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## Partial Heart Transplantation: Introducing Living Valve Replacement in Congenital Heart Disease

*Seth E.M. Wolf, MD; Rebekah Boyd, MD; Douglas M. Overbey, MD, MPH; Joseph W. Turek, MD, PhD, MBA*

The treatment of heart valve disease in infants and children has long been constrained by a fundamental limitation: prosthetic and cadaveric valves do not grow with the patient. As a result, children requiring valve replacement often face a lifetime of repeated cardiac operations, each with increasing surgical complexity and cumulative risk. Despite technical advances in congenital heart surgery, the absence of a valve substitute capable of growth has remained a major barrier to durable treatment.

A recent study published in JAMA describes the first clinical series with partial heart transplantation (PHT), a novel surgical strategy designed to address this limitation by implanting

living donor heart valves capable of somatic growth. The report summarizes outcomes from the initial 19 patients undergoing PHT in the semilunar position at a single high-volume pediatric heart center between April 2022 and December 2024.

The cohort included neonates, infants, children, and young adults with complex Congenital Heart Disease and valve pathology not amenable to conventional repair or replacement. The median age at operation was 97 days, reflecting the emphasis on early intervention in patients with life-threatening disease. Valve grafts were obtained using multiple procurement strategies, including donation after circulatory death,



*Dr. Joseph Turek in the OR with team*



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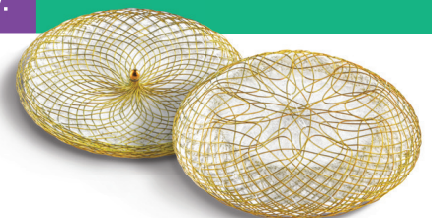
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*Dr. Douglas Overbey (center left), Dr. Joseph Turek (center right) with team*



*Kix Soderblom held by mom with family*

“domino” recovery from explanted hearts during full heart transplantation, and split-root techniques allowing one donor heart to benefit more than one recipient.

Unlike cryopreserved homografts, in which the tissue is nonviable, partial heart transplantation uses viable donor valves that are maintained with immunosuppression following implantation. Most patients received tacrolimus monotherapy after an initial postoperative period, with dosing strategies designed to preserve graft function while minimizing long-term immunologic risk.

The principal endpoint of the study was growth of the transplanted valve. Among the nine patients in the earliest cohort who underwent systematic longitudinal evaluation, both valve annular diameter and leaflet length demonstrated statistically significant increases over time. Median annular diameter increased from 7 to 14 mm for the aortic valve and from 9 to 17 mm for the pulmonary valve. Importantly, growth was accompanied by corresponding increases in leaflet length, confirming genuine tissue growth rather than passive dilation.

Functional performance of the transplanted valves was favorable. No patient required reintervention on the implanted valve during follow-up, and clinically significant stenosis or regurgitation was not observed. At most recent review, a small

number of patients demonstrated mild regurgitation of the aortic or pulmonary valve, without evidence of deteriorating performance.

The safety profile of partial heart transplantation was also encouraging. One patient required discontinuation of immunosuppression. Notably, the valve continued to demonstrate growth despite cessation of therapy. Other adverse events included transient kidney dysfunction in two patients and a single respiratory infection, all of which were managed without long-term sequelae. No deaths were directly attributable to the intervention or to complications of immunosuppression.

Beyond its technical novelty, partial heart transplantation represents an important advance in organ utilization. Hearts unsuitable for full transplantation may be repurposed for valve donation, expanding the available donor pool. The domino technique further increases access by redirecting healthy valves from transplant recipients to new patients. Given that approximately 500 pediatric heart transplants are performed annually in the United States, this strategy could substantially increase the availability of viable valve tissue nationwide.

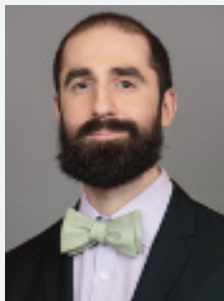
The authors also describe broader applications of partial heart transplantation beyond infancy. Among older children and young adults, PHT has been incorporated into a modified Ross procedure (“Living Ross”), in which a PHT graft is utilized for the pulmonary position instead of a cryopreserved cadaveric valve. This innovation may improve long-term outcomes in a population already known to benefit from biologic valve replacement.

