CONGENITAL CARDIOLOGY TODAY
Timely News & Information for Congenital/Structural Cardiologists & Cardiothoracic Surgeons Worldwide

International Edition
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Table of Contents

Matters Of The Heart And Mind: Teamwork

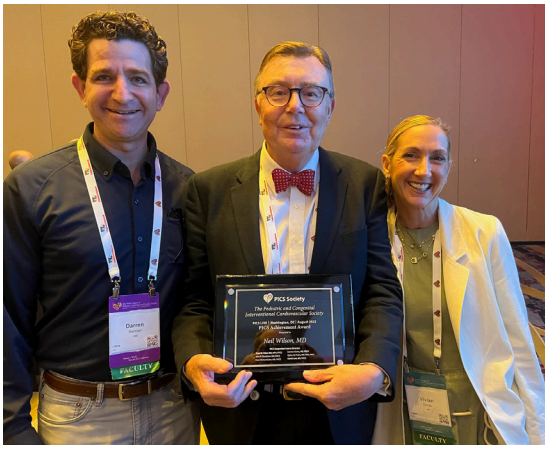
Neil Wilson, MBBS, DCH, FRCPCH, FSCAI

Editor's Introduction

I am delighted to introduce this month's lead article by Dr. Neil Wilson. Neil is well known in the pediatric cardiology community. He retired recently after a long and distinguished career as a general cardiologist and a pioneering interventionalist in the United Kingdom and the United States. He is loved and admired by his patients, trainees and peers for his profound humanity and dedication, as well as for his characteristic wit and good humor.

We are fortunate that Neil continues to share his experience and wisdom through periodic *Matters of the Heart and Mind* columns in *Congenital Cardiology Today*. Like the bard in *Chaucer's Canterbury Tales*, he tells stories about what we encounter on our journeys as pediatric cardiologists and caregivers, highlighting complex and difficult situations, deep feelings, and profound truths.

– John Moore, MD, Medical Editor



Dr. Neil Wilson, at PICS Live 2023 in Washington, DC, won the PICS Society's Achievement Award, posing with Drs. Darren Berman and Vivian Dimas

Matters Of The Heart And Mind: Teamwork

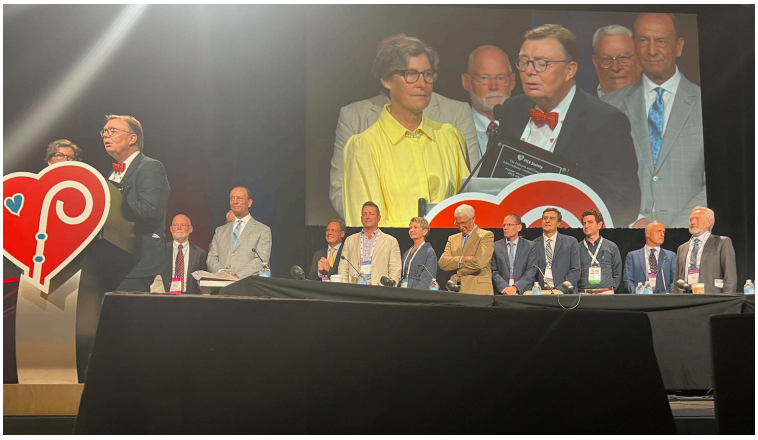
You are unlikely to have been to Liverpool, just because, why would you travel there? What does it have to do with paediatric cardiology? This is not a travelogue feature but a testament to great teamwork on several fronts. You have certainly heard of The Beatles, they were a great team. You have almost certainly heard of the Liverpool Football Club. They are a great soccer team. My perception is that for some reason they are very popular in the USA and continents beyond. Ask Dan McLennan. You will probably not have paid much attention to paediatric cardiology and congenital surgery in Liverpool, unless you happen to have worked there or had friends and colleagues who have. Well, you should have. Great work was done there.

My paediatric cardiology career started in Liverpool at The Royal Liverpool Children's Hospital on Myrtle Street, right on the edge of Toxteth. Then it was a troubled suburb--high unemployment, poverty, crime. I might one day tell the story of Dr.

