

# PEDIATRIC CARDIAC CARE

AT CHILDREN'S MERCY



**Children's Mercy**  
KANSAS CITY

LOVE WILL.

# CHILDREN'S MERCY KANSAS CITY

At the Ward Family Heart Center at Children's Mercy Kansas City, patients benefit from the expertise of more than 30 board-certified pediatric cardiologists and cardiovascular surgeons. The heart center is setting the standard for groundbreaking efforts to improve treatments. The Fetal Cardiac Program brings potentially lifesaving care to families from the moment of fetal diagnosis, through delivery and beyond. Research efforts are focused on better understanding the causes of congenital heart defects. And Children's Mercy is sharing its home monitoring technology for single-ventricle patients, called CHAMP, with other pediatric cardiology programs to improve national outcomes.

Research conducted by our team spans the spectrum of medical research from bench to bedside. Multiple disciplines within the Ward Family Heart Center contribute to translational research in pharmacogenomics, imaging and outcomes research. The team is also collaborating with the Genomic Medicine Center at Children's Mercy to investigate genetic causes of congenital heart disease.

The size and scope of our program means we are always ready to care for any child, no matter how rare their condition might be. And even though we care for some of the most complex kids, our survival rates continue to surpass the national average. Year after year, Children's Mercy is recognized as one of the top cardiology and heart surgery programs in the nation by U.S. News and World Report.

At Children's Mercy Kansas City, love is the driving force behind everything we do. It pushes our researchers to find answers others could not. Gives us the strength we never knew we had. And reminds us that anything is truly possible.

Please join us as we share the important progress our team has made—progress that is making a difference for kids every single day.



22,901

EKGs

19,002

Echocardiogram  
Procedures

822

Stress lab  
procedures

18,256

Outpatient visits

366

Cardiac  
catheterizations

143

Electrophysiology  
Procedures

513

Surgical  
Procedures



Girish Shirali, MBBS, FACC, FASE;  
Division Director, Cardiology;  
Co-Director, the Ward Family Heart Center

James E. O'Brien Jr., MD, FACS,  
Chief, Section of Cardiothoracic Surgery;  
Co-Director, the Ward Family Heart Center



# WE'RE SHARING TECHNOLOGY TO IMPROVE OUTCOMES FOR INTERSTAGE SINGLE-VENTRICLE PATIENTS

Gerish Shirali, MBBS, FACC, FASE; Division Director, Cardiology; Melva and Randall L. O'Donnell PhD Chair in Pediatric Cardiology; Co-Director, the Ward Family Heart Center; Professor of Pediatrics



In the four years since Children's Mercy launched the Cardiac High Acuity Monitoring Program (referred to as CHAMP), the mortality rate for all babies with single-ventricle heart defects being monitored via CHAMP has been reduced to 2.4 percent. This program offers home monitoring of these babies by a multidisciplinary team, supported by the proprietary CHAMP app, which is connected to a central database.

A study published in the World Journal of Pediatric and Cardiac Surgery in April 2018, confirmed additional benefits. The study compared traditional three-ring binder home monitoring of interstage patients to monitoring via the CHAMP app during a three-year period, and showed:

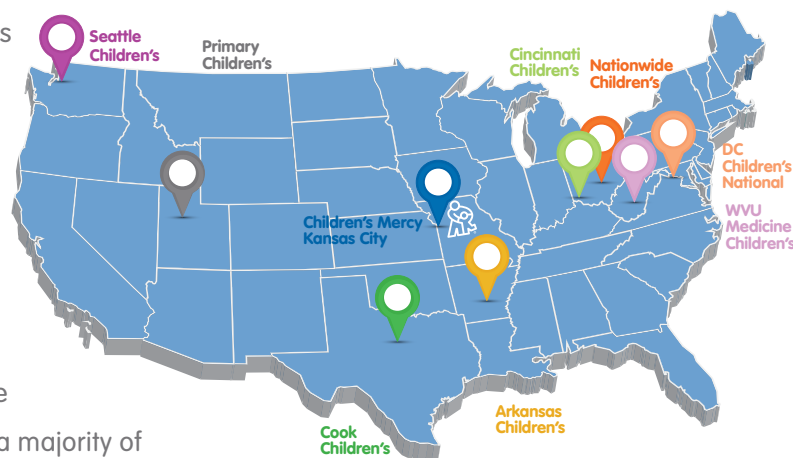
- Fewer unplanned intensive care unit days per 100 interstage days
- Shorter delays in care
- Lower resource utilization at readmissions
- Lower incidence of interstage growth failure
- Preferred by a majority of caregivers

Initially the CHAMP app was developed on a single mobile platform. To create a more consumer-friendly approach, work is underway today to create a platform-agnostic model of the app. By summer 2019, the CHAMP app

will also be available on all commonly-used mobile platforms including Apple, Android and Windows.

## Recent Publication

**Interstage Outcomes in Infants With Single Ventricle Heart Disease Comparing Home Monitoring Technology to Three-Ring Binder Documentation: A Randomized Crossover Study.** Bingle M, Erickson L, Reid K, Lee B, O'Brien J, Apperson J, Goggin K, Shirali G. World Journal for Pediatric and Congenital Heart Surgery (May 2018); <https://doi.org/10.1177/2150135118762401>.



## Sharing CHAMP Nationally

From the outset, Dr. Shirali and his team planned to share CHAMP with other hospitals. In 2016, Lori Erickson, APRN, CHAMP Clinical Program Manager, led the effort to begin bringing additional sites on board with CHAMP. Today, nine additional sites are utilizing the CHAMP app, and babies in 17 states are being followed. That translates into 280 babies who have been monitored via CHAMP so far – 130 at Children's Mercy and another 150 from the other nine sites combined. The combined mortality across all sites is 2.4 percent.

# WE'RE PASSIONATELY PURSUING QUALITY OUTCOMES

James E. O'Brien Jr., MD, FACS, Chief, Section of Cardiothoracic Surgery; Jerry Smith Chair in Pediatrics; Co-Director, the Ward Family Heart Center

Children's Mercy was one of the first pediatric cardiac surgery programs in the nation to voluntarily share surgical outcomes with the public via the Society of Thoracic Surgeons' (STS) website.

"That level of transparency is critical to quality improvement for patients, families and staff, as well as for pediatric heart surgery programs nationwide," Dr. O'Brien said.

