience annually. The Symposium continues to expand its content with focused preparation for the RDMS fetal echo board exam and fetal cardiac pathology review.

Remaining the largest fetal cardiac program in the Southwest, the Fetal Heart Program provides coordinated care to families throughout the region. Collaboration with the Arizona Fetal Care Network provides comprehensive prenatal evaluation and coordinated delivery plans with obstetricians and maternal-fetal medicine specialists at statewide delivery hospitals.





# Echocardiography



Phoenix Children's Heart Center performs more than 21,000 echocardiograms per year for newborns, children and adults with congenital heart disease.



The Noninvasive Cardiac Imaging Program is the largest, most advanced, full-service imaging program in the Southwest, and is the only echocardiography lab in Arizona accredited by the Intersocietal Accreditation Commission (formerly ICAEL) for transthoracic, transesophageal and fetal echocardiography studies.

**Phoenix Children's Heart Center performs more than 21,000 echocardiograms per year for newborns, children and adults with congenital heart disease.** Eleven pediatric cardiologists, each with specialized training and experience, evaluate congenital and acquired heart disease. The Noninvasive Cardiac Imaging Laboratory provides comprehensive advanced imaging in a safe, pleasant environment for children and families. Daily transesophageal echocardiograms are performed at the Heart Center to guide and facilitate surgical and catheter-based procedures. The program integrates the latest cardiac ultrasound machines and 3-D multimodality with advanced imaging techniques into the workflow of patient care. The main laboratory is located at Phoenix

Children's Hospital, along with satellite facilities throughout Arizona. A new command center known as "Mission Control" has been constructed to allow a team of cardiologists to review and interpret multiple imaging studies in real-time throughout the Hospital and within the state of Arizona. Redesign of patient imaging rooms and the sonographer's workroom has improved workflow and patient satisfaction. An advanced virtual echo interpretation suite is now up and running, allowing for better education and training of sonographers, medical students, residents and physicians.

In addition to clinical echocardiography, our physicians are involved in clinical research and teaching. Sonographers, medical students, residents and adult cardiology fellows rotate through the pediatric echocardiography laboratory, learning both basic and advanced imaging skills. Bimonthly didactic lectures are provided covering the breath of congenital cardiac lesions, with emphasis on cardiac imaging. Monthly quality assessment is reviewed and discussed among the physicians and sonographers that encompass the echocardiography laboratory.



# Advanced Cardiac Imaging



**With continual improvements in technology and expertise, the number of patients referred for a cardiac CT or MRI at Phoenix Children's Hospital has tripled over the past ten years.**

As a leading comprehensive imaging center for congenital heart disease, the cardiac computed tomography (CT) and magnetic resonance imaging (MRI) program at Phoenix Children's Hospital continues to rapidly expand in size and complexity. Our dedicated team of cardiac technicians, anesthesiologists and imaging physicians has the advanced training and extensive experience required to obtain high quality images, while correctly interpreting even the most challenging of cardiac cases. This expertise ranges from the assessment of tiny premature infants with complex congenital heart disease to older adults with cardiac tumors or cardiomyopathy.

With continual improvements in technology and expertise, the number of patients referred for a cardiac CT or MRI at Phoenix Children's Hospital has tripled over the past ten years. As a regional referral center with several hundred cardiac studies each year, we continue to develop new ways of maximizing image quality, minimizing or eliminating radiation exposure and making the patient experience as brief and as pleasant as possible.

We are excited about our growing experience with the imaging assessment of patients with heart failure. Using cardiac MRI, we are increasingly able to identify evidence of myocardial fibrosis, inflammation, or perfusion abnormalities in even young children with failing hearts. This information can be extremely valuable in helping to determine the underlying cause of heart failure, the risk of sudden death and the likelihood of future cardiac recovery. We are also working with our cardiac surgeons in using cardiac MRI to improve outcomes in patients with single ventricles, including the optimal placement of surgical shunts and in identifying the best candidates for biventricular repair.

In collaboration with the bioengineering department at Arizona State University, our dedicated 3-D Cardiac Imaging Lab is now able to perform virtual cardiac transplantation. Using cardiac CT or MRI images from the patient and our database of virtual heart models, our transplant team has been able to expand the potential donor pool for some children listed for heart transplantation, thereby potentially decreasing the wait time. We are also investigating if outcomes are improved in infants with complex congenital heart disease if the surgeon can review a 3-D printed model of the patient's heart prior to surgery.