NOVEMER 2024

International Edition Vol. 22 - Issue 11

TABLE OF CONTENTS



Dr. Neil Wilson giving his acceptance speech at PICS Live 2023

Bob Arnold, a star consultant paediatric cardiologist at the hospital, who had his car stolen twice in one day from the consultant's car park. Second time, it was found burnt out on a tract of derelict land. The hospital was very small. I guess probably no more than 70 beds, but it did house almost the entire complement of paediatric cardiology facilities for the North West of England. We served a referral population of six – seven million. One cardiac surgeon, three consultant (attending) cardiologists. One echo machine, one cath lab. Superb nursing staff. One senior registrar (senior fellow), one registrar (mid fellowship) and one senior house officer (me, rookie). There was not much senior about my job, but it was fantastically enjoyable despite the alternate nights and weekend resident call commitment. It was exhausting but I loved every minute of the experience the business brought.

Cardiac Intensivists did not exist in Liverpool in those days so it was Coxing and Boxing (look it up) between Roger Massey, the registrar, and me. Roger was much more experienced in paediatrics and cardiology, he looked after me well. He always seemed quite pleased when his call came round. This, he later confessed, was that his young twin babies had an aversion to nocturnal sleep and he reckoned he got more sleep in the hospital than at home! We both enjoyed the unstinting help of an anaesthesiology registrar, Dave Hallworth. Dave was calm, incredibly competent and had a knack for appearing on your shoulder in the ward or CICU when you had been called because a patient had 'gone off.' In the heat of an emergency 'Whispering Dave' was invaluable help. Later in our careers we worked together in Glasgow where his modus operandi above saved many lives and kept my heart rate at acceptable levels during many interventional cases in the cath lab.

I guess it is almost exactly 44 years since I worked at Myrtle Street. I had been in post about a month. Everything I knew about Congenital Heart Disease could have been listed on the back of a postage stamp and leave plenty of room for the address. Despite my ignorance, I was quite good at doing as I was told, and of course, I needed plenty of that. At about six o'clock one Friday evening, David Dickinson, the Senior Registrar, pages me (yes, in those days) and tells me there's an admission coming from a hospital near Manchester (another good soccer team), "Sounds like total veins." At 8:15pm a newborn baby arrives. He is a 37-weeker weighing 1.8kg and in obvious respiratory distress with saturations in the mid 80s. His chest X Ray was one of those where it was almost impossible to discern the cardiac silhouette from the lungs.

I was working on IV access… successfully, when a minute or two later in walks David pushing the echo machine. In those days the echo machines were about the size of four supermarket trolleys stacked together. The wheels were about the size of a toddler's stroller. With great expertise the machine was positioned and within five minutes David says "Yep, it is total veins, infracardiac, needs surgery. Neil, get the lines in and bloods off, I'll page you with some instructions." Total veins. Of course he meant total anomalous pulmonary venous drainage TAPVD. TAPVC, if you like, but I prefer drainage to connection, whatever Professor Anderson says.

Bloods off, umbilical lines in. Good pressures, saturations steady. Whispering Dave H appears, right on cue as always, makes a comment about me having got the umbilical artery and vein lines in and makes some allusion to 'monkey and a typewriter.' I take that as a compliment. Arterial gases are good. At about 9:15pm my pager goes. It's Senior Registrar David Dickinson, as promised. There is a terrific lively party noise in the background. "Neil, that baby's going to theatre (OR) at five o'clock, just make sure the pump bloods are ready." David can read my body language telephonically as I am wondering why five o'clock in the morning. "Yes, it's because Dr. Jackson Rees 'Jack' (Anaesthesiologist pioneer supremo RIP) has tickets for the members enclosure at Haydock Park Racecourse tomorrow and doesn't want to be late. The team are all happy with it." I did not really appreciate that gesture at the time. It seemed a perfectly good reason. What is more, I might get a decent night's sleep before the baby is back out of theatre. I did not – a couple of IV resitings on CICU and a baby whose cardiac output needed a bit of encouragement. Usual sort of stuff.

Nevertheless, I did get a good breakfast and as I walked into CICU at eight o'clock the baby was being wheeled in back from the OR. On a ventilator, pink, I can see urine filling his urinary catheter. Peripheral temperature is good. There is a 'warm' atmosphere in the room. The team are asking Jack for tips for the day's racing. All had gone really well. They are lifting the baby onto the incubator. Jackson Rees says, "Thanks for the arterial line Neil, saved me a bit of time." David Hamilton (RIP), the nicest, calmest modest surgeon you will ever have met, stands by taking off his mask and surgical cap. He says nothing, then, "Thanks, Neil, just let me know if you have any problems, Francesco (the surgical fellow) is

going to hang around until lunchtime." He did not say it, but it was an understood fact that Mr. Hamilton (yes, Mr, another British anachronism) played golf on Saturday morning and everyone in the team tried their very best not to call. Not least of all if you did need him you had to call Hoylake Golf Club who then had to send out a pro in a cart to get him back to the clubhouse to take the call. These days, of course, the surgeon would have a mobile phone. But then, a single-handed surgeon had to be cut some slack for goodness sake. I never did have to call him but there were others higher up the food chain who might have.

