# CONGENITAL CARDIOLOGY TODAY

Timely News and Information for BC/BE Congenital/Structural Cardiologists and Surgeons

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#### CONGENITAL CARDIOLOGY TODAY

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# Prevention of Sudden Cardiac Death in Children and Adolescents: Individual Initiatives in Orange County, California

By Anjan S. Batra, MD; Anthony C. Chang, MD, MPH

Orange County (OC), California has an estimated population of just over 3 million, making it the second most populous county in California, behind Los Angeles County and ahead of San Diego County<sup>1</sup>. It is the sixth most populous county in the United States. The county is famous for its tourism, as the home of such attractions as Disneyland and Knott's Berry Farm. It is also the county with the highest per capita National Collegiate Athletic Association (NCAA) and Olympic athletes. This may be the reason for what appears to be a heightened awareness of prevention of Sudden Cardiac Death (SCD) in the young athletes in OC.

A pre-participation cardiovascular screening is currently recommended by the American Heart Association for all athletes with the aim of identifying conditions that increase the risk for adverse events, including SCD. History and physical examination is the mainstay of cardiovascular screening of young athletes. The ability to identify athletes at-risk, however, based on history and physical examination alone is low, and inclusion of an electrocardiogram (ECG) or an echocardiogram as a screening tool has been suggested to improve the sensitivity of screening. Universal agreement regarding the most appropriate method for cardiovascular screening is lacking. The addition of a resting 12-lead ECG or an echocardiogram to a comprehensive personal and family history and physical examination will increase detection of those athletes with potentially lethal cardiovascular disorders at risk for SCD. However, complex issues regarding feasibility, false positive results, cost-effectiveness, and physician and health system infrastructure still remain regarding large-scale implementation of ECG screening in the United States. As the medical community continues to debate about "if and how" to implement such programs, individual initiatives within communities have evolved to prevent SCD in the young. Although the 2007 AHA screening recommendations do not endorse mandated national ECG screening for all competitive athletes, in no way do the recommendations discourage individual initiatives which offer ECG or echocardiogram screening.

This article will highlight some of the individual initiatives for prevention of SCD in the young that have evolved in OC, California. We tried to collect information about: the reasons behind the initiation of each effort, the goals of each organization, the fund-raising methods used to provide services, and the achievements of each organization.



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# Life Threatening Events Associated with Pediatric Sports (LEAPS):

LEAPS is an effort in Orange County that was spearheaded by the medical community (University of California Irvine, Children's Hospital Orange County, St. Joseph's Hospital) and the OC Department of Education in collaboration with the OC Fire Authority, local schools and the community. The first annual LEAPS symposium was held in January, 2008 and focused on education and implementation of programs for prevention of SCD in children and adolescents in OC. The symposium was geared specifically for the families, school educators, coaches and school nurses. In response to the 2008 LEAPS recommendations, four workgroups were created to further study critical areas in prevention of SCD. The four workgroups focused on how health professionals and others might engage school and athletic program leaders in research, developing ideas and recommendations for preventing, responding to treating and learning from medical emergencies in OC youth sports and high school athletic programs.

"A pre-participation cardiovascular screening is currently recommended by the American Heart Association for all athletes with the aim of identifying conditions that increase the risk for adverse events, including SCD."

The first workgroup on sports medicine helped develop ideas and make recommendations for school and community educational programs for athletic directors, high school and youth sports coaches, student-athletes and parents. They created student-athlete health screening guidelines for OC schools emphasizing adoption of American Academy of Pediatrics pre-season physical exam and an emphasis on pre-participation physical exams to be done in a clinic setting rather than mass screening on school grounds.

The second workgroup worked on developing rationale and recommendations regarding EKG's as part of the pre-season physical for all students and implementing use of Electronic Medical Records for student-athletes. With its efforts, a screening program, which includes ECGs, was implemented in collaboration with the industry, local hospitals, and physician and staff volunteers. Various independent organizations within OC that had already been doing screening for cardiac causes of sudden death joined forces to make this a success. A nominal fee of \$10 was collected from each student, and given back to the schools for implementation of programs to foster this effort. A formal research protocol was set up to evaluate the true and false positives, and hence, the efficacy of implementing such a program.