Dr. O'Brien is a member of the Society's Congenital Heart Disease Database Task Force, as well as one of the auditors for the STS database.

The public reporting initiative continues to grow, increasing from 23 percent of enrolled participants in January 2015 to 73.9 percent in the Spring 2018 data release.

"At Children's Mercy, we have been early adopters of transparency," Dr. O'Brien said. "By evaluating this objective information, we have improved the care we provide patients and their families, helping us rank among the top programs in the country."

For more information go to [childrensmercy.org/heart](http://childrensmercy.org/heart) or visit [publicreporting.sts.org](http://publicreporting.sts.org).



Surgical Mortality Percentage Categorized by Complexity of Procedure				
STAT* Category	CM** 1-Year Average	STS*** 1-Year Average	CM 4-Year Average	STS 4-Year Average
1 (least complex)	1.0	0.4	0.3	0.4
2	1.1	1.3	1.2	1.6
3	4.2	2.1	1.3	2.3
4	11.7	6.2	4.2	6.4
5 (most complex)	6.3	11.9	13.0	14.6

\*Society of Thoracic Surgeons - EACTS Congenital Heart Surgery Mortality Categories

\*\*Children's Mercy, 2018

\*\*\*Society of Thoracic Surgeons

# WE ARE ADVANCING CARE WITH MULTI-MODALITY CARDIAC IMAGING

Sanket Shah, MD, MHS, FAAP, Assistant Professor of Pediatrics

Children's Mercy serves as a regional referral center for western Missouri and the state of Kansas, providing advanced multi-modality cardiac imaging, including CT-MRI, 3D echocardiography and 3D printing/modeling.

"We have been early adopters of these advanced imaging techniques, including 3D modeling technology," Dr. Shah said. By combining CT and MRI data with 3D printing capabilities, the division is creating 3D models for select, complex anatomies including:

- Double outlet right ventricle
- Aortopulmonary collateral arteries
- Aortic arch anomalies
- Anomalous systemic and pulmonary venous return

"Our cardiac surgeons find these models very helpful in improving surgical planning and reducing time in the operating room," Dr. Shah said.



# OUR CARDIOLOGIST AWARDED AHA CAREER DEVELOPMENT GRANT

Daniel Forsha, MD, MHS, Assistant Professor of Pediatrics

In 2018, Dr. Forsha was awarded the American Heart Association's Career Development Grant. This is an early career three-year grant that will allow him to complete a research project evaluating the cardiovascular effects of weight loss in an overweight and obese population of adolescents with intellectual and development disabilities (IDD) such as Down syndrome and Autism spectrum disorder.

"My research study evaluates heart and blood vessel function before and after weight loss over an 18 month period," Dr. Forsha said. "By adolescence, more than 50 percent of the IDD population are overweight or obese and past research tells us that their heart and blood vessel function are already negatively affected. This current study will confirm those findings in this population and evaluate the reversibility of this early dysfunction with weight loss stimulated by an improved diet and increased exercise."

Dr. Forsha will be working with mentors and partners to complete this research. This includes Joseph Donnelly, EdD, from Kansas University Medical Center, a long time NIH-funded researcher with a specialty in weight loss; Michael Artman, MD, Department of Pediatrics Chairman of Children's Mercy Kansas City and a pediatric cardiologist with a history of research; and Joseph Kisslo, MD, from Duke University, a former echo lab director and past president of the American Society of Echo with a long history of echo research and innovation; as well as many other partners.

## Recent Publications

**Remote Exercise for Adults with Down Syndrome.** Ptomey LT, Szabo AN, Willis EA, Greene JL, Danon JC, Washburn RA, Forsha DE, Donnelly JE. *Transl J Am Coll Sports Med.* 2018 Apr 15;3(8):60-65. PMID: 29930988

**Frequent Activation Delay-Induced Mechanical Dyssynchrony and Dysfunction in the Systemic Right Ventricle.** Forsha D, Risum N, Smith PB, Kanter RJ, Samad Z, Barker P, Kisslo J. *J Am Soc Echocardiogr.* 2016 Nov;29(11):1074-1083. doi: 10.1016/j.echo.2016.08.002. Epub 2016 Sep 10. PMID: 27624591





# WE'RE USING TELEMEDICINE TO SEE OUR PEDIATRIC ELECTROPHYSIOLOGY PATIENTS REMOTELY

Lindsey Malloy-Walton, DO, MPH, Pediatric Electrophysiologist; Assistant Professor of Pediatrics



By providing teleconsultation visits for our electrophysiology patients, the Ward Family Heart Center is at the forefront of an initiative which is consistent with the American Heart Association's scientific statement on the use of telemedicine in pediatric cardiology.

"Utilizing teleconsultation, we have expanded our electrophysiology care to three separate locations as far as 200 miles away," Dr. Malloy-Walton said.

Electrophysiology patients in the communities of Joplin, Mo., Junction City, Kan., and Wichita, Kan., can have their visits performed at a local Children's Mercy clinic equipped with a telemedicine robot and staffed with a telemedicine nurse facilitator. Dr. Malloy-Walton is based at the Children's Mercy Adele Hall Campus during these appointments.

"For the 12-month period ending September 2018, I saw approximately 10 percent of my electrophysiology patients via teleconsultation," Dr. Malloy-Walton said. Because the same standard of care was met, reimbursement for these visits was equal to in-person visits.

New and follow-up patient diagnoses included supraventricular tachycardia (pre- and post-ablation), genetic arrhythmias, high-grade heart block, incision checks, device interrogations, dysautonomia and programming changes.

"We recently conducted a patient and family satisfaction survey which showed telemedicine improves access to sub-specialty care and enhances patient/family satisfaction in a cost-efficient manner," she said.

## Recent Publication

**Telemedicine in Pediatric Cardiology: A Scientific Statement From the American Heart Association.** Satou CM, Rheuban K, Alverson D, Lewin M, Mahnke C, Marcin J, Martin GR, Schmitz Mazur L, Sahn DJ, Shah S, Tuckson R, Webb CL, and Sable CA. Originally published 13 Feb 2017. *Circulation*. 2017;135:e648–e678.