For the first time, clinicians have demonstrated that transplanted human heart valves may grow in vivo. This represents a paradigm shift in pediatric valve therapy: from repeated replacement to biologic restoration. Partial heart transplantation introduces the possibility that a single operation in infancy could provide durable valvular function into childhood and beyond. As further experience accumulates, partial heart transplantation may redefine both the surgical framework of pediatric valve management, shifting from palliation toward true tissue replacement and recovery.

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Ochsner Children's Hospital – New Orleans

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Ochsner Children's provides services for all pediatric cardiac sub-specialties including heart failure/transplant, EP, ACHD, interventional cardiology, imaging including echocardiography and cardiac MRI and CT, and fetal cardiology, comprehensive single ventricle program, and neurodevelopmental clinic. The heart center includes 21 cardiologists, 3 congenital heart surgeons, 6 cardiac intensivists practicing in a dedicated pediatric 12 bed cardiac intensive care unit and 3 pediatric cardiac anesthesiologists. The program performs approximately 250 cardiac surgeries, 400 cardiac catheterizations (75% interventional) and 19,000 ambulatory visits at 15 locations across Louisiana and Mississippi per year. Our heart center has been ranked by US New and World Report for the last 6 years and is the only ranked program in Louisiana; survival after cardiac surgery for our most complex patients (STS STAT 4 and 5 categories) is in the top 10% of programs reporting to STS.

Our comprehensive Ochsner Children's program is the region's leading integrated provider of multispecialty care for newborns, infants, children, adolescents, and young adults. We offer a full range of pediatric complex specialty services including, liver and bone marrow transplantation, a comprehensive surgical sub-specialty group, advanced GI and Hepatology, advanced spine surgery, Hematology-Oncology and AYA Oncology, Cleft Palate/Cranio-Facial Surgery and the region's only comprehensive multidisciplinary developmental pediatrics center.

Ochsner Children's Hospital includes a 67-bed Level IV Neonatal Intensive Care Unit, a 14-bed PICU, a 12-bed pediatric CV-ICU, a NAEC-accredited level IV, 4 bed Pediatric EMU and a 44-bed Pediatric Acute Care unit, with a dedicated pediatric emergency room, supported by a 24-7 pediatric and neonatal transport team utilizing rotary and fixed wing aircraft, as well as ground transport. **Last year we broke ground on a new 5-story Children's Hospital on our main campus in New Orleans, with expected opening in quarter 1 of 2028.**

In addition to direct patient care, Ochsner Children's Hospital has an ACGME-accredited pediatric residency program and is also responsible for teaching pediatric residents from the Tulane-Ochsner Pediatric Residency program as well as medical students from both Tulane and the University of Queensland, Australia. Ochsner Health and Xavier University of Louisiana recently announced an agreement to establish a joint allopathic College of Medicine, the Xavier Ochsner College of Medicine which is in the LCME accreditation process currently. Our faculty have an opportunity for academic appointment at the University of Queensland and Xavier, participate in numerous research studies and multi-center trials, and publish hundreds of research papers annually.

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# Program Directory 2025-2026

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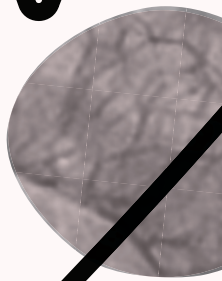
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# The 5<sup>th</sup> Edition of Anderson's Pediatric Cardiology Textbook: The "Red Line" and Learner-Centered Design

Justin T. Tretter, MD; R. Krishna Kumar, MD, DM, FAHA; Rohit S. Loomba, MD; Diane E. Spicer, BS, PA (ASCP); Liesl J. Zühlke, MBChB, DCH, FCPaed Cert Card, MPH, MSc, PhD; Hani K. Najm, MD, MSc, FACC, FRCSC, FRCS (Glasgow); Robert H. Anderson, MD, BSc, PhD (Hon); Colin J. McMahon, MD, MHPE, MBA FRCPI, FACC

Anderson's Pediatric Cardiology, 5<sup>th</sup> edition, (Figure 1) is set to be published in May 2026. We hoped to share the efforts, including the educational research-based approach, which guided our "Red Line" and **Learner-Center Design** of the 5<sup>th</sup> edition. Our aim in sharing this approach is both to emphasize the attention and efforts given to the 5<sup>th</sup> edition, which we anticipate will further establish it as an authoritative reference and "responsive, learner-centered" educational tool, but also to provide a suggested framework for others aiming to optimize educational learning resources within the field of pediatric and congenital cardiac care.