The third workgroup on emergency preparedness advocated for Automated External Defibrillators (AEDs) and basic cardiopulmonary

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Interested individuals should forward their curriculum vitae to Shuping Ge, MD, Chief, Section of Cardiology Co-Director, Heart Center for Children, St. Christopher's Hospital for Children, 3601 A Street Philadelphia, PA 19134. For further information on our opportunities at St. Christopher's Hospital for Children, please contact Shuping.Ge@drexeImed.edu.

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#### **Pediatric Cardiologist**

The Division of Pediatric Cardiology at the University Of Utah School Of Medicine is recruiting a pediatric cardiologist with a major interest in Adult Congenital Heart Disease. The candidate should have a strong clinical background in all areas of pediatric cardiology with expertise in caring for adults with congenital heart disease. The candidate will be joining a 24-member division of Pediatric Cardiology including one pediatric cardiologist currently running the Adult Congenital Heart Disease Program. The Division has a very active clinical program, currently seeing a large volume of adults with congenital heart disease. The Division also has a very active clinical research program and is one of the participating centers in the Pediatric Heart Disease Clinical Research Network funded by the NIH. There will be protected time for clinical research with mentoring available within the Division for clinical research studies. This faculty position will be involved in a very active academic teaching program.

The successful candidate will receive a faculty appointment at the University of Utah. The Pediatric Cardiology Division is based at Primary Children's Medical Center, a tertiary referral center for a three-state area located on the hills overlooking Salt Lake City. Adults with congenital heart disease are seen at the children's hospital and at nearby 'adult' hospitals. The area offers an excellent quality of life with immense cultural and recreational opportunities close and available.

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Interested individuals should send or email a cover letter and curriculum vitae to:

Lloyd Y. Tani, M.D. Chief, Division of Pediatric Cardiology University of Utah School of Medicine 100 N. Mario Capecchi Drive Salt Lake City, UT 84113 Email: lloyd.tani@imail.org



resuscitation-life support (BCLS) training and certification of all OC school staff and all middle and high school students. The group helped draft sample policy, procedures and guidelines for adoption and implementation of AED's in all OC schools. It also explored the legal and legislative issues of AED use in public schools. Since the first LEAPS meeting, there has been a shift from almost none of the school districts having an AED program to a majority of the school districts in OC today having either successfully implemented or in the process of implementing an AED program.

To better understand the incidence and etiology of life-threatening events in OC schools, the fourth workgroup created a critical incident review team under the leadership and guidance of the OC Health Officer. The purpose of this review team was to learn from lifethreatening events occurring at OC schools, and to provide feedback to the schools after incidents involving a life-threatening event or sudden death. The feedback included a record review and information gathering, including a visit to the site of the incident, as well as interviews of people at the incident to be conducted within 72 hours. A report regarding the incident was given to the Department of Education superintendent, and any systemic problems needing to be addressed were noted. The workgroup also planned to support the school community during and after the medical emergency event.

The third annual LEAPS symposium will be held on January 13, 2011 at the Disney's Grand California Hotel in Anaheim, California, and will focus on achievements within the community thus far, and where we need to be in the future. This meeting will precede a national symposium being held at the same venue January 14 and 15, 2011 on sudden cardiac arrest geared mainly for the medical community.

#### Shauna Ann Stuewe Foundation

On February 15, 2006, the Stuewe Family was struck by an unthinkable tragedy: the sudden and unexplained death of their 14 year old daughter Shauna during cheerleading practice. Up to that point, they had no idea that she was at risk for SCD. She was physically fit and active in gymnastics, cheerleading and various outdoor activities.

They could not believe that a healthy 14 year old could just die suddenly. Shauna had appeared completely normal. The family subsequently found out that there are many causes of SCD, and that their daughter had a rare condition called Catecholaminergic Polymorphic Ventricular Tachycardia (CPVT). The victims can go undiagnosed even despite an adequate screening, and unfortunately, their first symptom can be sudden cardiac death. They also learned that Automatic External Defibrillators (AED) can give victims of sudden cardiac arrest another chance. After going through their tragedy and knowing what they learned from it, they felt they needed to do something to help prevent SCD in other children. They determined that AEDs must be in schools. With the aid of a Cheer and Song Booster club, they conducted their first fundraiser in October 2007. They raised enough money to place AEDs in one of the OC School District's High Schools. To continue this effort, they established the Shauna Ann Stuewe Foundation or SAS. SAS was incorporated as a 501(c)(3) Public Charity in August 2008. Their ultimate objective was that all schools, athletic facilities, and other public gathering locations have AEDs in place. Recognizing the need to raise the public's awareness about the risks of SCA in our youth, they have taken several opportunities to educate the public. They are also advocates of effective cardiac pre-screening of young athletes before they enter competitive sports.