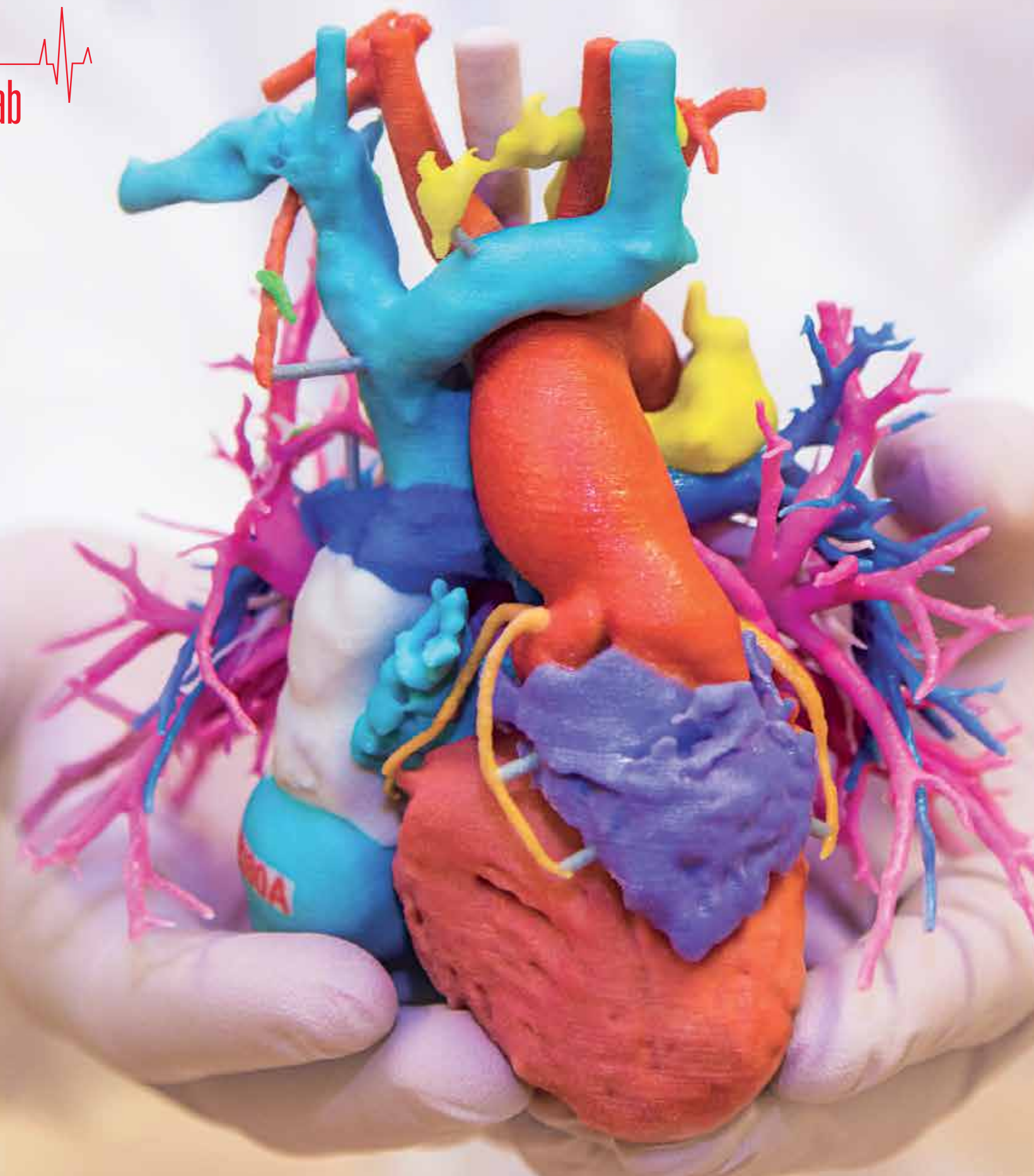
# Cardiac 3-D Print Lab

## Innovation: Patient-Centric and Patient-Specific

The advent of medical imaging and image processing technologies has enabled significant advances in pre-procedural planning, allowing cardiovascular anatomy to be visualized noninvasively before an operation. This pertains to three dimensional modeling and printing that provides a mechanism to construct patient-specific, scale models that surgeons and

**The lab has supported over 200 interventions and surgeries through advanced 3-D modeling and 3-D printing.**

interventionalists can examine prior to a procedure. Phoenix Children's Heart Center was one of the first programs to recognize the role that advanced 3-D modeling and 3-D printing could play in clinical care. In 2012, Phoenix Children's Hospital established one of the first hospital-based 3-D print laboratories – the Cardiac 3-D Print Lab. The lab is home to three 3-D printers, supporting more than six departments and collaborating with more than twenty outside institutions.



Phoenix Children's Cardiac 3-D Print Lab is among the first and most active clinical-based 3-D printing laboratories in the world. To date, the lab has supported over 200 interventions and surgeries through advanced 3-D modeling and 3-D printing. The lab has also developed novel virtual surgical tools to enhance selection of mechanical circulatory support devices and donor hearts for transplant. In the two years since the development of these tools, the Cardiac 3-D Print Lab has performed over 40 virtual surgeries spanning 29 institutions in more than six different countries. The lab works to bring personalized medicine, through the lens of advanced imaging, to patients locally and abroad.

The 3-D Print Lab has continued to explore new territories. Traditionally, 3-D printing has focused on viewing the outside of the heart and great vessels. Our 3-D Print Lab has now begun reconstructing three-dimensional intracardiac structures and views to provide a virtual landscape for the surgeon. An intracardiac blueprint will undoubtedly facilitate complex surgeries such as cases of septal defects requiring complex baffles. Phoenix Children's Hospital is at the forefront of this technology, thanks to Foundation grant support.