## Initial Needs Assessment

We began our approach by reviewing the table of contents of the prior 4<sup>th</sup> edition, comparing it to other popular textbooks within the field of congenital and pediatric cardiac care. We then reviewed the common structure of lesion-based chapters within these same textbooks, comparing them not only to those within the congenital and pediatric cardiac fields, but also to the evolving structure of successful textbooks within adult cardiac care. We recognized that the strength of our textbook has always been its solid anatomical foundation, which is grounded in evidence-based developmental and anatomical investigations, with a focus on clinically-relevant anatomical concepts and terminology. Its deficiency has been the application towards physiology, and clinical evaluation and management, or what is known in the field of medical education as the "**Red Line**." Historically, anatomical and clinical sections are often written in isolation, limiting clinical application of the anatomical concepts reviewed. And while many congenital cardiac providers have experience in lecturing, writing and teaching, few involved in the creation of medical textbooks possess formal training in medical education. We also took note that significant foundational content deficiencies were present in the table of contents of

our prior 4<sup>th</sup> edition, while at the same time including non-essential topics. This is partly related to failure in identifying a clear target audience. Our overall approach was then compared to other contemporary textbooks, along with assessing prior usage data of the individual online chapters.

## Changes to the Editorial Board

On the basis of this understanding, our intent to be guided by successful, established modern medical education approaches, coupled with our aim to cater to a global audience with overlapping but different needs, required directed changes to our editorial board. The combined resulting expertise spans all pediatric and congenital cardiac subspecialties, including two individuals who are both clinical congenital cardiologists and trained cardiac anatomists, ensuring this necessary "**Red Line**." The board also provides global representation, with expertise spanning global health, health equity, and congenital cardiac care in low- and middle-income countries. And of utmost importance, the board includes those with formal training in medical education, with extensive experience in creating printed and online educational material.

## Stakeholder Input

We then aimed formally to obtain learner feedback in order to better guide pedagogical innovations, the results of which were published in *Cardiology in the Young*.<sup>1</sup> This feedback was placed into the context of the current status of training and evolving developments in medical education pertinent to congenital cardiology.<sup>2</sup> During this editorial process, fellows, early-career cardiologists, and educators provided structured feedback emphasizing a preference for consistent structure, concise visuals, and interactive learning elements. This iterative model mirrors established educational design frameworks, which prioritize stakeholder engagement

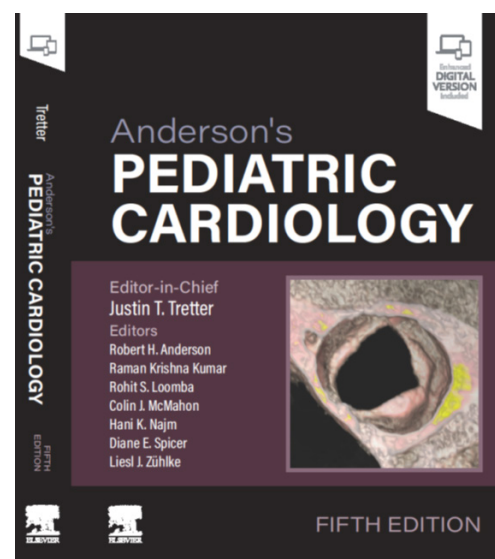


FIGURE 1 Anderson's Pediatric Cardiology 5<sup>th</sup> Edition Textbook Cover



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and continuous improvement. This process supported the 5<sup>th</sup> edition in becoming both an authoritative reference but also a "responsive, learner-centered" educational tool.

## Guided Changes to the 5<sup>th</sup> Edition

This methodical process led to the following instrumental changes in both the table of contents and the chapter constructs.