**Anthony Bates Foundation** 428 E. Thunderbird, #633 Phoenix, AZ 85022 Tel: (602) 482-5606

Sharon Bates sharon@anthonybates.org Education and awareness of the leading killer of young people, HCM (Hypertrophic Cardiomyopathy) through organizing and training in cardiac screening programs for young people everywhere.

The Foundation continues to hold charitable fundraising events to support its mission (cut-a-thons, bowl-a-thons, golf tournaments, jump-a-thons and more). With the help of their supporters, Shauna's parents have successfully placed nearly 40 AEDs in schools throughout Southern California. They have also presented and attended various public forums whose mission it is is to raise public awareness about the risk of SCD (e.g., Parent Heart Watch Conference, LEAPS Conference, Care & Kindness Conference, SADS Conference, and at various schools).

#### **Sparkling Angel Charities**

The Weaver Family, along with family and friends, founded Sparkling Angel Charities - The Kelly Weaver Memorial Fund, after the SCD of their 21 year-old daughter Kelly in 2001. Soon after her death they learned she died of a heart arrhythmia, Long QT Syndrome (LQTS).

Sparkling Angel decided to take a hands-on approach to spreading awareness of heart arrhythmias by providing no cost ECG screenings. Its efforts are focused on high school-aged students, both athletes and the general student body. The ECG screenings are held at OC high schools, and approximately 100-400 students participate each time a screening is held. As of 2010 Sparkling Angel Charities screenings have reached upwards of 8,000 young people. Several instances of LQTS have been discovered, as well as a variety of other cardiac abnormalities that have required further evaluation and treatment.

Sparkling Angel owns all the necessary equipment, from ECG machines to portable tables and privacy screens. Its costs are covered by grants and private donations. It also depends on volunteer staff which consists of: firefighters, paramedics, nurses, ambulance company employees, medical office personnel and many others from the private sector.

Its mission is to make the community aware of the importance of an ECG screening as part of every child's wellness program, and hopefully, save young lives.

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#### The Derrick Faison Foundation

The Derrick Faison Foundation was established in 2004, in memory of Derrick Faison who passed away while playing basketball on June 27, 2004 from an undetected hypertrophic cardiomyopathy. The goals of the foundation are to provide education and public awareness of SCD, and to help save lives through placement of AEDs, CPR training and screening efforts. It also provides scholarships for underprivileged kids. The foundation raises funds through charitable events, CPR Classes, and grants. The foundation has collaborated with other organizations in placing AEDs in OC High Schools, local gyms and public places. It also supports screening efforts, and provides a fund for families that can't afford screenings so that their costs are covered.

#### Heartfelt Cardiac Project

The Heartfelt Cardiac Project was initiated by Holly Morrell who began her community screening efforts in 1999. SCD in the form of hypertrophic cardiomyopathy has stalked the Morrell family for three generations, claiming six lives and forever haunting those left behind. Heartfelt Cardiac Projects provides cardiac screening in order to save lives from SCD. Echocardiograms and EKGs are offered for a nominal tax deductible donation, per screening. Heartfelt Cardiac Projects also helps contribute to research studies and assists in standardizing a screening protocol in the US. Like most similar organizations, Heartfelt Cardiac Projects raises funds through grants, individual contributions, corporate sponsorships, and fundraising events. The project has provided screening (both echocardiograms & EKGs) to over 16,000 people over the past 11 years. Although a vast majority of these screenings were offered free of cost, currently the program asks for a nominal tax deductible donation, per screening.