# Stress Lab

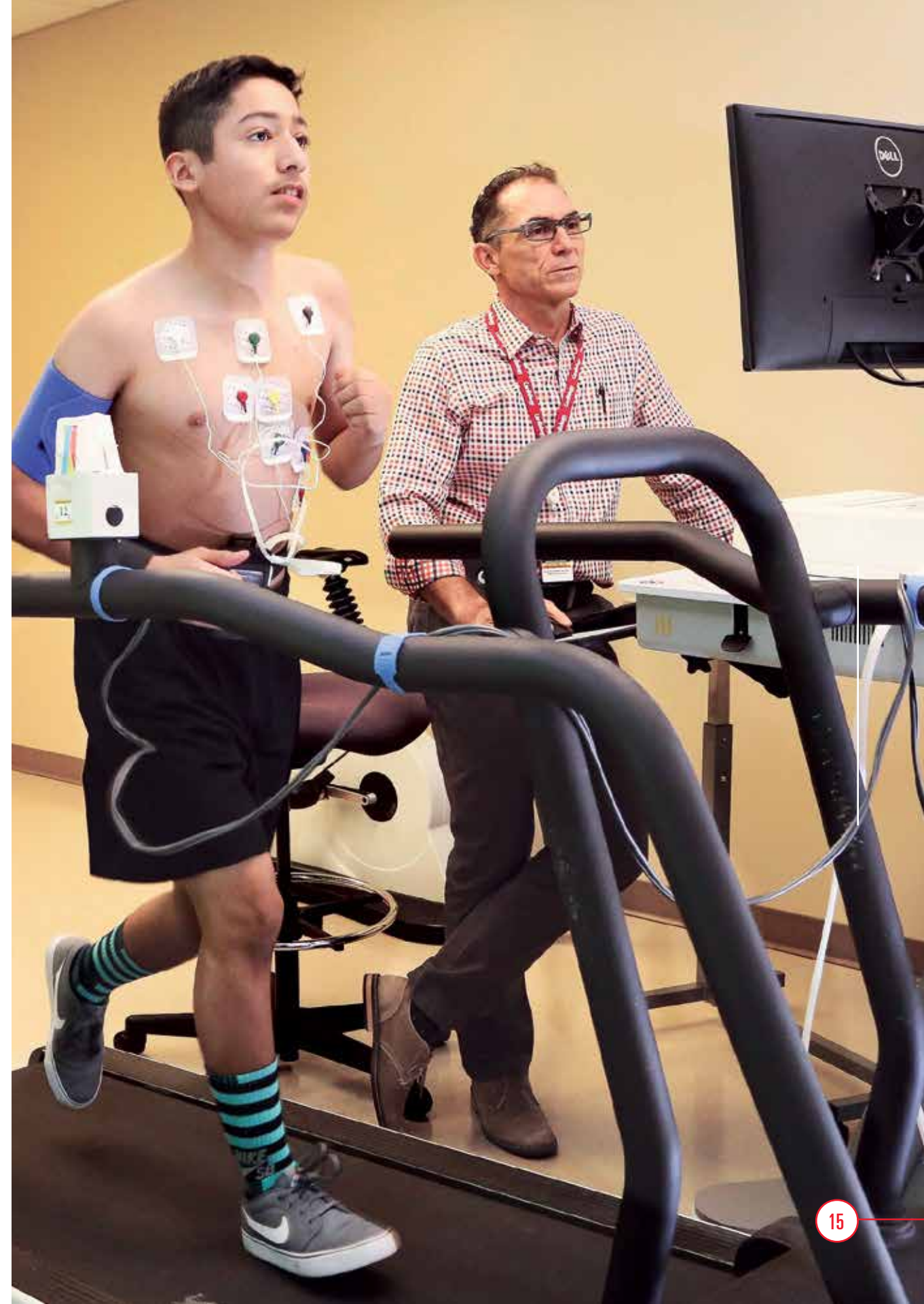


**The Human Performance Lab performs more pediatric stress tests than anywhere in Arizona.**

The Human Performance Lab performs stress tests for a wide variety of indications and patients. By performing stress tests either on a ramp-type treadmill or on a bicycle ergometer, we are able to tailor the test to meet our patient's needs. Recently, the Human Performance Lab was upgraded to the most state-of-the-art system available. The lab is the only one in Arizona able to perform metabolic evaluations in children.

Exercise stress tests are helpful in the evaluation of the cardiovascular response to increasing workload under carefully monitored and controlled conditions. A standard stress test is performed with a continuous electrocardiogram and blood pressure assessment. A metabolic test has the expanded capacity to evaluate the complex interplay between the cardiovascular, respiratory and neuromuscular systems, and will determine the maximum exercise capacity which is crucial to assess the functional capacity or cardiorespiratory fitness of an individual.

Data obtained from a stress test is used to help guide a patient's care. Based on the results of a metabolic stress test, care can be tailored either through medical management, interventional based procedures, or surgery to improve exercise performance and quality of life. The Human Performance Lab performs more pediatric stress tests than anywhere in Arizona. In 2014, we performed a total of 438 tests, with 122 of those tests as metabolic stress tests. Our exercise lab is actively involved in a number of multi-center research studies. This year we are participating in a National Institutes of Health-funded NHLBI National Pediatric Heart Network trial to assess the utility of a pulmonary vasodilator in patients with single ventricle physiology.







# Arrhythmia Services

The Arrhythmia Program follows more than **500** patients with cardiovascular implantable electronic devices.

Arrhythmia Services at Phoenix Children's Hospital is comprised of three International Board of Heart Rhythm Examiners who are board-certified pediatric and congenital electrophysiologists, along with a dedicated arrhythmia nurse specialist. In 2015, Arrhythmia Services published seven peer-reviewed studies and delivered 20 presentations at regional, national and international meetings. Arrhythmia Evaluations and Device Clinics are available at our central Phoenix Children's Heart Center location, along with our East Valley satellite offices, and starting in 2015, at our Albuquerque New Mexico affiliate office.

**The Arrhythmia Program is divided into five subspecialty arrhythmia service lines.**

## **Fetal Arrhythmia Program**

The Fetal Arrhythmia program is a collaborative multidisciplinary program of fetal cardiology and high-risk obstetrics, which provides expert consultation for medical management and prenatal monitoring of the fetus with prenatally diagnosed arrhythmias. These range from simple premature beats, which usually do not require therapy to sustained tachyarrhythmias requiring transplacental drug therapy. The Fetal Arrhythmia Program also provides immediate pacing support for newborns with congenital heart block in a side-by-side operating suite. An obstetric team performs the delivery in one room while the neonatologist, electrophysiologist and cardiac surgeon take over care for the newborn infant in the adjacent room.

## **Ambulatory Arrhythmia Program**

The Phoenix Children's Heart Center provides a full-line of arrhythmia diagnostic and monitoring services including EKGs, Holter monitors and cellular-based ambulatory rhythm monitors. The cellular-based monitors allow for nearly real-time detection of heart rhythm abnormalities with transmission to a central monitoring service and prompt physician notification for significant events. In addition, the program has recently begun implanting the world's smallest subcutaneous loop recorders (the size of a paper clip), which automatically detects and records arrhythmias, and transmits them through a home wireless console to a central monitoring center. This allows our Arrhythmia Team to follow patients from all over the Southwest without having to disrupt a family's busy schedule. In a state where it is not uncommon to drive 3 – 4 hours to see a cardiologist, use of such technology allows rhythm transmissions to occur in minutes, so children do not have to miss school and parents do not have to miss work.

## **Pacemaker and Defibrillator Services**

The Arrhythmia Program at Phoenix Children's Hospital follows approximately 800 patients with internal pacemakers and defibrillators. In addition to office-based device checks, remote Internet-based home monitoring is available for those with compatible devices, which allows for more frequent monitoring of new symptoms, as well as reducing travel time and time off from school or work.