### Changes to the Table of Content

Non-essential, non-traditional, and previously minimally accessed chapters were removed to generate space in the page count allotment to incorporate missing foundational chapters. The table of content was then re-organized. This included emphasizing the "**Red Line**" concept by incorporating missing physiological



chapters into the previous “anatomical only” section, and to create a new, robust section on “Normal Development, Structure and Function of the Cardiovascular System.” The prior subspecialized focus of fetal cardiology was consolidated into one high-yield chapter, given the aims and target audience of the textbook for general congenital cardiology trainees and providers. An extremely important chapter on Global Burden of Pediatric Heart Disease and Health Equity was added into the section on “Epidemiology of Cardiovascular Disease and Fetal/Perinatal Cardiology.” All general cardiac diagnostic and therapeutic chapters were placed into a single section, filling in the gaps with missing chapters, such as History and Physical Examination, an expanded and dedicated chapter on Cardiac Computed Tomography, Cardiac Intensive Care and Mechanical Ventilation, and Cardiovascular Pharmacology. Given the “Red Line” focus on how an understanding of granular cardiac anatomy can be clinically interrogated and visualized to guide personalization in management, it was additionally believed important to provide a chapter on Three-Dimensional Reconstruction, Advanced Visualization, and Extended Reality. A new section on “The Conduction System and Its Management” was added, with chapters covering Development and Anatomy of the Conduction System, and the Pathways for Abnormal Conduction and Normal Electrocardiogram to complement the existing chapter on Electrophysiology, Pacing and Defibrillation. Lesion-based chapters were separated into congenital and acquired malformations, maintaining the prior separate six-chapter section on Functionally Univentricular Heart. The remaining chapters were divided into sections on “Heart Failure and Transplantation,” “Considerations in the Adolescent and Young Adult with Congenital Heart Disease,” and “Beyond the Heart.”

## Pedagogical Innovations

The following pedagogical innovations were employed:

- Re-focusing towards our target audience: the congenital cardiac trainee and practicing congenital cardiologist.
- Adoption of a consistent lesion-based framework (“Red-line”) linking anatomy, physiology, and clinical features.
- Expansion of concise visual elements such as tables, figures, algorithms, flowcharts and chapter summary tables.
- Incorporation of clear learning objectives throughout.
- Avoiding redundancy in chapter body text repeated within descriptive figure legends.
- Supplementation with enhanced digital resources, including the addition of heart specimen demonstration videos in addition to the previously incorporated imaging and surgical videos.

In selecting authorship, the editorial board aimed to provide global representation of established experts, with intimate involvement of the editorial board to ensure this “Red line,” and ensuring the incorporation of the discussed educational innovations aimed towards the target audience.

We hope the reader can appreciate the attention and efforts which have gone into optimizing the 5<sup>th</sup> edition of Anderson's Pediatric Cardiology in providing an authoritative reference and “responsive, learner-centered” educational tool. Like most major undertakings, this textbook is the product of a large team-based effort. This team has not only included the editorial board, publishing company, and authors, but also our stakeholders, the congenital cardiac trainees and providers. While we aim for the description of our efforts to highlight

the authoritative, “responsive learner-centered” nature of this textbook, we additionally aim for our account to provide a framework for others aspiring to create similar educational resources.

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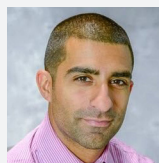
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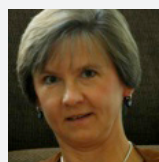
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# Heart Camps Unite in Shared Mission

*Sara Meslow, Executive Director, Camp Odayin*

There are many camps across the US and Canada that serve young people with congenital heart disease, and our common goal is to provide community building experiences for heart kids in a safe and supportive environment. What began as virtual meetings during the pandemic has evolved into a powerful network of compassionate leaders of these camps, united in our mission to support the emotional needs of the pediatric heart disease community. We call ourselves "Heart Camps United."

Our monthly meetings typically focus on a particular topic. We dedicate time to staff training, exploring how to best prepare camp counselors and cabin nurses who truly understand what these kids need. Sharing creative ideas for programs and activities at camp is always a highlight. We tackle fundraising strategies, swap marketing tips for reaching more families, and explore whatever challenges or opportunities are front and center for our camps.