# CHILDREN'S MERCY BRINGS HEART CARE CLOSER TO HOME

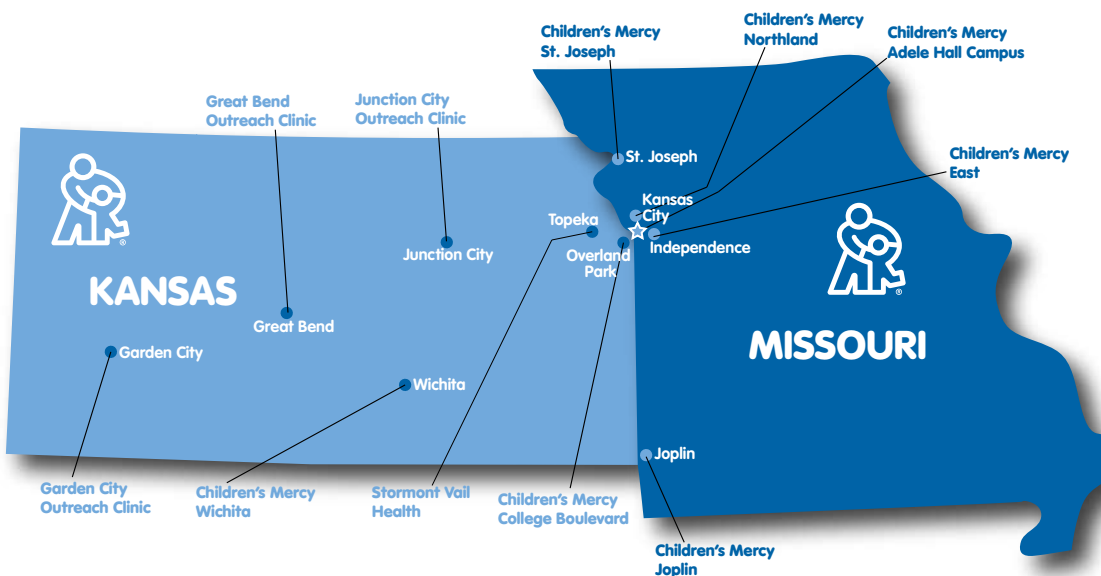
Mark Gelatt, MD, Director of Outpatient Services; Assistant Professor of Pediatrics

The Ward Family Heart Center at Children's Mercy Kansas City is committed to providing outpatient cardiac care close to home for patients in its 150-county service area, from all of Kansas to Western and Southern Missouri. These outreach clinics provide thousands of patients the opportunity to receive the advanced care they need in their own community.

Outpatient Cardiology Clinic locations include:

- Children's Mercy Adele Hall Campus, Kansas City, Mo.
- Children's Mercy College Boulevard, Overland Park, Kan.
- Children's Mercy East, Independence, Mo.
- Children's Mercy Northland, Kansas City, Mo.
- Children's Mercy Wichita, Wichita, Kan.\*
- Children's Mercy Joplin, Joplin, Mo.
- Children's Mercy Junction City, Junction City, Kan.
- Children's Mercy St. Joseph, St. Joseph, Mo.
- Garden City Outreach Clinic, Garden City, Kan.
- Great Bend Outreach Clinic, Great Bend, Kan.
- Stormont Vail Health, Topeka, Kan.

\* Specialty clinics in Wichita include preventive cardiology and electrophysiology.



# WE SERVE AS THE ECHOCARDIOGRAPHY CORE LAB FOR FDA INVESTIGATION OF NEW TRANSCATHETER PULMONARY VALVES

Girish Shirali, MBBS, FACC, FASE; Division Director, Cardiology; Melva and Randall L. O'Donnell PhD Chair in Pediatric Cardiology; Co-Director, the Ward Family Heart Center; Professor of Pediatrics



Since 2012, the Echocardiography Lab at the Ward Family Heart Center has served as the Echocardiography Core Lab for FDA investigation of the safety and effectiveness of transcatheter pulmonary valves.

These valves are being developed by Edwards Life Sciences and include the SAPIEN III and Alterra transcatheter heart valves. The lab continues surveillance of patients who received the SAPIEN valve, which now has been approved for use.

In order to monitor valve safety and effectiveness over a five-year time frame, patients receive from five to nine different echo studies pre- and post-implant for each device under investigation.

"We have performed more than 1,400 echo studies related to these valves over the past six years," Dr. Shirali said. "Our selection as the core lab for these devices validates our expertise in pediatric echocardiography, and provides us with access to longitudinal follow-up data on hundreds of patients."

Dr. Shirali also contributed to a recent research paper published in the Journal of the American College of Cardiology demonstrating excellent valve function and clinical outcomes at 3-year follow-up for the transcatheter pulmonary valve replacement using the Edwards SAPIEN transcatheter heart valve.

## Recent Publication

**3-Year Outcomes of the Edwards SAPIEN Transcatheter Heart Valve for Conduit Failure in the Pulmonary Position From the COMPASSION Multicenter Clinical Trial.** Kenny D, Rhodes JF, Fleming GA, Kar S, Zahn EM, Vincent J, Shirali GS, Gorelick J, Fogel MA, Fahey JT, Kim DW, Babaliaros VC, Armstrong AK, Hijazi ZM. JACC Cardiovasc Interv. 2018 Oct 8;11(19):1920-1929. doi: 10.1016/j.jcin.2018.06.001.

# OUR ELECTROPHYSIOLOGY TEAM CONTRIBUTES TO INTERNATIONAL GUIDELINES, MULTICENTER STUDIES

John Papagiannis, MD, Director of Electrophysiology

A team of three physicians, Dr. Papagiannis; Svtelana Tisma-Dupanovic, MD, CEPS, CCDS; Lindsey Malloy-Walton, DO, MPH, (pictured right) and six EP nurses and technicians performs all levels of interventional EP procedures in children, even in the smallest patients, including infants with hypoplastic left heart syndrome and patients on mechanical circulatory support. More than 220 interventional procedures were performed in our lab in 2018.

Our team serves patients with genetic arrhythmias, arrhythmias with cardiomyopathy, complex syncope, fetal arrhythmias, with the multidisciplinary care that is

required for our most complex patients. Dr. Papagiannis served as a member of an international committee of pediatric and adult congenital electrophysiologists who revised the guidelines for catheter ablation in children. He is also the lead investigator of a collaborative international 16-center study examining the outcome of catheter ablation in AV node reentry tachycardia in patients with congenital heart disease.