The baby's progress was amazing. The immediate post op chest x ray looked virtually normal. Lung fields perhaps slightly hazy. Heart size normal. On Saturday evening, Dr Jackson Rees appears popping his head through the CICU door, the smell of cigarette smoke accompanying him and his cigarette held low out of Sister's (Head nurse) view. "Everything OK? Where's Dave?" Upon which Whispering Dave appears five seconds behind him. Dave extubated him on the Sunday morning. I can't remember exactly but I think he went back to the referring hospital on Tuesday. Obstructed TAPVD, 1.8kg baby in and out in four days. And remember, that was 44 years ago. Great teamwork. Most of us are human so I doubt if I have always been the great team worker but believe me, I have tried. I did buy surgeons coffee now and then. Do you?

P.S. I forgot to mention… The party noise in the background when David Dickinson paged me was a leaving party in the hospital for the Cardiac OR Head Nurse. Do not ask any more questions…

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A Promising New Option to Prevent Thromboembolism in Pediatric Heart Disease

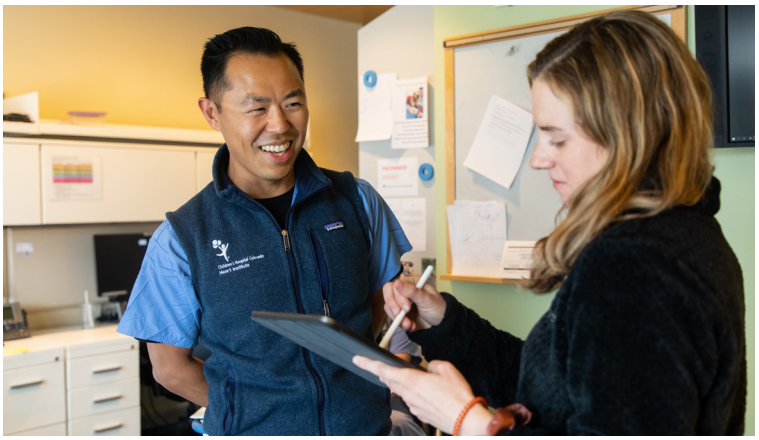
John S. Kim, MD

Key Takeaways

- This study reported results of a multinational Phase 2 trial on the safety of apixaban, a direct oral anticoagulant, for children with congenital or acquired heart disease.
- Compared to standard treatments that require frequent laboratory testing and/or daily injections, apixaban was found safe and effective for preventing thromboembolism in these patients.
- Neither of the treatment groups experienced any thromboembolic events, and there were few incidents of major or clinically relevant non-major bleeding.
- While more research is needed on long-term outcomes, findings support using apixaban in this population as a safe and well-tolerated alternative to the standard treatment.

"Direct oral anticoagulants do not require injections or frequent lab tests, so apixaban is a potential game changer for these patients."

– John S. Kim, MD



John S. Kim, MD

Research Study Background

Children with certain types of Congenital or Acquired Heart Disease, including Single Ventricle Disease and Kawasaki Disease, are at high risk for thromboembolism. Prophylaxis with a vitamin K antagonist (VKA), such as warfarin, or low-molecular-weight heparin (LMWH) is the current standard of care for these patients. Neither therapy is ideal for children. VKAs have many drug interactions and require dietary restrictions and frequent lab testing. LMWHs must be injected twice daily and also require frequent lab testing. Apixaban, part of a new class of anticoagulant drugs called direct oral anticoagulants (DOACs) found to be safe and effective in adults, has potential as an alternative to VKA and LMWH for preventing thromboembolism in children. This phase 2, open-label, multinational trial was the first to assess the safety and efficacy of apixaban in children with heart disease, as well as evaluate the pharmacokinetics and pharmacodynamics of age-appropriate pediatric formulations of the drug. Children's Hospital Colorado was one of the participating sites, led by a pediatric cardiologist who developed the hospital's multidisciplinary Cardiac Antithrombosis Management Program and Cardiac Thrombosis Clinic.

The trial included patients as young as 28 days old and up to 18 years old. After recruitment and enrollment, participants were randomized 2:1; the majority took daily weight-based doses of apixaban, and the rest proceeded with the standard of care. Participants had a broad range of diagnoses including single ventricle disease (74%), Kawasaki disease (14%) and other heart disease (12%).