We consistently hear the same types of comments from campers and families after they've attended camp. Campers feel respected, supported and like they truly belong. They finally find a community of peers who understand their medical journey. As practitioners, we hope you'll consider sharing these awesome camps with your patients. **Camp is good medicine!**



**Sara Meslow**  
Executive Director, Camp Odayin  
[Sara@campodayin.org](mailto:Sara@campodayin.org)  
651.351.9185

**"It's not just a camp, it's medicine. A treatment. I have met so many amazing people. I've never felt more at home and more myself than when I'm at Camp."**

**– Camper Savannah**



**"We are so blessed and lucky to have Heart Camp in our family's life. It is wonderful to plan our summer around Heart Camp and have that as something she and I both look forward to her attending. She gets excited to see her heart friends, and she returns tired, hungry and somehow a bit more mature and deeply happy. As a parent I appreciate that last part the most because she deserves to have special experiences that light her up inside. Life can be tough for these kids, but Camp is always out there to look forward to." – Nancy, Mom to camper Sophie**







## Share the Magic of Camp and Reach Out to Learn More!

### CAMP NAME

Nick and Kelly Children's Heart Fund  
Camp Del Corazon  
Camp Oki  
Camp Boggy Creek  
Camp Strong Heart

Camp Braveheart, Children's Healthcare of Atlanta  
Center for Courageous Kids - Camp Bravehearts  
Camp Bon Coeur  
Keeping the Beat Retreat

Madden Open Hearts Camp  
North Star Reach  
Camp Odayin  
Camp Systole  
Camp Rhythm

Children's Heart Foundation - Camp Mend-A-Heart  
Hope With Heart  
Camp Simcha Special  
Camp LUCK  
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Bill Neeches Heart Camp For Kids  
Follow Your Heart Camp

Camp Pump it Up  
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# ACC/AHA Issue New Guideline on Managing Congenital Heart Disease in Adults

The American College of Cardiology (ACC) and the American Heart Association, along with several other leading medical associations, have issued a new guideline for managing Congenital Heart Disease in adults. The guideline was jointly published today in JACC, the flagship journal of the American College of Cardiology, and Circulation, the flagship journal of the American Heart Association.

Congenital Heart Disease—being born with defects in the heart's structure—is the most common birth defect. According to the Centers for Disease Control and Prevention, it affects nearly 1% of births, or about 40,000 babies per year, in the U.S.. Advances in surgical treatments over the last few decades have contributed to over 90% of babies born with heart defects in the United States now surviving well into adulthood. This has led to a rapidly growing population of adults with congenital heart disease (ACHD) who remain at increased risk of cardiac complications as they age, despite early interventions.

The new guideline provides updated recommendations for monitoring, counseling and treating adults with congenital heart disease. It includes evidence from research published between 2017-2024 and replaces the previous guidance issued in 2018.

"We have moved the field forward, in that we have more evidence than we did with the last set of guidelines," said Michelle Gurvitz, MD, a Cardiologist at Boston Children's Hospital, Associate Professor of Pediatrics at Harvard Medical School and Chair of the Guideline Writing Committee. "While we always want more evidence, we are doing better. The growth of the field has been almost exponential in the amount of data being gathered and research being published."

The new guideline includes additions related to the role of clinicians with specialized expertise in guiding the care of adults with Congenital Heart Disease; updates regarding mental health, physical activity, pregnancy and heart failure; and new recommendations about specific types of heart defects and treatment approaches.

Congenital Heart Disease encompasses a wide range of conditions, including more than 30 recognized types of heart defects, which can be classified as simple, moderate, or complex. The symptoms or functional differences that result from these defects include abnormal heart rhythms, diminished exercise capacity, low blood oxygen levels, and signs of heart failure, among others. Many people with congenital heart defects are diagnosed early in life and some may undergo surgeries in infancy or early childhood, while a smaller proportion of individuals with milder defects may only learn about their condition during adulthood.

The guideline authors emphasize the importance of access to ongoing specialized care for adults with Congenital Heart Disease. Even when congenital heart defects are diagnosed and treated in childhood, many patients stop seeing Congenital Heart Disease specialists after they become adults. Common barriers include a lack of awareness about the importance of care continuity, availability of specialists where they live, and socioeconomic or insurance-related challenges. The new guideline provides recommendations about when specialized expertise is warranted and how specialists can partner with other clinicians to broaden access to care.