## Recent Publications

**Early Childhood Onset of High-Grade Atrioventricular Block in Hunter Syndrome.** Chlebowski MM, Heese BA, Malloy-Walton LE. *Cardiol Young*. 2018 May;28(5):786-787. doi: 10.1017/S104795118000215. Epub 2018 Mar 6. PMID: 29506582

**Atrioventricular Nodal Reentrant Tachycardia in Patients With Congenital Heart Disease: Outcome After Catheter Ablation.** Papagiannis J, Beissel DJ, Krause U, Cabrera M, Telishevska M, Seslar S, Johnsrude C, Anderson C, Tisma-Dupanovic S, Connolly D, Avramidis D, Carter C, Kornyei L, Law I, Von Bergen N, Janusek J, Silva J, Rosenthal E, Willcox M, Kubus P, Hessling G, Paul T; Pediatric and Congenital Electrophysiology Society. *Circ Arrhythm Electrophysiol*. 2017 Jul;10(7). pii: e004869. doi: 10.1161/CIRCEP.116.004869. Epub 2017 Jul 7. PubMed PMID: 28687669.

**External Cardioversion of Supraventricular Tachycardia in Omphalo-Thoracopagus Conjoined Twins.** Afzal MR, Malloy-Walton L, Tisma-Dupanovic S, Miles AL, Shah S, Papagiannis J. *JACC Clin Electrophysiol*. 2017 Mar;3(3):310-312. doi: 10.1016/j.jacep.2016.08.003. Epub 2016 Sep 14. PMID: 29759526.

# OUR CATH LABS ARE EXPERIENCING SIGNIFICANT GROWTH

Stephen Kaine, MD, Director, Cardiovascular Laboratory; Associate Director, the Ward Family Heart Center; Associate Director of Fellowship; Associate Professor of Pediatrics



From 2012 to 2018, the Cardiac Catheterization Labs at the Ward Family Heart Center have experienced significant growth, performing 665 catheterization and electrophysiology procedures in 2018. The lab's standardized adverse event rate is 4.6 percent with no mortality. The national average is 6.2 percent.

The labs offer a comprehensive suite of cutting-edge services including rotational angiography for select complex interventional procedures, and 3-D mapping for electrophysiology studies.

In addition, the team has developed expertise in treating pulmonary atresia

patients with intact ventricular septum. Over the past 15 years, 28 of these patients have been treated without complications or mortality.

"We utilize radiofrequency wire perforation of the atretic pulmonary valve, followed by balloon

valvuloplasty; eight of these infants received a ductal stent to augment pulmonary blood flow," Dr. Kaine explained.

The team also has collaborated closely with the hospital's radiologists to minimize radiation exposure during interventional procedures. In fact, according to IMPACT Registry data, the mean time for fluoroscopy per procedure at Children's Mercy is 15.9 minutes, compared to the national mean of 20.0 minutes. The mean dose area product per procedure for Children's Mercy is 1505 cGy-cm<sup>2</sup>, while the national mean is 3315 cGy-cm<sup>2</sup>.

"Our radiation exposure per case at Children's Mercy is less than half the national average," Dr. Kaine said. "We have been able to successfully reduce exposure, without sacrificing image quality or patient care."

## Recent Publications

**The Effect on Somatic Growth of Surgical and Catheter Treatment of Secundum Atrial Septal Defects.** Chlebowski MM, Dai H, Kaine SF. *Pediatr Cardiol.* 2017 Oct; 38(7):1410-1414. PMID: 28721547

**Epidemiology of Noninvasive Ventilation in Pediatric Cardiac ICUs.** Romans RA, Schwartz SM, Costello JM, Chanani NK, Prodhan P, Gazit AZ, Smith AH, Cooper DS, Alten J, Mistry KP, Zhang W, Donohue JE, Gaies M. *Pediatr Crit Care Med.* 2017 Oct; 18(10):949-957. PMID: 28742724

**Novel Direct Approach for Placement of Permanent Transvenous Pacing Leads After Fontan Procedure.** Randall JT, Aldoss OT, Law IH, Divekar AA. *Ann Pediatr Cardiol.* 2018 May-Aug; 11(2):187-190. PMID: 29922016

**Urgent Hybrid Palliation for Interrupted Aortic Arch in a Preterm Infant.** Romans RA, Armstrong AK, Aiyagari R. *Cardiol Young.* 2018 Feb; 28(2):344-346. PMID: 29110739

**Modified Stumper Technique for Acute Postoperative Bifurcation Stenosis Causing Right Ventricular Failure After Ross Procedure.** Divekar AA. *Ann Pediatr Cardiol.* 2016 Sep-Dec; 9(3):248-50. PMID: 27625524

**Modified Technique to Create Diabolo Stent Configuration.** Aldoss O, Divekar A. *Pediatr Cardiol.* 2016 Apr; 37(4):728-33. PMID: 26739005



# WE'RE EXPANDING OUR RESEARCH INTO PEDIATRIC HEART DISEASE

Jennifer Marshall, MPH, RN, RRT, CCRC, Director of Research and Quality for the Ward Family Heart Center

Research at the Ward Family Heart Center has grown over the last decade from a one-person staff to a team of seven. Currently, they are involved with more than 100 active research projects ranging from animal to bench top to clinical research.

Research funding also has grown, more than doubling since 2012 from sources such as the National Institutes of Health and the American Heart Association. In 2018, 25 research papers were published in high-impact journals, including the Journal of Pediatrics and Heart.

Research projects of note include:

- The Heart Center serves as an auxiliary site for the Pediatric Heart Network, and currently is involved in three research projects: the Fuel, Do-It and Saxophone studies.
- Heart Center researchers have received AHA grants to determine the cardiac benefits of weight loss in the understudied population



Pictured above are the medical team and researchers that are part of the CHAMP team.

of children with intellectual and developmental disabilities; and cardiac pharmacogenomics is focused on fine-tuning dosing of statins in the pediatric population.

- The Cardiac High Acuity Monitoring Program, or CHAMP App, was developed with private funding, but recently received a \$50,000 Magnet prize from the ANCC to expand this research. Today, nine hospitals across the nation are using CHAMP to reduce deaths in the interstage period.

## Recent Publication

**Long-term Transplant-free Survival Following Repair of Total Anomalous Pulmonary Venous Connection.** St. Louis J, McCracken C, Turk E, Hancock H, Menk J, Harvey B, Vincocur J, Oster M, Moller J, Spector L, Kochilas L. *Annals of Thoracic Surg*, 105(1):186-92, Jan 2018.