The mean duration of drug exposure was 330.6 days for all participants, and adherence to both treatments was high. There were few incidences of major or clinically-relevant, nonmajor bleeding, occurring in one patient taking apixaban and three patients receiving the standard of care. The rate of all bleeding events, including minor bleeding events like nosebleeds, was similar between the two treatment groups at 37%. The incidence of adverse events was no different between both groups (20.6% with apixaban vs. 21.0% with the standard of care). There were no thromboembolic events

detected by imaging or clinical diagnosis in either treatment group, consistent with adult trial results. The levels of apixaban in children at steady state were also comparable to the adults. Importantly, quality of life surveys conducted during the study suggested child-reported lower anxiety when taking apixaban compared to VKAs or LMWHs.

Clinical Implications

Study findings support the use of apixaban for chronic thromboprophylaxis in children with heart disease as a safe and well-tolerated alternative to VKAs and LMWHs. Comparable conclusions were reported in a recent meta-analysis of patients with Fontan circulation, as well as other pediatric studies of DOACs in children with venous thromboembolism.

A limitation of the trial is that newborns were not included since DOACs were not frequently used in this group when it was designed. Future research should prioritize investigating diverse long-term outcomes linked with DOACs.

To read the full study, visit:
https://www.childrenscolorado.org/advances-answers/recent-articles/apixaban-for-pediatric-heart-disease/

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Research Reveals 36% Higher Heart Defect Risk in IVF Babies

The risk of being born with a major heart defect is 36% higher in babies who were conceived after assisted reproductive technology, such as in vitro fertilization (IVF), according to results of a very large study published in the European Heart Journal today (Friday).

Researchers say the finding is important since congenital heart defects are the most common form of birth defects, and some of them are associated with life threatening complications.

The study also shows that the increase in risk is particularly associated with multiple births which are more common in assisted reproduction.

The study was led by Professor Ulla-Britt Wennerholm from the University of Gothenburg in Sweden. She said: "Previous research shows that there are increased risks for babies conceived with the help of assisted reproductive technology. These include preterm birth and low birth weight. We wanted to investigate whether the risk of heart defects was higher for babies born following assisted reproduction."

The research included all liveborn children born in Denmark between 1994 and 2014, all children born in Finland between 1990 and 2014, those born in Norway between 1984 and 2015 and those born in Sweden from 1987 to 2015; more than 7.7 million in total.

Researchers compared data on babies born following assisted reproduction, including IVF, intracytoplasmic sperm injection (ICSI) and embryo freezing, with data on babies conceived naturally.

They assessed how many liveborn children in each group were diagnosed with a major heart defect or with a serious heart defect either in the womb or in the first year of life. They took into account other factors that can increase the risk of congenital heart defects, such as: child's year of birth, country of birth, mother's age at delivery, if the mother smoked during pregnancy, or if the mother had diabetes or heart defects.

This showed that heart defects were around 36% more common in babies born after assisted reproduction, compared to babies conceived without such treatment (absolute risk 1.84% versus 1.15%). This risk was similar regardless of the type of assisted reproduction used (IVF or ICSI, fresh or frozen embryos). However, the risk was greater for multiple births following assisted reproduction compared to singleton births following assisted reproduction (2.47% versus 1.62%).

In an accompanying editorial Dr. Nathalie Auger from University of Montreal Hospital Research Centre in Canada and colleagues said: "Assisted reproductive technology is a popular intervention in reproductive medicine, with these procedures accounting for 2% to 8% of births depending on the country. While most neonates born after assisted reproductive technology are healthy, these procedures are not without risks.

"In one of the largest studies to date, the researchers found that assisted reproductive technology was associated with the risk of major heart defects diagnosed prenatally or up to one year of age."

"Patients who use assisted reproductive technology tend to differ from the general population. These patients may have underlying morbidities that affect both fertility and the risk of heart defects."

Congenital Cardiology Today Recognized by PICS Society with Distinguished Partnership Award

Kate Baldwin, Publisher & Editor-in-Chief

All of us at Congenital Cardiology Today (CCT) are extremely honored to have been recognized by The PICS Society at their annual conference in San Diego in early September for our 21-years of contributions to the field of Congenital Cardiology. We could not have grown and flourished as we have without the continuous support of practicing doctors and industry. Our goal has always been to meet the communication needs of this sub-specialty.