#### The Dick Butkus Center for Cardiovascular Wellness

The Dick Butkus Center for Cardiovascular Wellness - This 501(c)(3) nonprofit organization in OC is a cardiac screening program that uses ECGs and echocardiograms to help identify those at risk of SCD. Since



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We seek to recruit an Interventional Cardiologist to join two other full time faculty in our cardiac catheterization program, which is directed by David Balzer, MD. The program offers the full range of diagnostic and interventional procedures, including an active program in percutaneous valve placement, and works closely with the Adult Congenital Heart Disease program at Barnes-Jewish Hospital. Approximately 750 cardiac catheterizations are performed yearly, of which about 300 are interventional procedures. The program is based in a pair of biplane cineangiography laboratories, one of which will undergo renovation this year as a hybrid room. The ideal candidate must be eligible for licensure in Missouri, be board certified (or eligible) in pediatric cardiology, and have had advanced training and experience in interventional cardiac catheterization.

We also seek to recruit a cardiologist with a primary interest in echocardiography, ideally with a focus on either fetal echocardiography or noninvasive imaging. Depending on qualifications, this is a potential leadership position, and would include appointment as Co-Medical Director of the recently-established Fetal Care Center, a joint program of St. Louis Children's Hospital, Barnes-Jewish Hospital and Washington University. Currently our program performs approximately 400 fetal studies yearly. In addition, the Mallinckrodt Institute of Radiology at Washington University is an important resource for research and patient care, with state-of-the-art imaging capabilities. The ideal candidate must be eligible for licensure in Missouri, be board certified (or eligible) in pediatric cardiology, be skilled in echocardiography, and have had advanced training and experience in fetal echocardiography and/or noninvasive imaging.

Washington University School of Medicine is consistently ranked as one of the best medical schools in the country, and is a longstanding leader in funding for pediatric research. St. Louis Children's Hospital is a 250 bed free-standing children's hospital established in 1879, and is listed on the U.S. News and World Report Honor Roll of best children's hospitals, attesting to its strong programs in all aspects of children's health care. The St. Louis Children's Heart Center includes an active surgical program, a 12-bed Cardiac Intensive Care Unit, and one of the nation's largest heart failure and heart transplantation programs.

#### Interested candidates should provide a curriculum vitae and contact:

George F. Van Hare, M.D. Director, Pediatric Cardiology Co-Director, St. Louis Children's Heart Center 1 Children's Place St. Louis, MO 63110 e-mail: vanhare@kids.wustl.edu Phone: 314-454-4217

Washington University is an Equal Opportunity Affirmative Action Employer. We welcome CVs and resumes from women and from minority candidates.



#### Need to Recruit a Pediatric Cardiologist?

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The center also offers patients and their families' access to educational programs and support resources to empower them with the tools to prevent, delay or even reverse the onset of cardiovascular disease. The Center's Cardiac Screening Program is provided on-site at the center's facilities or off-site at events, community centers, athletic programs, and corporations.

#### Conclusion

The sudden and unexpected loss of a young person is a tragic occurrence that causes significant concern in both the general public and medical community. Strategies to prevent these catastrophes are and will remain a prominent public health debate. Although implementation of these strategies is difficult at a national level, individual initiatives such as those mentioned above are appearing to be successful. Our hope is that we can learn from these initiatives to see how such prevention strategies can be implemented at a larger scale.

The third annual LEAPS conference will be held at the Disney's Grand California Hotel and Spa in Anaheim, California on January 13, 2011, and will evaluate the current and future initiatives on prevention of sudden cardiac arrest in Orange County. This will be followed by a national symposium on the diagnosis, therapy and prevention of sudden cardiac arrest in children and adolescents on January 14-15, 2011 with invited faculty from various major medical centers. We are hopeful that this symposium will help us get educated on other initiatives around the country and come up with future initiatives that can be implemented nationally.

Registration information for the symposium on *Sudden Cardiac Arrest in Children and Adolescents* can be found at www.choc.org/ cardiacconference or by calling 1-800-329-2900.

<sup>1.</sup> "Orange County QuickFacts from the US Census Bureau". Quickfacts.census.gov. http://quickfacts.census.gov/qfd/states/ 06/06059.html. Retrieved 2010-07-22.

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Anthony C. Chang, MD, MPH Medical Director CHOC Children's Heart Institute 455 S. Main Street Orange, CA 92868 USA

# SCAI View - A Monthly Column from The Society for Cardiac Angiography and Interventions -**Congenital Heart Disease** Symposium at SCAI 2011 Starting to Take Shape

By Daniel S. Levi, MD, FSCAI

The educational program for the Congenital Heart Disease Symposium at SCAI 2011 Scientific Sessions is taking place May 4-7, 2011, in Baltimore, MD. SCAI 2011 will feature two-and-a-half days of uninterrupted, focused programming on interventional therapies for congenital and structural heart disease.