# WE PROVIDE COMPREHENSIVE HEART CARE BEFORE BIRTH

Tara Swanson, MD, Director of Fetal Cardiology



Each year, nearly 400 families visit the Perinatal Clinic at the Elizabeth J. Ferrell Fetal Health Center at Children's Mercy Kansas City for a consultation. About one-third of families who come to the Fetal Health Center have a baby with a heart condition. Our fetal cardiologists, nurses and nurse practitioners help these families through the process of getting an accurate diagnosis, understanding the condition and finding the best possible

course of treatment both before and after delivery.

At Children's Mercy, our goal is not only to improve prenatal diagnosis of congenital heart defects, but to also provide the expertise, counseling and state-of-the-art care necessary to support these children and their families prenatally and beyond. To be certain each concern is addressed, the program's nurse coordinators maintain

a fetal checklist, a record of everything the team discusses with the family.

Since the development of the successful checklist, it has become widely requested by other fetal cardiology and counseling programs across the nation. The National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC), a group of parents and providers who are working to improve outcomes for children with heart defects, is using the checklist to help improve prenatal counseling.

Programs are welcome to download a copy and use it. For a copy of the Fetal Cardiac Program Counseling Checklist, visit: [childrensmercy.org/fetalcardiology](http://childrensmercy.org/fetalcardiology).

## Recent Publications

**Improving Wait Time for Patients in a Pediatric Echocardiography Laboratory - a Quality Improvement Project.** Parthiban A, Warta A, Marshall JA, Reid KJ, Mann K, Shirali G, Swanson T. *Pediatr Qual Saf.* 2018 Jun 6;3(3):e083. doi: 10.1097/pq9.000000000000083. eCollection 2018 May-Jun. PMID: 30229195

**Rapidly Expanding Giant Left Atrial Pseudoaneurysm in the Fetus.** Ramlogan SR, Swanson T, St Louis J, Lay A. *World J Pediatr Congenit Heart Surg.* 2017 Jul;8(4):527-528. doi: 10.1177/2150135117697313. Epub 2017 Apr 13. PMID: 28403663

# WE ARE INVESTIGATING THE IMPACT OF PHARMACOGENOMICS ON PEDIATRIC STATIN DISPOSITION

Jon Wagner, DO, Pediatric Cardiologist/Clinical Pharmacology

Dr. Wagner's work focuses on statin optimization in pediatrics. His early work focused on how genetic variation of the liver-specific transporter OATP1B1 impacts the amount of statin in the blood after a dose is given. Increased amount of statin in the blood places patients at higher risk of side effects and treatment failure. Dr. Wagner's ultimate goal is to provide precision-based drug treatment to the individual child that may require a statin.

Two studies into this important topic have completed:

- The first investigated the cholesterol-lowering drugs pravastatin and simvastatin. Both studies confirmed the genotype-phenotype relationship observed in adults. However, other sources of variability in drug exposure were found (e.g. obesity, drug conversion) in conjunction with OATP1B1 genotype. "Concerning was the finding that twenty five percent of the children in our simvastatin study didn't receive anything close to adequate exposure to the medicine," Dr. Wagner said. "This could result in treatment failure for these patients. Our ongoing work at the bench is to

mechanistically this finding to understand why these children didn't form to the active drug."

- A second trial looked at the drugs rosuvastatin and atorvastatin. In his presentation at the 21st Annual Update on Pediatric and Congenital Cardiovascular Disease, Dr. Wagner revealed a similar genotype-phenotype relationship with rosuvastatin. Data analysis related to atorvastatin will complete spring 2019.

## PI Grant Support

### National Institutes of Health-NICHD

1 U54 HD090258-02, GOLDILOKS: Genomic- and Ontogeny-Linked Dose Individualization and Clinical Optimization for Kids, April 2018-present

**Pilot Project:** Validation of OATP Endogenous Biomarkers in Children

**Pilot Project Amount:** \$30,000

**KL2 Clinical and Translational Mentored Career Development Award (KL2TR002367), September 2017—present**

**Project:** Statin Optimization in Pediatrics

**Award Amount:** \$356,886

**American Heart Association National Affiliate Clinical Research Program, July 2013–July 2016**

**Project:** Pharmacokinetics of pravastatin and simvastatin in pediatric dyslipidemia patients: Clinical impact of genetic variation in statin disposition

**Award Amount:** \$150,000

**Children's Mercy Hospital Marion Merrell Dow Clinical Scholar Award, July 2014–present**

**Project:** Pharmacokinetics of rosuvastatin and atorvastatin in pediatric dyslipidemia patients: Clinical impact of genetic variation in statin disposition

**Award Amount:** \$100,000

**Children's Mercy Hospital Clinical Fellowship Research Award, July 2013–June 2015**

**Project:** Cardiology Pharmacogenomics Repository

**Award Amount:** \$15,000



## Recent Publications

**Pharmacokinetics of Pravastatin in Pediatric Dyslipidemia: Clinical Impact of Genetic Variation on Statin Disposition.** Wagner J, Rahman S, Van Haandel L, Raghuvver G, Kauffman R, Gaedigk A, Gaedigk R, Leeder JS. Clin Pharmacol Ther. 2018 Dec 14. doi: 10.1002/cpt.1330. [Epub ahead of print]. PMID:30549267

**Considerations for Implementing Precision Therapeutics in Children.** McLaughlin MJ, Wagner J, Shakhnovich V, Carleton B, Leeder JS. Clin Transl Sci. 2018 Dec 5. Doi: 10.1111/cts.12607. PMID 30516322.

**Impact of SLC01B1 Genotype on Pediatric Simvastatin Pharmacokinetics.** Wagner JB, Rahman S, Van Haandel L, Raghuvver G, Kauffman R, Gaedigk A, Gaedigk R, Leeder JS. J Clin Pharmacol. 2018 Feb 22. doi: 10.1002/jcph.1080. PMID 29469964.