"We know we need to be diligent in our efforts to get pediatric patients into Adult Congenital Heart Disease care," Gurvitz said. "We still have a lot of patients who stop receiving specialized care as they transition and transfer from pediatric to adult care, and a lot of patients who can't access physicians for other reasons like insurance or geography."

Some adults with Congenital Heart Disease experience mental health or neurocognitive conditions—including mood disorders, as well as cognitive and memory problems—that can worsen if they are not diagnosed and treated.

In the new guideline, Gurvitz said, "we renewed our emphasis on mental health and neurocognitive assessment. Our patients have a lot of challenges with anxiety and depression, so it's important to discuss that with patients or consider sending them for further evaluation."

The guideline also includes updated recommendations around exercise. Physical activity is an important part of a heart-healthy lifestyle for everyone, including people with Congenital Heart Disease. However, patients with heart defects are often concerned about what level of activity is safe.

"We looked at using exercise testing to guide physical activity recommendations and spelled this out more broadly than in the prior guidelines," Gurvitz said. "Many of our patients play sports, and we are now saying that adults with CHD are not just 'allowed' to play, they are encouraged to participate in physical activity, after being properly evaluated."

In addition, the guideline includes new and updated recommendations on birth control options, pregnancy and childbirth. Individuals with ACHD interested in pregnancy should receive preconception counseling, in collaboration with an ACHD cardiologist, about genetic testing, how a pregnancy could affect their health, fetal risks associated with pregnancy and safe birthing options. The majority of



pregnant patients with ACHD can have a safe delivery, with appropriate individual risk stratification and monitoring.

Updated guidance on surgical practices, heart failure and treatments for specific forms of congenital heart disease is also provided. The writing committee emphasize that patients with more complex heart defects often require close monitoring and may need additional procedures or medical devices during adulthood, such as valve replacements, ablations or pacemakers to correct arrhythmias (irregular heartbeats), or a heart transplant if heart functioning deteriorates severely. Further research is needed to inform the optimal timing for such interventions, as well as to inform geriatric care approaches as more patients reach older adulthood.

"We'll continue to push the field to answer the questions because the patient population is not going anywhere—it's only getting larger," Gurvitz said. "In particular, our most complex patients are our fastest-growing group, and my hope is that some of the identified gaps will push people to try to answer those questions around what is the most efficient and effective way to deliver care to our patients."

The writing committee included specialists in ACHD cardiology and interventional cardiology, congenital cardiac surgery, heart failure and electrophysiology, in addition to advanced practice nurses and a patient advocate. The guideline was developed in collaboration with and endorsed by the Heart Rhythm Society, the International Society for Adult Congenital Heart Disease and the Society for Cardiovascular Angiography and Interventions.



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## Director of Pediatric Heart Failure/ Heart Transplant Cardiology

Ochsner Children's Hospital – New Orleans

**Ochsner Children's Hospital is seeking Director of Pediatric Heart Failure/Heart Transplant physician along with a second Pediatric Heart Failure/Heart Transplant physician in the only pediatric heart transplant center in Louisiana.**

Responsibilities will focus on all aspects of non-invasive imaging including fetal echocardiography, transesophageal echocardiography and general echocardiography with teaching responsibilities for pediatric residents, medical students, and sonographers. There is also an opportunity for cross-sectional imaging as part of our growing cardiac MRI and CT program. The job with also include outpatient clinic, inpatient service and telemedicine.

Ochsner Children's provides services for all pediatric cardiac sub-specialties including heart failure/transplant, EP, ACHD, interventional cardiology, imaging including echocardiography and cardiac MRI and CT, and fetal cardiology, comprehensive single ventricle program, and neurodevelopmental clinic. The heart center includes 21 cardiologists, 3 congenital heart surgeons, 6 cardiac intensivists practicing in a dedicated pediatric 12 bed cardiac intensive care unit and 3 pediatric cardiac anesthesiologists. The program performs approximately 250 cardiac surgeries, 400 cardiac catheterizations (75% interventional) and 19,000 ambulatory visits at 15 locations across Louisiana and Mississippi per year. Our heart center has been ranked by US New and World Report for the last 6 years and is the only ranked program in Louisiana; survival after cardiac surgery for our most complex patients (STS STAT 4 and 5 categories) is in the top 10% of programs reporting to STS.