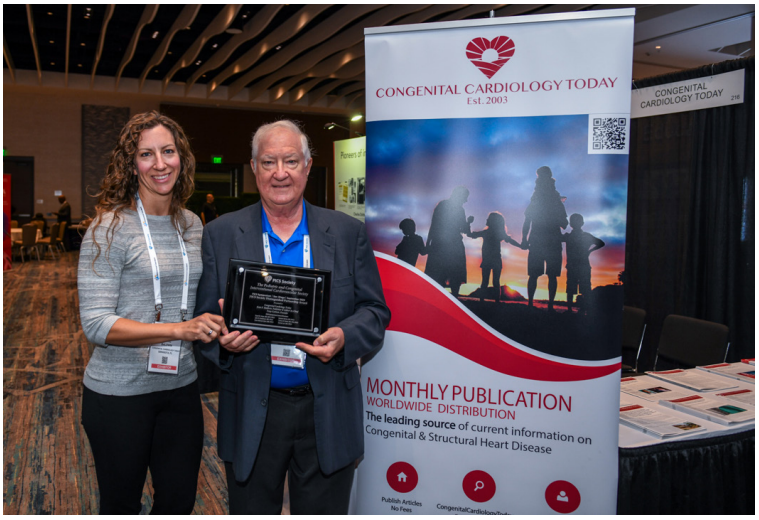
CCT has come a long way since 2003. It was originally conceived on the side-lines of the youth soccer fields in Potomac, Maryland USA in the late 1980s. With little kids running around the soccer fields, two dads had several casual conversations about "what they did." One was a Pediatric Cardiologist, and the other was an experienced sales and marketing executive specializing in high-tech custom publishing. It took a while to get into what Pediatric Cardiology was all about, how it was a small specialty serving a relatively unique patient population but needs lots of technologies to do so. Details about technical journals and newsletters also arose from those talks: targeting technical audiences, monthly publications with short times to print, timely articles written by experts, news items of unique interest to our target audience, etc. As soccer season ended, the two dads, Dr. John Moore and Tony Carlson, concluded that Pediatric Cardiology would benefit from a monthly publication.

Tony enlisted Richard Koulbanis, a colleague in the publishing business, and launched Pediatric Cardiology Today at PICS 2003. We provided a monthly newsletter that was readily available to focus solely on Pediatric Cardiologists treating children with Congenital Heart Disease (CHD). By 2005, we recognized the need to include adult interventionalists as the sub-specialty grew and patients grew up! Our publication also grew and became Congenital Cardiology Today. We expanded our editorial to include Pediatric and Adult Cardiologists as well as Interventional Cardiologists focused on Congenital and Structural Heart Disease. In 2008, we started producing an annual Program Directory of Congenital and Pediatric Cardiac Care Providers throughout North America.

As we attended various cardiology-focused conferences, many cardiologists from Europe and other parts of the world asked if CCT was published outside of North America. In response to those requests, CCT started publishing a monthly International Edition in 2005 that now serves Europe, Latin/South America, Asia and the Middle East. CCT now has over 3,500 subscribed readers from around the world.

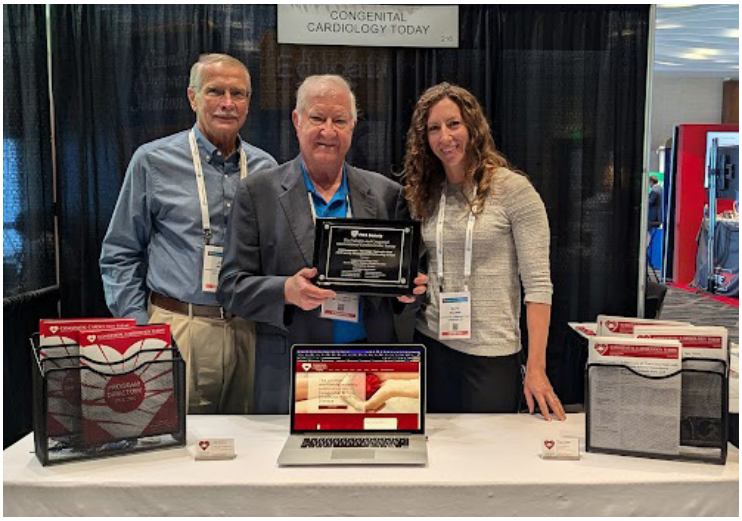
Our mission continues to be forward thinking as we continue to partner with you. Know we are here because you provide us with articles, insights, verbalization of your needs, industry support, your readership, and of course, your friendship.

We appreciate and respect this important partnership. Thank you one and all!