**Our Arrhythmia Team of specialists continues to provide innovative comprehensive EP Services in a family-centered environment.**



More recently, the program has switched to cellular-based wireless transmission, allowing for remote monitoring of patients without conventional landline telephones. The Arrhythmia Program performed 62 device implants in 2014. Our Remote Pacemaker Program not only allows the Electrophysiology Team to follow patients from the four corners of Arizona, but also to our college students across the states.

In 2015, the program implanted the first MRI-compatible implantable cardioverter defibrillator (ICD) in a pediatric patient. The program has continued to use MRI-compatible pacemakers for the majority of new implants. Having MRI-compatible devices has been a major advancement in device-based therapy, since patients with neurologic or orthopedic conditions requiring MRI scans can now receive these scans safely and with good quality diagnostic imaging.

In addition in 2014, the Arrhythmia Program implanted the first subcutaneous defibrillator in a small child requiring long-term hemodialysis. This device allows for the prompt detection and treatment of ventricular arrhythmias, but does not require leads or electrodes in the central venous circulation. This enables automatic internal defibrillator coverage in those without vascular access or in those patients with cyanotic congenital heart disease who would be at significant risk of stroke and thromboembolic events if conventional transvenous leads were utilized.

#### **Sudden Cardiac Death Prevention and Inherited Arrhythmia Clinic**

This multidisciplinary clinic currently follows approximately 200 families with inherited life-threatening arrhythmia conditions including long QT syndrome, short QT syndrome, Catecholaminergic polymorphic ventricular tachycardia (CPVT), and Brugada syndrome. The primary function of this Clinic is to screen and identify patients who are potentially at risk for dangerous ventricular arrhythmias, as well as evaluation and follow-up of first-degree relatives of those newly diagnosed with a genetic or inherited arrhythmia condition. This program also emphasizes community advocacy and assists in obtaining automated external defibrillators (AEDs) for schools and institutions throughout the city. The Arrhythmia Program has also championed the adoption of a universal sports physical screening form for the State of Arizona.



#### **Arrhythmia Ablation Service**

**In 2014, 124 catheter ablations were performed at Phoenix Children's Hospital with a 94% acute success rate.** The Ablation Program continues to use the latest technology for mapping and ablating cardiac arrhythmias including conventional radiofrequency, high-powered irrigated radiofrequency and transcatheter cryothermal ablation modalities. In addition, the Arrhythmia Service utilizes an advanced electroanatomic mapping system that essentially functions as "GPS for the heart." This technology has allowed for an over fivefold reduction in radiation exposure and even zero fluoroscopy for simple right-sided ablation procedures.

In addition, the program has continued to support a specialized Arrhythmia Clinic for adults with congenital heart disease. Along with conventional ablation, pacemaker and ICD services, the program has continued to perform pulmonary vein isolation for the treatment of atrial fibrillation, using the second-generation Arctic Front cryo-balloon catheter. The program performed the first ablation for atrial fibrillation in adults with congenital heart disease in 2013.

Our Arrhythmia Team of specialists continues to provide innovative comprehensive Electrophysiology (EP) Services in a family-centered environment. Our EP Team is actively involved in teaching medical students at the University of Arizona College of Medicine-Phoenix and in 2014 mentored two medical students on a four-year in-depth scholarly project. Our team of physicians is academically engaged not just in the Arizona community, but throughout the U.S., holding national leadership positions within the Pediatric and Congenital Electrophysiology Society, Heart Rhythm Society, American College of Cardiology, and has been on the organizing committees for more than seven national and international pediatric cardiology scientific meetings.



# Pediatric Cardiac Catheterization Laboratory

Interventional pediatric cardiology has evolved substantially over the past decade, with the ability to treat or palliate many cardiac defects via catheter-based therapies, rather than open surgical procedures. The Cardiac Catheterization Lab at Phoenix Children's Hospital has been on the forefront of this evolution, offering the most contemporary catheter-based treatment strategies for our congenital cardiac patients.

The Biplane Hybrid Catheterization Lab at Phoenix Children's Hospital is equipped to allow excellent cardiac angiographic imaging, as well as offering a state-of-the-art operating room to allow for collaborative hybrid procedures with both Cardiac Surgery and Interventional Cardiology. Staffed with three interventional pediatric cardiologists, approximately 450 cardiac catheterization procedures were performed in the laboratory in 2014. The majority of the procedures were interventional, including device closure procedures for intracardiac defects, valvuloplasty procedures for valve stenosis and stent placement for aortic coarctation or pulmonary artery stenosis.

**Our transcatheter pulmonary valve program utilizing the Melody Valve continues to expand and is currently the largest and most successful in Arizona, with approximately 50 valves implanted to date.** This procedure has eliminated the need for surgical intervention in some of our complex patients and nearly all of these patients are discharged within 24 hours. Patients are therefore able to resume normal activities within two to three days without the pain and recovery from traditional surgery, making this an outstanding option for patients requiring pulmonary valve replacement.

While offering the latest and most contemporary catheter-based devices and therapies, we continue to participate in the clinical trial of new therapies, such as emerging devices for the treatment of atrial septal defects in children. We continue to participate in an ongoing trial of a device to treat ventricular septal defects. In 2014, the laboratory enrolled in the national IMPACT registry (Improving Pediatric and Adult Congenital Treatment), collecting diagnostic and interventional catheterization data to allow continued improvement in our patient outcomes. We are also embarking on a quality improvement project to ensure the safety of our patients by reducing radiation exposure during these complex procedures.



**Our transcatheter pulmonary valve program utilizing the Melody Valve is the largest and most successful in Arizona.**





# Heart Failure and Transplantation



**As of 2014, 36 heart transplantations have been performed with a 94% one year survival rate, a rate that exceeds national benchmarks.**



The Heart Transplant Program at Phoenix Children's Hospital was established in 2010 for local and regional children with challenging end-stage heart failure. The program's dedicated team of physician's, surgeons and advanced nurse practitioners has more than 50 years of combined pediatric heart transplant experience. The program has already become one of the largest pediatric heart failure and transplant centers in the Southwest.

The broader transplant and advanced heart failure team includes a dedicated staff in social work, child life, pharmacy, finance, nutrition, rehabilitation, pathology, immunology and blood bank services.