Our comprehensive Ochsner Children's program is the region's leading integrated provider of multispecialty care for newborns, infants, children, adolescents, and young adults. We offer a full range of pediatric complex specialty services including, liver and bone marrow transplantation, a comprehensive surgical sub-specialty group, advanced GI and Hepatology, advanced spine surgery, Hematology-Oncology and AYA Oncology, Cleft Palate/Cranio-Facial Surgery and the region's only comprehensive multidisciplinary developmental pediatrics center.

Ochsner Children's Hospital includes a 67-bed Level IV Neonatal Intensive Care Unit, a 14-bed PICU, a 12-bed pediatric CV-ICU, a NAEAC-accredited level IV, 4 bed Pediatric EMU and a 44-bed Pediatric Acute Care unit, with a dedicated pediatric emergency room, supported by a 24-7 pediatric and neonatal transport team utilizing rotary and fixed wing aircraft, as well as ground transport. **Last year we broke ground on a new 5-story Children's Hospital on our main campus in New Orleans, with expected opening in quarter 1 of 2028.**

In addition to direct patient care, Ochsner Children's Hospital has an ACGME-accredited pediatric residency program and is also responsible for teaching pediatric residents from the Tulane-Ochsner Pediatric Residency program as well as medical students from both Tulane and the University of Queensland, Australia. Ochsner Health and Xavier University of Louisiana recently announced an agreement to establish a joint allopathic College of Medicine, the Xavier Ochsner College of Medicine which is in the LCME accreditation process currently. Our faculty have an opportunity for academic appointment at the University of Queensland and Xavier, participate in numerous research studies and multi-center trials, and publish hundreds of research papers annually.

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# Mount Sinai Health System Receives \$8.5 Million NIH Grant Renewal to Advance Research on Long-Term Outcomes in Children with Congenital Heart Disease

*Expanded national collaboration will help uncover how health care systems and access to care influence survival and quality of life for children born with heart defects.*

The National Institutes of Health has awarded the Icahn School of Medicine at Mount Sinai an \$8.5 million renewal grant to continue groundbreaking work aimed at understanding and improving long-term outcomes for children with Congenital Heart Disease—the most common type of birth defect in the United States.

The project, led by Brett Anderson, MD, MBA, MS, Director of the Center for Child Health Services Research in The Mindich Child Health and Development Institute at the Icahn School of Medicine, expands upon the earlier work of Dr. Anderson and her team, who created the first statewide data network to study long-term outcomes and health care use for children after congenital heart surgery. Known as the Congenital Heart Surgery Collaborative for Longitudinal Outcomes and Utilization of Resources (CHS-COLOUR), the network united data and surgical leaders from nearly all New York State congenital heart centers and the New York State Department of Health, linking clinical registry and insurance data and revealing how the staff and logistics of health care systems affect long-term outcomes.

The CHS-COLOUR found that children on Medicaid spent, on average, more

than 90 days in hospitals and doctors' offices in the first five years after congenital heart surgery, with large variation across patient demographics—even among clinically similar groups. Further, the team found that differences among the providers who treated patients appeared to explain up to 20 percent of the observed differences in outcomes.

The renewed grant expands the collaborative, uniting clinical leadership and registry data from all 25 congenital heart surgical centers across four states (New York, Massachusetts, Colorado, and Texas) and 14 interdisciplinary co-investigators from across the country to create the most comprehensive national resource to date to study how differences in health care systems and structures can improve outcomes for kids after cardiac surgery.

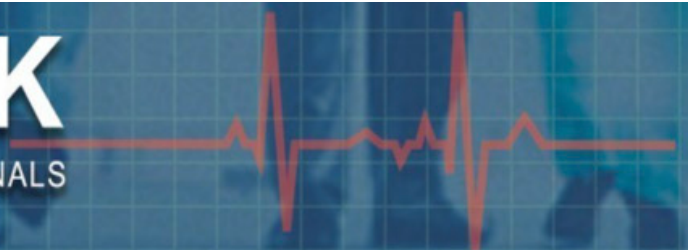
"This grant truly represents teamwork at its best," said Dr. Anderson. "We've brought together congenital heart surgeons, fetal and pediatric cardiologists, pediatricians, public health experts, health economists, biostatisticians, and medical anthropologists to tackle these complex issues. From our earlier work, we know that children from different backgrounds often see different providers—even

when they have similar insurance. Now we're asking how families connect with these providers and how the health care system can work more effectively to ensure better outcomes for all children." Dr. Anderson, a Pediatric Cardiologist, is also an Associate Professor of Pediatrics, and Population Health Science and Policy, at the Icahn School of Medicine.