# WE'RE IMPROVING CARE FOR EVERY HOSPITALIZED CONGENITAL HEART DISEASE PATIENT WITH DAILY ROUNDING

James E. O'Brien Jr., MD, FACS, Chief, Section of Cardiothoracic Surgery; Jerry Smith Chair in Pediatrics; Co-Director, the Ward Family Heart Center; Associate Professor of Surgery

Stephen Kaine, MD, Director, Cardiovascular Laboratory; Associate Director, the Ward Family Heart Center; Associate Director of Fellowship; Associate Professor of Pediatrics

At the Ward Family Heart Center, the 35 to 40 team members who have a role in caring for our patients start every day at 7 a.m., not on the floor, but in a conference room.

15 on the floor and five to six in the NICU," Dr. O'Brien said.

Originally, the brainchild of Dr. Kaine, the idea to pull everyone together who cares for our congenital heart disease patients grew out of conversations he had with his colleagues at other pediatric heart programs around the nation.

"I know there are a few other hospitals where they do something similar for their surgical patients, but I'm not aware of any other pediatric hospital where they review every cardiac patient's case, every morning," he said.

Today, Dr. O'Brien said no one would go back to traditional rounds.

"Over the past three years, daily rounding has become embedded in the natural flow of our day," Dr. O'Brien said. "It increases communication and collaboration among disciplines, and ultimately improves the quality and efficiency of the care we provide."

There, team members receive updates on each patient's status, reviewing diagnostic imaging and lab results to develop the day's care plan. When rounding

is finished, each team member knows the plan and does their part to implement it. Specialists round on their individual patients later.

"Typically, we have about 40 patients in the house every day; 20 in the ICU,





# OUR CARDIAC NEURODEVELOPMENTAL PROGRAM IMPROVES QUALITY OF LIFE FOR CHILDREN

Elizabeth Willen, PhD, Neuropsychologist

The Cardiac Neurodevelopmental Program at Children's Mercy has grown into one of the most comprehensive, robust multidisciplinary programs in the nation, having evaluated more than 400 patients since 2013.

This multi-faceted program is designed to meet the neurodevelopmental needs of infants, children and adolescents with congenital or acquired heart conditions, including sudden cardiac arrest.

Key program elements include:

- Serial neurodevelopmental/ neuro psychological assessment beginning at 6 months of age
- Targeted evaluation by CND specialists, including physical, occupational and speech/ language therapies, neurology, psychology and social work
- Development of 504 and individual education plans (IEPs).



- National and international outreach and advocacy through participation in the Cardiac Neurodevelopmental Outcomes Collaborative (CNOC)

In 2018, Children's Mercy Kansas City was the hosting sponsor of the annual Cardiac Neurodevelopmental Symposium. Becky Gregory, PhD(c), RN,

CNOR, Cardiac Neurodevelopmental Program Coordinator, has been a member of the Steering Committee since 2013 and worked along with Dr. Willen and others to bring the group to Kansas City. Nearly 250 people were in attendance from across the United States and Canada.

# OUR CARDIOLOGIST HELPS AUTHOR IMPACT REGISTRY REPORTS

Natalie Jayaram, MD, MSB



Dr. Jayaram authors several of the first reports released by the National Cardiovascular Data Registry's (NCDR) IMPACT Registry (Improving Pediatric and Adult Congenital Treatment). The multi-center clinical registry collects data on pediatric and adult patients undergoing

diagnostic or interventional cardiac catheterization procedures.

Participation in the registry is voluntary, with more than 90 hospitals nationwide taking part, including Children's Mercy. The registry collects data on patients' demographics, medical history and risk factors, detailed procedural information, hemodynamic data, information related to adverse events, and detailed data for six commonly performed interventional procedures. The goal is to gather data to set national benchmarks for diagnostic and certain specific interventional procedures.

One of Dr. Jayaram's most recent publications looks at risk-standardization methodology to adjust for patient characteristics when comparing major adverse outcomes in the NCDR's IMPACT Registry. The study found the creation of a validated risk-standardization model for adverse outcomes after congenital cardiac catheterization can support reporting of risk-adjusted outcomes in the IMPACT Registry as a foundation for quality improvement.

## Recent Publications

**Modeling Major Adverse Outcomes of Pediatric and Adult Patients With Congenital Heart Disease Undergoing Cardiac Catheterization: Observations From the NCDR IMPACT Registry (National Cardiovascular Data Registry Improving Pediatric and Adult Congenital Treatment).** Jayaram N, Spertus JA, Kennedy KF, Vincent R, Martin GR, Curtis JP, Nykanen D, Moore PM, Bergersen L. *Circulation*. 2017 Nov 21;136(21):2009-2019. doi: 10.1161/CIRCULATIONAHA.117.027714. Epub 2017 Sep 7. PMID: 28882885

**Impact of Telemonitoring on Health Status.** Jayaram NM, Khariton Y, Krumholz HM, Chaudhry SI, Matterna J, Tang F, Herrin J, Hodshon B, Spertus JA. *Circ Cardiovasc Qual Outcomes*. 2017 Dec;10(12). pii: e004148. doi: 10.1161/CIRCOUTCOMES.117.004148. PMID: 29237746

**Acute Success of Balloon Aortic Valvuloplasty in the Current Era: A National Cardiovascular Data Registry Study.** Boe BA, Zampi JD, Kennedy KF, Jayaram N, Porras D, Foerster SR, Armstrong AK. *JACC Cardiovasc Interv*. 2017 Sep 11;10(17):1717-1726. doi: 10.1016/j.jcin.2017.08.001. PMID: 28882282

**Relationship Between Hospital Procedure Volume and Complications Following Congenital Cardiac Catheterization: A Report from the IMPROVING Pediatric and Adult Congenital Treatment (IMPACT) Registry.** Jayaram N, Spertus JA, O'Byrne ML, Chan PS, Kennedy KF, Bergersen L, Glatz AC. *Am Heart J*. 2017 Jan;183:118-128. doi: 10.1016/j.ahj.2016.10.004. Epub 2016 Oct 8. PMID: 27979036

# OUR SURGEON CONTRIBUTES TO ICD CODING AND WORLD SURGICAL DATABASE CREATION

James St. Louis, MD, Surgical Director Cardiac Transplantation and Joseph Boon Gregg/Missouri Endowed Chair in Pediatric Surgery; Professor of Surgery

The World Society for Pediatric and Congenital Heart Surgery (WSPCHS) was founded with the mission to “promote the highest quality comprehensive cardiac care to all patients with congenital heart disease, from the fetus to the adult, regardless of the patient’s economic means, with an emphasis on excellence in teaching, research, and community service.” Early on, the Society’s members realized that a crucial step in meeting this goal was to establish a global database that would collect vital information, allowing cardiac surgical centers worldwide to benchmark their outcomes and improve the quality of congenital heart disease care.