The program meets the educational and emotional needs of our patients and families through Heart Transplant Support Group meetings. In addition, a Ronald McDonald House on the Phoenix Children's Hospital campus allows long distance families to be near their child before and after transplant.

As of 2014, 36 heart transplantations have been performed with a 94% one year survival rate, a rate that exceeds national benchmarks.

Phoenix Children's Heart Center is a participant in the Pediatric Heart Transplant Study, an international multi-institutional registry for advancing the field of cardiac replacement for children.

Phoenix Children's Heart Center has a dedicated advanced heart failure service with subspecialty programs for patients with cardiomyopathy, failing single ventricle physiology and neuromuscular disorders.

The clinical transplant team at Phoenix Children's Heart Center, in collaboration with engineers at Arizona State University, have been designing innovative applications for adult-designed support devices for utilization in children. This work has led to computer applications that can predict the fit of Total Artificial Heart and Ventricular Assist Devices in children, as well as enabling the process of "virtual transplant" to assess donor recipient matching in real time.





# Cardiovascular Intensive Care Unit



The pediatric Cardiovascular Intensive Care Unit (CVICU) at Phoenix Children’s Hospital is a 24-bed unit that offers the highest level of critical care services to children with a variety of cardiac conditions. The CVICU is designed to provide an optimum environment to care for the complex and unique needs of our cardiac patients. The dedicated team of physicians, nurse practitioners, nurses and comprehensive ancillary services provides around the clock multidisciplinary expertise to heart patients from admission through discharge.

The CVICU is one of the premier units in the Southwest dedicated to the care of children with congenital heart disease. Patients range from newborn babies with complex congenital cardiac diseases, children with nonsurgical cardiac medical conditions and adults with congenital heart disease.

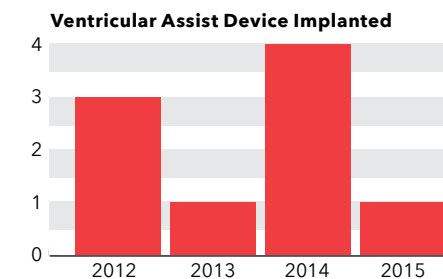
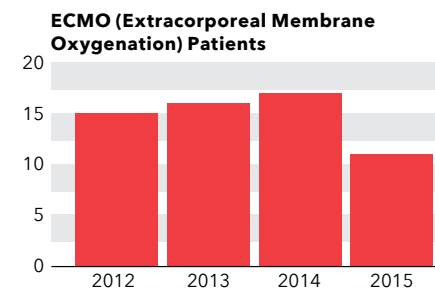
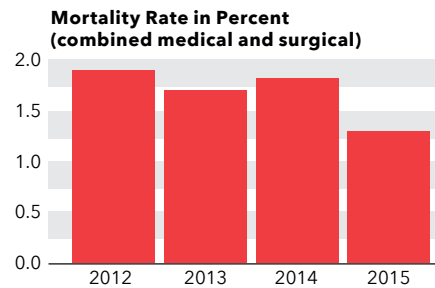
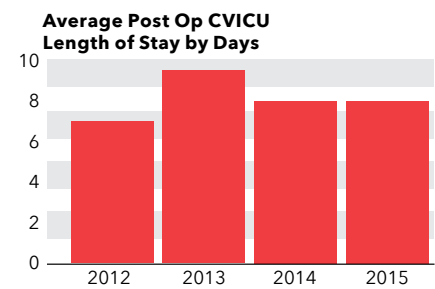
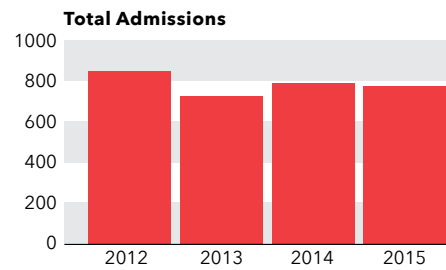
Our team is specifically trained and equipped to provide the highest level of care to patients of all ages, from neonates to adults. The pediatric cardiac critical care physician team is comprised of individuals with specialized training and expertise in congenital heart disease. Family-centered

rounds are conducted each morning with as many of the medical team responsible for a child’s care as possible (cardiologists, intensive care specialists, cardiac surgeons, and nursing) at the bedside to assess each patient’s status and formulate plans for the day. With our family-centered team environment, parents are actively involved in these daily rounds. These medical professionals are responsible for supervising the clinical care of critically ill patients admitted for surgery, cardiac catheterization or medical illness. A member of Phoenix Children’s in-house pediatric cardiac intensive care team is available in-house 24/7 to provide critical care services for children who have congenital heart disease, as well as any other cardiac or thoracic illness.





## Cardiac Intensive Care Unit, continued



Most patients are admitted and discharged from this state-of-the-art unit without being transferred to another unit or location within the Hospital. This model provides for consistency and continuity; all patients are cared for by the same medical and nursing team during their admission. Dedicated cardiac intensivists, cardiothoracic surgeons, cardiologists, cardiac nurse practitioners, nurses, respiratory therapists, pharmacists, child life specialists and social workers all participate in multidisciplinary rounds, and are directly involved in the daily care of each patient.

### Success and Achievements:

- Excellent post-op outcomes at par or exceeding those of other recognized children's hospitals (The Society of Thoracic Surgeons Congenital Heart Surgery and Pediatric Health Information Systems Databases)
- Established the first unit-based Medication Safety Committee with significant improvement in avoidance of medication error, resulting in an overall improvement in patient care and safety
- Ongoing quality improvement circles with best practice application by implementing various care bundles including VAP (Ventilator-associated pneumonia), Central Line Dressing, intra-atrial line care, etc.
- Successful implementation of post-implantation training of Syncardia (Total Artificial Heart), Heartmate 2 and Berlin Heart
- 24-hour in-house Cardiac Intensivist and Nurse Practitioner coverage
- Constant evaluation of CVICU care standards with national key performance indicators, thus enabling us to benchmark with other high performance pediatric cardiovascular intensive care units in the country

### Key Quality Performance Indicators Constantly Monitored:

- Ventilator-Associated Pneumonia
- CLABSI (Central Line-Associated Bloodstream Infection)
- Surgical Sternal Wound Infection
- Intra-Atrial Line Complications
- IV Infiltrate





## Adult Congenital Heart (PAAtCH) Program



The presence of adult cardiologists in the same outpatient office as pediatric cardiologists provides a collaborative model for our growing patient population.