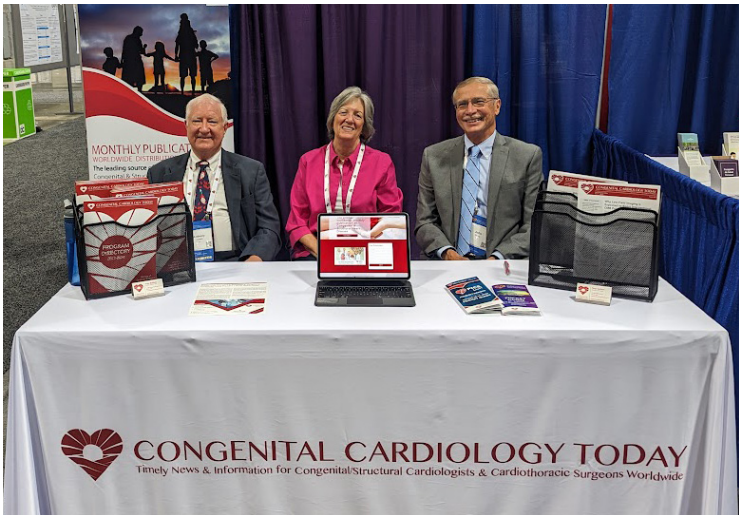


Tony Carlson, Founder & Senior Editor, and Kate Baldwin, Editor-in-Chief, at PICS in 2024 after accepting the PICS Society Distinguished Partnership award

Tony Carlson, Founder & Senior Editor, at PICS in 2003 launching the publication Pediatric Cardiology Today



Dr. John Moore, Co-Founder & Medical Editor, Tony Carlson, Founder & Senior Editor, and Kate Baldwin, Editor-in-Chief, at PICS 2024



Tony Carlson, Loraine Watts, Staff Editor, and Dr. John Moore at The World Congress in 2023

Richard Koulbanis, Editor-in-Chief Emeritus, at PICS in 2003 launching the publication Pediatric Cardiology Today

Hope for Newborns with Heart Disease

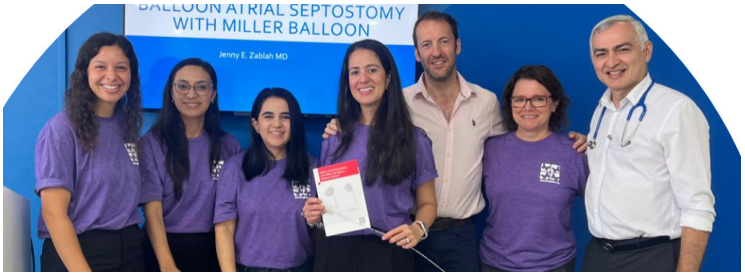
Mending Kids made a special mission to El Salvador with the support of Edwards Lifesciences Foundation and Drs. Jenny Zablah and Gareth Morgan from the Children's Hospital Colorado.

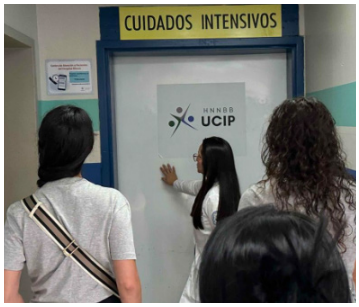
Together, we trained local cardiologists and frontline doctors on performing atrial septostomy—a life-saving procedure critical for newborns suffering from Transposition of the Great Arteries (TGA). We also invited two Guatemalan cardiologists who serve children in hospitals far from their capital, where they previously had no options to help newborns with TGA. Many of these babies wouldn't survive the long journey to receive care. What's remarkable about this procedure is that it's done bedside in the NICU, without the need for a cath lab or general anesthesia. While not a cure for TGA, it buys the child time to receive life-saving surgical care.

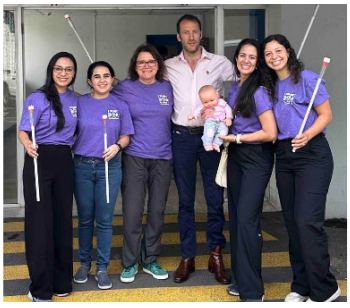
Including Guatemalan doctors was part of our effort to expand the footprint of this knowledge exchange beyond El Salvador. Recently, Edwards redesigned the specialized balloon required for the procedure, making this training possible. We will expand this program to two more countries in the next few months, ensuring that even more lives can be saved. This investment in the future is evergreen—the impact will continue for years to come.

Thank you to Edwards Lifesciences Foundation, Dr. Zablah, Dr. Morgan, and all the dedicated doctors working to bring hope, love, and mending to these communities.