"This renewal allows us to build something transformative," said Jane Newburger, MD, MPH, Commonwealth Professor of Pediatrics, Harvard Medical School; Associate Cardiologist-in-Chief for Academic Affairs, Boston Children's Hospital; and Co-Investigator on this grant. "Bringing together data, surgical and public health leaders, and innovative quantitative and qualitative expertise from across the country, we will be able to develop a deeper knowledge of how patients navigate insurance, prenatal care, and birth center selection; how they choose and access the pediatricians, cardiologists, and surgeons they see; and how these factors influence downstream care and outcomes across the life course."

Congenital heart defects are the most common and resource-intensive birth defects in the United States, affecting about one in every 100 live

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births or roughly 40,000 newborns each year. Treatment often requires open-heart surgery, sometimes multiple procedures. More than 10 percent of infants die from these surgeries, and those who survive often live with ongoing health problems. Research has shown that Hispanic and non-Hispanic Black children experience 15-20 percent higher mortality than non-Hispanic white children—even after adjusting for clinical risk factors, family income, neighborhood socioeconomic, and surgical center—but the reasons behind these variabilities remain poorly understood.

“Dr. Anderson’s work exemplifies Mount Sinai’s commitment to driving improved health outcomes for all children through data-driven science,” said Bruce D. Gelb, MD, Dean for Child Health Research, Icahn School of Medicine at Mount Sinai. “By linking robust clinical information with real-world health care data, this project has the power to change how we, as providers and policymakers, structure and deliver care for children with heart disease nationwide.” Dr. Gelb is also the Gogel Family Chair and Director of The Mindich Child Health and Development Institute and Professor of Pediatrics, and Genetics and Genomic Sciences, at the Icahn School of Medicine at Mount Sinai.



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### Regional Pediatric Cardiologists

Ochsner Children’s Hospital

**Ochsner Children’s Hospital seeking BC/BE Pediatric Cardiologists to join our successful regional practices in Baton Rouge, Lafayette, and Monroe, Louisiana and Gulfport, Mississippi.**

Responsibilities will focus on all aspects of non-invasive imaging including fetal echocardiography, transesophageal echocardiography and general echocardiography with teaching responsibilities for pediatric residents, medical students, and sonographers. There is also an opportunity for cross-sectional imaging as part of our growing cardiac MRI and CT program. The job will also include outpatient clinic, inpatient service and telemedicine.

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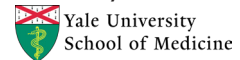
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# Giving Babies Time

At the 9<sup>th</sup> World Congress of Pediatric Cardiology & Cardiac Surgery in Hong Kong, we had the chance to offer something that felt both practical and urgent: a hands-on atrial septostomy workshop. With support from MAP International, the Edwards LifeSciences Foundation, and the recently FDA-approved redesigned Miller Balloon, cardiologists were able to learn how to safely perform this life-prolonging procedure at the bedside with guided echo. For babies born with transposition of the great arteries (TGA), this is the difference between having hours to live and having months to reach the surgery they need to survive. Without an atrial septostomy, they simply don't make it.



Dr. Gareth Morgan from Children's Hospital Colorado led the training, and we brought cardiologists from leading institutions across Africa, Asia, and Australia together for hands-on atrial septostomy training. Instead of traveling to each institution separately, we used the unique opportunity of the pediatric cardiac world gathering under one roof to share skills, exchange knowledge, and send these physicians home with the tools they need, literally to save the next child who arrives in crisis.

This work is part of our Training, Research, and Innovation Program, and, as our final mission of the year, it was one focused entirely on training. The babies who benefit from these interventions will still face the challenges of receiving the surgeries required to repair their congenital heart defects, but now they have the one thing they were previously denied: time.

Mending Kids exists to bridge these gaps, build local capacity, and give children a fighting chance. This workshop was one more step in that direction.



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