The Phoenix Adult Congenital Heart (PAAtCH) Program experienced dramatic changes in 2014. The Phoenix Children's Heart Center recruited an adult congenital cardiologist to provide clinical expertise to our growing population of adolescents and adults. PAAtCH is currently involved in 10 multi-center research trials involving adolescents and adults with congenital heart disease. The program has established a transitional care model for our adolescent patients as they move from the pediatric realm of care to a progressively more independent level of patient responsibility commensurate with the adult health care experience. Our program has integrated active research efforts with a contemporary care model in adults with Eisenmenger syndrome, pulmonary hypertension secondary to congenital heart disease, and hypertrophic cardiomyopathy and pregnancy. The program is also involved with a Pediatric Heart Network multi-centered, randomized, controlled, drug trial evaluating exercise capacity in single ventricle patients who underwent a Fontan palliation.

In 2015, the PAAtCH Program established a bi-weekly multidisciplinary educational case conference designed to foster collaboration across multiple specialties for our most complex patients. This

conference has active participants from across the country sharing expertise across various cardiology disciplines. Cases for discussion may be submitted online and future participation is encouraged by sending an email to [patchprogram@phoenixchildrens.com](mailto:patchprogram@phoenixchildrens.com).

The PAAtCH program recently began an initiative to improve the care of our patients with single ventricle physiology who have undergone Fontan palliation. Fontan survivors are at an increased risk of hepatic dysfunction secondary to the unique position of the organ relative to the pulmonary and splanchnic venous bed.

The care of the adult congenital patient requires a multidisciplinary team-based, patient-centered approach. The incorporation of an adult cardiologist in the same outpatient office as pediatric cardiologists provides a collaborative model for our growing patient population.

Our program has initiated formal quality metric strategies to improve the quality of care and overall experience for our adolescent and adult patients and their families.



# Pulmonary Hypertension Program



Currently, 100 patients are followed in the Pulmonary Hypertension Program

The Pulmonary Hypertension Program at Phoenix Children's Hospital offers comprehensive care for patients from diagnosis to long-term treatment and follow-up. Through early detection and treatment, the goal of the Pulmonary Hypertension Program is to improve the quality of life of the patient. Our staff is board-certified in pediatric cardiology and pediatric critical care, along with providing a full spectrum of care in both inpatient and outpatient arenas.

We utilize a multidisciplinary approach with involvement by cardiologists, intensivists, neonatologists and pulmonologists. State-of-the-art modalities are available for the care of patients with pulmonary hypertension, including non-invasive modalities such as focused echocardiography, cardiac MRI, cardiac CT ventilation perfusion scans and invasive modalities including cardiac catheterization. Our program is also supported by dedicated pharmacists and clinical staff who are familiar with all aspects of pulmonary hypertension. We consult and collaborate with specialists from other institutions as needed to ensure that we offer the best possible treatment options to each and every case. Recently, we have added an adult congenital cardiologist with a special interest in the care of adolescents and adults with congenital heart disease and pulmonary hypertension to provide care for transitional aged patients and adults.

**Currently, 100 patients are followed in the Pulmonary Hypertension Program**, along with inpatient and outpatient consultations for Phoenix Children's Hospital and other institutions in the Valley.

Our faculty are active members of the Pulmonary Hypertension Association and PH Clinicians and Researchers (PHCR). We are active in multi-center clinical trials, as well as single site Institutional Review Board-approved research projects to advance our knowledge of pulmonary hypertension, while offering new therapies to this growing field. Our involvement in clinical trials gives our patients a distinct advantage in offering them cutting-edge therapies for this complex disease.





## CCriB (Neurodevelopment) Clinic



The Cardiology Critical Brain Development (CCriB) Program provides developmental support for patients with congenital heart disease within Phoenix Children's Hospital. Improvements in congenital heart surgery and perioperative care have resulted in increased survival rates over the last two decades. This is especially true in neonatal congenital heart surgery. As more children are surviving into adolescence and adulthood, the neurodevelopment morbidities associated with congenital heart disease have become more apparent. Children with complex heart problems are at higher risk for developmental delays and poor school performance compared to their heart-healthy peers.

The CCriB Program provides proactive neurodevelopment screening and evaluations for children with complex congenital heart disease within the period of critical brain development. The program also provides periodic developmental surveillance throughout the first five years of life to identify

any significant development of delays or disabilities. The goal of the CCriB Clinic is in alignment with the American Heart Association to optimize neurodevelopmental outcomes in children with complex heart defects.

Our CCriB team consists of a pediatric cardiologist, pediatric neurodevelopment physician and two nurse practitioners. The clinical team assesses developmental domains using standardized neurodevelopment testing tools. This testing focuses on developmental treatments on areas of greatest need and helps to maintain the motivation needed for maximum progress within the critical brain development period.

The program also educates parents about developmental stimulation and helps to coordinate medical services that are needed for appropriate medical therapies. In 2014, the CCriB Program evaluated 47 children.



# 22q Clinic



**The 22q Clinic has treated approximately 100 patients and their families, including 6 families with a parent and a child with 22q11.2 deletion.**

## 22q11 in the Community

- Annual 22q11 Day at the Phoenix Zoo
- 22q11 Family Symposium
- 22q11 Barrow Neurological Institute at Phoenix Children's Hospital/Barrow Craniofacial Clinic Speech Camp

Dr. Theresa Grebe has presented to several different physician organizations throughout the Valley, including to pediatricians, cardiologists and anesthesiologists. The success of the 22q Clinic is also, in part, due to a family lead support group. This group meets monthly and allows families to ask questions, share concerns, provide support and promote awareness.

Overall, the 22q Clinic has been well received by the community of patients and providers, and continues to grow through the dedicated efforts of all involved.