MENDING KIDS







Study Reveals Key Genetic Markers for Early Onset Bicuspid Aortic Valve Complications

Genetic variants linked to a rare form of Bicuspid Aortic Valve Disease that affects young adults and can lead to dangerous and potentially life-threatening aortic complications have been identified by researchers at UTHealth Houston.

The study was published in the *American Journal of Human Genetics*.

"We previously found that young individuals who present due to early onset thoracic aortic dissections are more likely to have bicuspid aortic valves and more likely to have rare variants in bicuspid aortic valve-associated genes. When we observed that bicuspid aortic valve is kind of a risk marker for this group with bad outcomes, we specifically wanted to see whether young individuals who present clinically due to problems related to bicuspid aortic valve disease may also have rare genetic variants that predict complications such as needing valve surgery."

– Siddharth Prakash, MD, PhD, Co-Principal Investigator of the study and Associate Professor of Medical Genetics and Cardiovascular Medicine in the Department of Internal Medicine at McGovern Medical School at UTHealth Houston

About one in 100 people are born with a bicuspid aortic valve, making it the most common cause of Congenital Heart Disease.

The comparison between the rare subgroup of early onset bicuspid aortic valve to the common population of the disease allowed researchers to determine which group of patients will benefit from genetic testing, thus enabling earlier, more aggressive treatment. According to researchers, patients with bicuspid aortic valve disease often wait too long to be seen, leading to more severe cardiovascular symptoms, such as heart failure and even sudden death.

A bicuspid aortic valve is a congenital heart defect where the value has two flaps, or cusps, instead of three, so the valve does not open and close properly with each heartbeat. This can lead to complications such as blocked, reduced, or backward blood flow through the heart chambers, causing shortness of breath, chest pain, fainting, and difficulty exercising. In more severe cases, the disease can lead to an aortic dissection, or tear in the aorta, a life-threatening condition.

Researchers studied individuals who presented with specific complications of the disease before age 30 or who were immediate relatives to someone with early onset bicuspid aortic valve disease. Early onset symptoms of the disease were defined as moderate or severe aortic stenosis or aortic regurgitation, a large thoracic aortic aneurysm, needing to have aortic surgery, or aortic dissection.

Researchers aimed to identify genetic variants that may lead to an increased risk of the disease in young adults. "The average person in this study was affected in their 20s and had relatives with the disease, so we traced the onset of the disease in the families and we reported rare genetic variants that segregated with the disease in these participants and their relatives," Prakash said.

Prakash and his team analyzed whole-exome sequencing data, sourced from 215 families from over 20 institutions to identify the rare genetic variants known to cause Congenital Heart Disease in early onset bicuspid aortic valve disease in this rare subgroup. They compared those findings to the more common population of patients with later-onset bicuspid aortic valve disease.

The identified genes included genes that cause isolated nonsyndromic bicuspid aortic valve, as well as other types of congenital heart disease that are associated with bicuspid aortic valve or related congenital malformations. Researchers found damaging variants of genes with moderate or strong evidence to cause developmental cardiac phenotypes in 107, or 50%, of affected families in the study.

"We showed that the older patients with bicuspid aortic valves are unlikely to benefit from genetic testing because they are unlikely to have these kinds of genetic variants," Prakash said. "It's important for people to realize, as we saw in this study, that a lot of people with bicuspid aortic valves have affected relatives. In the future, family members may be tested for genetic variants that cause bicuspid aortic valve complications, and people who have these genetic variants could be treated early to prevent future complications from developing."

The research was funded by the National Institutes of Health (R01HL137028, R21HL150383, R01HL114823, and R21HL150373). The University of Washington Center for Rare Disease Research provided sequencing and data analysis, funded by the National Human Genome Research Institute, grants U01 HG011744 and UM1 HG006493.

Dianna M. Milewicz, MD, PhD, Professor of Medical Genetics, President George Bush Chair in Cardiovascular Medicine, and Director of the Division of Medical Genetics at McGovern Medical School at UTHealth Houston, was a co-principal investigator on this study.