Dr. St. Louis is on the board of directors of WSPCHS and was part of the working group tasked with establishing a web-based database available at no charge to pediatric heart surgery programs across the world. With input of multiple international experts, The World Database for Pediatric and Congenital Heart Disease went live on January 1, 2017.

“This is a unified database focused on quality improvement,” Dr. St. Louis said. “It is a common platform



that programs throughout the world can use to collect everything from diagnosis to procedure, to detailed information about surgery and outcomes.”

## Recent Publications

**The World Database for Pediatric and Congenital Heart Surgery “A Call to Service for North American Congenital Heart Surgery Programs”.** St Louis JD, Timkovich N, Lenderman S, Jonas RA, Guleserian KJ, Tchervenkov CI, Jacobs JP, Austin EH, Plunkett MD, Myers JL, Hraska V, Sinha P, O’Brien JE Jr, Jacobs ML, Kirklin JK. *Semin Thorac Cardiovasc Surg.* 2019 Jan 4. pii: S1043-0679(18)30319-8. doi: 10.1053/j.semtcvs.2019.01.002. [Epub ahead of print] PMID: 30616005

**Classification of Ventricular Septal Defects for the Eleventh Iteration of the International Classification of Diseases-Striving for Consensus: A Report From the International Society for Nomenclature of Paediatric and Congenital Heart Disease.** Lopez L, Houyel L, Colan SD, Anderson RH, Béland MJ, Aiello VD, Bailliard F, Cohen MS, Jacobs JP, Kurosawa H, Sanders SP, Walters HL 3rd, Weinberg PM, Boris JR, Cook AC, Crucean A, Everett AD, Gaynor JW, Giroud J, Guleserian KJ, Hughes ML, Juraszek AL, Krogmann ON, Maruszewski BJ, St Louis JD, Seslar SP, Spicer DE, Srivastava S, Stellin G, Tchervenkov CI, Wang L, Franklin RCG. *Ann Thorac Surg.* 2018 Nov;106(5):1578-1589. doi: 10.1016/j.athoracsur.2018.06.020. Epub 2018 Jul 19. PMID: 30031844

**History of the World Society for Pediatric and Congenital Heart Surgery: The First Decade.** Jacobs JP, Tchervenkov CI, Stellin G, Kurosawa H, Mavroudis C, Jatene MB, Al-Halees Z, Cicek SM, Sandoval NF, Backer CL, Cervantes J, Dearani JA, Ebels T, Edwin F, Finucane K, Fragata J, Iyer KS, Kinsley RH, Kirklin JK, Kreutzer C, Liu J, Maruszewski B, St Louis JD, Sarris GE, Jonas RA. *World J Pediatr Congenit Heart Surg.* 2018 Jul;9(4):392-406. doi: 10.1177/2150135118775962. PMID: 29945512

# WE'RE COLLABORATING WITH THE AHA AND PROJECT ADAM TO CREATE HEARTSAFE SCHOOLS

Lindsey Malloy-Walton, DO, MPH, Pediatric Electrophysiologist; Assistant Professor of Pediatrics

According to the Institute of Medicine, each year 12,500 youth experience out-of-hospital sudden cardiac arrest. Often, these events occur during the school day or at athletic events, but many schools are not well-equipped to respond appropriately.

That's why we are collaborating with the American Heart Association-

Kansas City and Project ADAM, a national non-profit program that has developed the processes and tools to prepare schools for sudden cardiac emergencies.

Project ADAM awards the HeartSafe school

designation to participating sites that successfully implement a sustainable and comprehensive CPR and AED program.

"Our goal is to have all schools in the Kansas City region establish effective sudden cardiac arrest preparedness procedures to help prevent the tragedy of sudden cardiac death and to achieve designation as HeartSafe schools," Dr. Malloy-Walton said.

Dr. Malloy-Walton is serving as the physician leader from Children's Mercy for this initiative, and is piloting the program at one of the hospital's partner schools in Kansas City, Mo. Her colleague, Arpan Doshi, MD, Children's Mercy Wichita Cardiology, is working to establish a similar program in the Wichita, Kan., schools.

"By helping area schools establish an emergency plan they can implement in the event of a cardiac emergency, we hope to save the lives of students, parents and teachers," Dr. Malloy-Walton said.





# WE OFFER ONE OF THE NATION'S ONLY PEDIATRIC CARDIO-ONCOLOGY PROGRAMS

Sanket Shah, MD, Assistant Professor of Pediatrics

The Ward Family Heart Center has one of the few Cardio-Oncology programs in the nation dedicated to monitoring potential cardio-toxicity in pediatric cancer survivors.

The program is a collaborative effort involving Dr. Shah and Aliessa Barnes, MD, Medical Director of Cardiac Transplantation, along with Jennifer Fulbright, MD, Director, Survive and Thrive Program, and Wendy Heim, APRN, CPNP, oncology advanced practice nurse.

Utilizing the most recent long-term follow-up guidelines from the Children's Oncology Group, this team monitors approximately 200 patients each year for cardiotoxicity and actively treats 15 to 20 who have varying degrees of cardiac dysfunction.

"Dr. Fulbright and Wendy see these patients post-treatment in the hospital's Survive and Thrive Clinic," Dr. Shah said. "Dr. Barnes and I

monitor their cardiac function during these check-ups using a combination of echocardiography, cardiac MRI and cardiac biomarker testing."

By systematically monitoring these patients, the team has been able to proactively identify and treat subclinical cardiac dysfunction before it becomes problematic.

They are also partnering with City of Hope Hospital in a randomized trial studying how well low-dose carvedilol works to prevent heart failure in cancer survivors exposed to high-dose anthracyclines for management of childhood cancer.



## Recent Publication

**Medium-term Assessment of Cardiac Function in Pediatric Cancer Survivors. Comparison of Different Echocardiographic Methods, Cardiac MRI and Cardiac Biomarker Testing in Adolescent Cancer Survivors.** Shah SS, McClellan W, Knowlton J, Mehta J, Goudar S, Ferguson A, Sherman A, Shirali G, Fulbright J. *Echocardiography* 2016; 1-7.