The 22q Clinic is the only comprehensive, multidisciplinary program in Arizona for children diagnosed with 22q11.2 deletion syndrome.

The 22q Clinic's mission is to provide a comprehensive care plan to children and their families. The Clinic offers families the education and support they require to optimize their child's health and well-being.

Children are seen by a team of specialists in one location. These specialists include pediatric physicians and allied health professionals experienced in caring for children with this genetic disorder.

The 22q Clinic allows patients to be thoroughly evaluated for medical problems associated with this syndrome. A dedicated team of subspecialists perform medical evaluations, laboratory tests and imaging studies. After members of the medical team evaluate each patient individually, they meet in a post-clinic conference and formulate a patient-specific medical treatment plan. A report is then prepared and sent to the patient's family and primary care physician. This plan ensures continuity of care and bridges communication gaps. In addition to addressing the medical needs of the child, the team also works with the family to implement effective learning and behavioral interventions. These interventions address the child's developmental and emotional growth.

The 22q Clinic has treated approximately 100 patients and their families, including 6 families with a parent and a child with 22q11.2 deletion. In addition to physician input, patients and their families have received coordinated care from numerous subspecialty providers. The lead clinicians of this Clinic, Theresa Grebe, MD, and her team, have been successful in outreach efforts to promote awareness of 22q11.2 deletion syndrome and the Clinic, along with securing philanthropic partners.







# Telemedicine

Telemedicine through Phoenix Children's Hospital Echocardiography Laboratory is connected to multiple hospitals and communities throughout Arizona to support cardiac assessment and care. Cardiologists can read and assess echocardiograms performed at outlying hospitals within minutes of being performed.

**Our cardiologists can assess echocardiograms from outlying hospitals within minutes, providing rapid diagnosis and improving direct patient care.**

Phoenix Children's Hospital cardiology supports hospitals throughout the city, as well as regionally, including the East Valley, West Valley, Prescott, Flagstaff, Summit and other areas via telemedicine links. Teleconference links are used to communicate and discuss patients and their care from Mayo Clinic in Scottsdale, Dignity Health St. Joseph's Hospital and Medical Center in Phoenix, University Medical Center in Tucson, along with California and other associated hospitals throughout the country.

Telemedicine is often performed for our Adult Congenital Heart Disease patients and when considering heart transplant

for children at Phoenix Children's Hospital in discussing preoperative care, and in assessing potential donor hearts.

Assessment of echocardiograms performed at delivery hospitals and especially at remote hospitals, performed in a timely fashion via telemedicine, can make rapid diagnosis and direct patient care. With newborn pulse oximetry screening, delivery hospitals need rapid access to echocardiogram assessment if a newborn fails the screening test. Often this assessment can prevent significant costs and unnecessary patient transfers if echocardiograms reveal normal or minor findings. Care can be discussed with the cardiologist and the primary care team and families, as well as outpatient follow-up arrangements when appropriate.

At the Phoenix Children's Hospital Echocardiography Laboratory, more than 100 studies per month are read and assessed via telemedicine.



# Interstage Monitoring

Newborns who have undergone Stage 1 Palliation or aorto-pulmonary shunt dependent physiology are a fragile population. This population requires careful monitoring at home and a variety of critical medical services to enhance their quality of life. **Since 2007, our multidisciplinary interstage monitoring team has successfully cared for more than 200 patients.** In 2009, the team became a part of the National Pediatric Cardiology Quality Improvement Collaborative, a network of 58 pediatric cardiac centers across the nation.

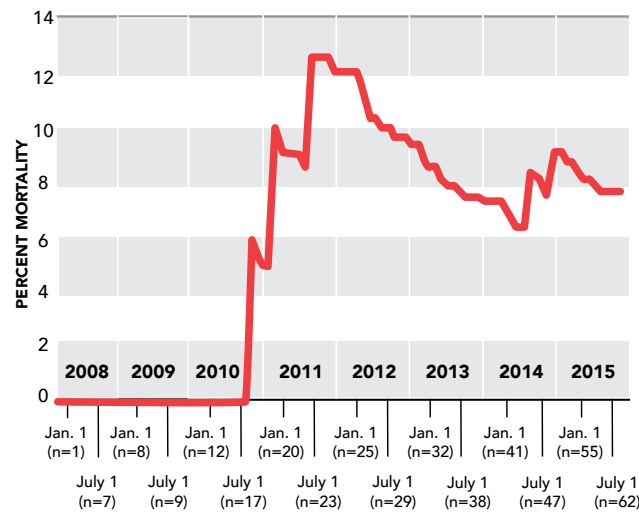
**The program continuously strives to reduce mortality and re-admissions, improve nutrition and quality of life.**

Utilizing quality improvement strategies, seamless collaboration with centers nationwide, and a multidisciplinary approach, the program continuously strives to reduce mortality and re-admissions, improve nutrition and quality of life.

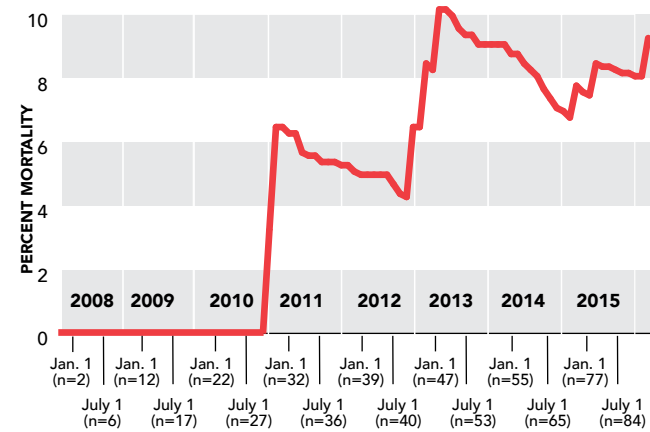
Weekly Pre-Visit Planning coordinates the care across disciplines, provides a foundation for care transition and ensures growth and clinical parameters

are adequately monitored. Our busy Interstage Clinic standardizes the care for all shunt-dependent physiology infants by reducing variation, and thus improving outcomes. Patients and families meet with nutritionists, therapy staff, nursing, case management, social workers and cardiologists in this unique environment. The outcomes mirror national standards and continue to improve.