First author of the study was Sara Mansoorshahi, BA, McGovern Medical School. Additional authors included Dongchuan Guo, PhD, Professor of Medical Genetics at McGovern Medical School; Dawn S. Hui, MD, The University of Texas Health Science Center at San Antonio; Shaine A. Morris, MD, MPH, Baylor College of Medicine; Angela Yetman, MD, University of Nebraska Medical Center; Malenka M. Bissel, MD, DPhil, University of Leeds; Yuli Y. Kim, MD, Hospital of the University of Pennsylvania and the Children's Hospital of Philadelphia; Hector I. Michelena, MD, Mayo Clinic; Anthony Caffarelli, MD, Stanford University; Maria G. Andreassi, PhD, and Ilena Foffa, PhD, Institute of Physiology in Pisa, Italy; Rodolpho Citro, MD, PhD, Responsible Research Hospital University of Molise, Campobasso, Italy; Margot De Marco, PhD, University of Salerno, Baronissi, Italy; Justin T. Tretter, MD, Cleveland Clinic; Simon C. Body, MD, MPH, Boston University; Jessica X. Chong, PhD and Michael J. Bamshad, MD, University of Washington.

New Registry Offers Insights into Quality of Life for Adults with Congenital Heart Disease

For the first time, adults living with congenital heart disease (CHD) now have valuable insights into their long-term quality of life through data from the Congenital Heart Initiative (CHI). CHI is the nation's first and largest patient-focused registry for adults with CHD and released its first study involving over 4,500 participants from all 50 states.

This research, published in JAMA Network Open, marks a significant step forward in making better information available for the 1.5 million adults in the United States who were born with CHD.

Studies like this, that leverage actual patient voices and experiences, help us get a better sense of how to advise, support and treat people with CHD as they age. Also, researchers get a clearer picture of the questions that need to be answered to make sure they have the best quality of life possible."

– Anitha John, MD, PhD, Director of the Washington Adult Congenital Heart program at Children's National Hospital and Senior Author of the study

The study also demonstrates two of the most successful models of current promising trends in clinical research:

- The power of patient engagement throughout the research process, including design and implementation.
- The impact of team science, highlighting the benefits of partnerships between patients, researchers and clinicians.

Key highlights include:

- Many participants (88%) reported having one or more additional health issues (comorbidities).
- 33% had arrhythmias (irregular heartbeat).
- 35% had mood disorders, including depression or anxiety.
- Quality of life is good or better for 84% of people who completed quality of life reporting measures, regardless of the type of congenital heart condition.
- People with more complex congenital conditions were less likely to meet physical activity recommendations; an important finding with immediate impact.

Treatments for children born with congenital heart disease have improved so significantly in the last two decades that life expectancy continues to increase as well.

"There are now more adults living with congenital heart disease than there are children with CHD," says Scott Leezer, patient co-principal investigator for the Congenital Heart Initiative registry and co-author of the study. "However, a significant gap remains in what we know about the adult CHD population. As an adult CHD patient, I was excited to contribute to creating this registry, bringing more answers to people like me who want to know how our unique hearts impact our bodies and quality of life over time."

The authors note that the study's findings and the registry data currently have a few limitations. First, the registry only contains patient-reported outcomes and no clinical data. The first sub-study of the CHI, the CHI-RON study, addresses this challenge by incorporating additional data sources for a subset of consenting CHI participants.

Additionally, recall bias, underlying neurocognitive challenges and survey fatigue, may have limited participation in the CHI to a smaller subset of adults with CHD. Efforts are underway to develop methods for people with congenital heart disease who have neurodevelopmental deficits or other disabilities to engage in the registry. The CHI is temporarily closed to new registrants as the study team redesigns the study to better align with the needs of the community.

"We are grateful for everyone who joined this registry, answered survey questions and shared their experiences," says Thomas Carton, Ph.D., chief data officer at Louisiana Public Health Institute and study co-author. "The CHI registry is a big step forward for adults with CHD, but also can serve as a model for how to bring together physicians, researchers and patients as active participants in care, research and advocacy."

As the registry grows in the future, it will focus on increasing diversity of participants, developing additional partnerships with other organizations, continued innovation in data usage and improved community engagement, all with the goal of guiding future research that will ultimately improve quality of life for all adults with CHD.

NOVEMBER

07TH-10TH

Great Wall International Congress of Cardiology 2024
Beijing, China
http://www.gw-icc.com/en

08TH-09TH

2nd International Pediatric Cardio-Oncology Conference
Cincinnati, Ohio, USA
https://www.cincyhearteducationseries.org/cardio-onc

DECEMBER

01ST-05TH

RSNA 2024
Chicago, Illinois, USA
https://www.rsna.org/annual-meeting

05TH-07TH

International Aortic Symposium
Orlando, Florida, USA
https://floridaaorta.cme.ufl.edu/

JANUARY

22ND-24TH

CSI America
Orlando, Florida, USA
https://www.csi-congress.org/america

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