# OUR PULMONARY HYPERTENSION CLINIC TREATS PATIENTS COLLABORATIVELY

Brian Birnbaum, MD, Pediatric Cardiologist, Clinical Assistant Professor of Pediatrics

Though we rarely see pulmonary hypertension in pediatrics, at the Ward Family Heart Center we follow approximately 50 patients with this condition in our Pulmonary Hypertension Clinic throughout the year.

About two-thirds of these patients are infants with prematurity, chronic lung disease and other congenital

abnormalities. The remaining one-third are adolescents diagnosed with primary pulmonary hypertension.

Established about four years ago, the clinic offers patients and families the expertise of Brian Birnbaum, MD, pediatric cardiologist, and Alvin Singh, MD, pediatric pulmonologist. A nurse practitioner provides additional care and follow-up.

The combined clinic makes ongoing care for these complex patients more convenient and efficient for families. The doctors see five to six patients at each clinic, which they conduct twice a month. Treatment often includes advanced intravenous and subcutaneous therapies available only from physicians at highly specialized centers, such as Children's Mercy.

"I think it is rare to have a clinic that combines cardiology and pulmonology," Dr. Birnbaum said. "Dr. Singh and I see these patients at the same clinic appointment, ensuring we have a treatment plan in place for each patient, and that the family and our team are all aware of the next steps in their care."



# FACULTY

## Cardiovascular Surgeons

**James E. O'Brien Jr., MD, FACS**  
Chief, Section of Cardiothoracic Surgery; Jerry Smith Chair in Pediatrics; Co-Director, Ward Family Heart Center

**William I. Douglas, MD**  
Congenital Cardiovascular Surgeon

**William Gibson, MD\***  
Cardiovascular Surgeon

**James St. Louis, MD**  
Surgical Director, Cardiac Transplantation, Joseph Boon Gregg/Missouri Endowed Chair in Pediatric Surgery

## Cardiologists

**Girish Shirali, MBBS, FASE, FACC**  
Division Director, Cardiology; Melva and Randall O'Donnell, PhD Chair in Pediatric Cardiology; Co-Director, Ward Family Heart Center

**Michael Artman, MD**  
Joyce C. Hall Eminent Scholar in Pediatrics; Chair, Department of Pediatrics; Senior Vice President and Pediatrician-in-Chief

**Aliessa Barnes, MD**  
Medical Director, Heart Failure and Cardiac Transplantation; Director, Pediatric Cardiology Fellowship Training

**Brian Birnbaum, MD**  
Director, Pulmonary Hypertension

**Karina Carlson, MD**

**Arpan Doshi, MD**  
Wichita, Kan.

**Unnati Doshi, MD, MPH**  
Wichita, Kan.

**Christopher Follansbee, MD\***

**Daniel Forsha, MD, MHS**

**Mark Gelatt, MD**  
Director, Outpatient Services

**Lalitha Gopinetti, MD**  
Wichita, Kan.

**Suma Goudar, MD**

**Hayley Hancock, MD**  
Director, CHAMP Program

**Howard Heching, MD**

**Natalie Jayaram, MD, MSB**

**Stephen Kaine, MD**  
Associate Director, Ward Family Heart Center; Director, Cardiovascular Laboratory; Associate Director, Fellowship Training Program

**Maria Kiaffas, MD**

**Nitin Madan, MD**

**Lindsey Malloy-Walton, DO, MPH**

**John Papagiannis, MD, CCDS, CEPS**  
Director, Electrophysiology

**Anitha Parthiban, MD**  
Director, Echocardiography

**John Plowden, MD**  
Topeka, Kan.

**Geetha Raghuv eer, MD**  
Director, Preventive Cardiology

**Toby Rockefeller, MD\***

**Ryan Romans, MD**

**Sanket Shah, MD**

**Tara Swanson, MD**  
Director, Fetal Cardiology

**Svetlana Tisma-Dupanovic, MD, CCDS, CEPS**

**Jonathan Wagner, DO**

**Luisa Madroñero Waitman, MD**  
Director, Cardiovascular Genetics

\* Joining in July 2019

## Cardiac Anesthesiologists

**Carrie M. Clarke, MD**

**William B. Daniels, DO**

**John Erkmann, DO**

**Kathy M. Perryman, MD, FAAP**

**Paul Sheeran, MD**

**Adam B. Striker, MD**

**Susan J. Whitney, MD**

## Cardiac Intensivists

**Jeremy Affolter, MD**

**Geoffrey L. Allen, MD**

**Bruce Banwart, MD**

**Jennifer Flint, MD**

**Laura Miller-Smith, MD**

**Erica A. Molitor-Kirsch, MD**

**Brian S. Olsen, MD, FAAP**

**Laura A. Ortmann, MD**

**Kelly S. Tieves, DO, MS**

## Cardiac Neonatologists

**John M. Daniel IV, MD, MS**

**Howard W. Kilbride, MD**

**Michael Nyp, DO**

**Steven L. Olsen, MD**

**Eugenia K. Pallotto, MD, MSCE**

**Joshua E. Petrikin, MD**

**Ayan Rajgarhia, MD**

**Julie Weiner, DO**

## Children's Mercy Kansas City

Children's Mercy Kansas City is ranked as one of "America's Best Children's Hospitals" in all 10 specialties rated by U.S. News & World Report and has received Magnet™ recognition for excellence in nursing services four consecutive times. With 366 licensed beds and a medical staff of more than 750 pediatric subspecialists, we care for children from all 50 states and from around the world. In addition, our leadership in pediatric genomic medicine and individualized pediatric therapeutics is driving research and innovation in neonatology, nephrology, endocrinology, gastroenterology, neurology, heart, cancer and other subspecialties to transform outcomes for children. Children's Mercy also is nationally recognized for innovation in psychosocial care and creating a family-centered environment focused on the unique needs of hospitalized children and their families. Our love for children powers everything we do, inspiring our research, innovations and our everyday care. Because love has no limits. And with it, neither do we.



**LOVE WILL.**

To learn more about how love is driving us to improve cardiology care, visit [childrensmercy.org/heart](https://childrensmercy.org/heart)

Cardiology Office: (816) 234-3880

For transport, admissions or consults, call:

1 (800) GO MERCY / 1 (800) 466-3729

In academic affiliation with the  
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