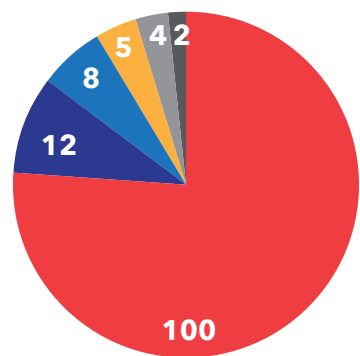
**DKS/Norwood/Hybrid Cumulative Mortality**



**Bialock-Taussig Shunt Only Interstage Mortality Rate**







- Nursing Coverage**
- CVICU
  - 9th Floor
  - Inpatient NP
  - Cardiology NP
  - Outpatient RN
  - Cath Lab

## Nursing in the Heart Center

Family-centered care, clinical collaboration, leadership, and accountability form the basis of nursing care within the Heart Center at Phoenix Children’s Hospital. By adhering to these core values, our nurses help to fulfill the mission of the Hospital – to provide hope, healing, and the best health care for children and their families.

Our dedicated staff tailors care for our patients, believing that each family is a unique entity, with individual needs and expectations. The family plays a vital role in the care pathway, so we partner with our parents and families to provide the best collaborative care possible. Our Family Advisory Council assists us to meet family needs, and is an integral part of the Children’s Heart Center, while being instrumental in the development of family resources.

The nurses at the Heart Center work in a variety of specialized departments – from the clinics to the intensive

care unit; from the pre-surgery admission unit to the operating room and catheterization suites. Each department requires the staff to possess skills specific to that area, an understanding of other areas and the ability for faultless interdepartmental communication. We aim to provide a flawless progression through the hospitalization – from initial consult to discharge and beyond.

This type of program requires a robust training approach, and our nurses are extensively trained in critical care, advanced cardiac transplant care, post-operative recovery and technologically advanced therapies such as ECMO (Extracorporeal Membrane Oxygenation) and ventricular assist devices. We encourage staff to become nationally certified, and we continue to exceed the Institute of Medicine’s 2020 goals with regard to baccalaureate education. However, we acknowledge that expert nursing care is created by building upon the foundations of good basic care. To that end, we continually monitor quality and safety indicators, while publishing the results on the Phoenix Children’s Hospital website.

Our proactive hiring plan ensures that nurses are hired in anticipation of positions opening up. This novel approach promotes the availability of pre-oriented staff to fill vacancies – significantly shortening the time between staff vacancy and filled positions.

Our goal is to provide our patients and families with the expert care that they deserve.



Child Life Specialists assess patients' psychosocial needs and advocate for family-centered care.

## Child Life Specialists

The hospital can be a stressful place for children. Phoenix Children's Child Life Program helps patients of all ages - and their families - develop ways to cope with fear, anxiety and separation from home and school. Child Life Specialists work closely with family members during hospitalization. As the medical staff is attending to the child's physical needs, our Child Life Specialists are attending to the child's developmental, psychosocial, educational and emotional needs - which can be critical in the treatment and healing process. The goal of Child Life Specialists within the Heart Center align with our overall theme of family-centered care.

Child Life Specialists in the Cardiovascular Intensive Care Unit (CVICU) provide support to families facing critical diagnoses. These specialists work to assess patients' psychosocial needs and develop individualized care plans specifically based on the developmental age of the child and their length of stay.

The Child Life Specialists advocate for family-centered care by empowering and educating families

about the importance of maximizing their involvement over the duration of their stay and beyond. They communicate with the care team by attending medical and interdisciplinary rounds in order to have a better understanding of each patient and their needs, as well as maintaining involvement with the transplant team and helping to plan and carry out support group meetings. In addition, Child Life Specialists host tours for patients and their families prior to surgery and educate them about the CVICU. Contributions by the Child Life Specialists are a major factor in Phoenix Children's family-centered care.

Our specialists know it's important for kids to be kids - even when they're in the Hospital.

### Goals of Child Life Specialists

- ✓ Educate Patients
- ✓ Normalize Hospital Environment
- ✓ Establish Coping Mechanisms
- ✓ Promote Family-Centered Support
- ✓ Integrate Developmentally Appropriate Care
- ✓ Create Incentive Charts to Motivate



# Arizona Heart Camp for Kids!

"It was great to see the kids run around and be kids no solely defined by their heart disease"



This year the Phoenix Children's Heart Center held its second Heart Camp for children with congenital heart disease in the beautiful pine country near Prescott, Arizona.

With the support of the Nick & Kelly Foundation, 103 children and teens attended this five day camp. The camp provides a setting that is supportive and inspires self-esteem building, along with socialization for children who live with Congenital Heart Defects.

Along with swimming, zip-lining and horseback riding, the theme of this year's camp was "Through the Decades." Our campers relived a 50's, 60's and 70's experience - even complete with tie dye t-shirts.

The camp not only left an indelible impression on the children, but also on the staff. As a camp staffer stated, "It was great to see the kids run around and be kids not solely defined by their heart disease".

## Heart Center Family Advisory Council

The Heart Center Family Advisory Council (HCFAC) was established in 2013 to serve as a consultative and advisory resource to the Phoenix Children's Heart Center leadership and staff. There are 8 - 12 families on the council whose children have been treated at Phoenix Children's for cardiac care. Members of the HCFAC meet on a monthly basis to help shape Hospital policies and programs, while providing feedback on the challenges families are facing. Our parents identify needs and establish goals to help meet those needs. The council promotes the core concepts of family-centered care: dignity and respect; information sharing; participation; and collaboration. The council hopes to create a family-focused environment that ensures all children and their families receive the best experience possible during their stay or visit at the Phoenix Children's Heart Center.



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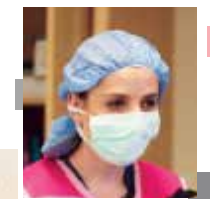
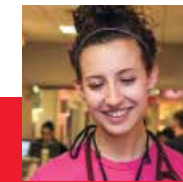
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