We'll be bringing back the enormously popular "Brain Scratchers" session to challenge you to solve hemodynamic, angiographic or interventional mysteries and to provide solutions for less than routine cases in the congenital catheterization laboratory. The "I Blew It" sessions will be returning for a twelfth year to educate, entertain, and shock with all the ways interventional cases can go awry and with the creative ways that our colleagues manage these complications. More importantly, the session addresses how to avoid such events in the future. If you have a case that might be a good learning tool or an unusual "Wow, I've never seen that before" type of case, please contact Frank Ing, MD, FSCAI at ing@bcm.edu.

Who will be delivering the Mullins Lecture this year? We are happy to announce that John P. Cheatham, MD, FSCAI will be doing the honors. Where do we start to describe John's contributions to advancing care of congenital heart disease? Over the years he has pioneered many new techniques and devices, as well as being a world leader in developing new Hybrid therapies. He developed the world's first hybrid cardiac catheterization suites and advanced imaging equipment at Nationwide Children's Hospital in Columbus, OH. Allowing the interventionalist and cardiothoracic surgeon to perform combined therapy this has been a huge development in improving clinical outcomes in patients.

Want to be part of this exciting program? Here's your chance. SCAI is now accepting abstracts

through December 15 in several categories including valvular, structural and congenital interventional therapies. Why should you submit your research to SCAI 2011? The Society provides presenting authors with free registration to the meeting. The top 10 abstracts will be selected for oral presentation during the program and all presented abstracts will be published in Catheterization & Cardiovascular Interventions. Better yet, presenting your research findings is an efficient and effective way to improve patient care. With the full attention of interventional cardiologists from all over the country, many from around the world, you can share information they will take back and immediately apply in their daily clinical practice.

SCAI abstract presentations provide a great stage for early-career cardiologists to present at a national meeting with the added benefit of getting immediate feedback from your peers, brainstorming next steps, and meeting potential collaborators for future trials. So what are you waiting for? Submit your research now. Further details are available online at www.scai.org/SCAI2011.

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Daniel S. Levi, MD, FSCAI Congenital Heart Disease Program Co-Chair, SCAI 2011 Mattel Children's Hospital at UCLA Westwood, CA USA (310) 825-5296

#### CONGENITAL CARDIOLOGY TODAY

#### CALL FOR CASES AND **OTHER ORIGINAL** ARTICLES

Do you have interesting research results, observations, human interest stories, reports of meetings, etc. to share?

> Submit your manuscript to: RichardK@CCT.bz

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- Optionally, a picture of the author(s) may be submitted.
- No abstract should be submitted.
- The main text of the article should be written in informal style using correct English. The final manuscript may be between 400-4,000 words, and contain pictures, graphs, charts and tables. Accepted manuscripts will be published within 1-3 months of receipt. Abbreviations which are commonplace in pediatric cardiology or in the lay literature may be used.
- Comprehensive references are not required. We recommend that you provide only the most important and relevant references using the standard format.
- Figures should be submitted separately as individual separate electronic files. Numbered figure captions should be included in the main Word file after the references. Captions should be brief.
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## Camp Odayin: Kids Play, Worries Rest, Fun Happens

By Jonathan N. Johnson, MD

Camp Odayin is a non-profit organization based Minnesota that offers day camps, family camps, and residential week-long camps for children with a history of heart disease. This includes children with structural heart defects, rhythm disorders, and those who have had a heart transplant. Many of these children might not be accepted for standard summer camps due to their sometimes complex medical histories. Camp Odayin, however, was created specifically for these children, to help them have a typical camp experience, while making sure their specific medical, social, and emotional needs are being met.

I have had the honor of working as a camp physician for one week each of the past two summers at Camp Odayin. Words cannot describe the amazing team of people who organize and make the residential camp happen. From the Executive Director, Sara Meslow, to the volunteer team of counselors, nurses, physicians, and camp staff, each and every person gives all of their energy to ensuring these children have an amazing camp experience. The children participate in activities including archery, canoeing, kayaking, arts and crafts, ropes

Cardiology

courses, horseback riding, and every water sport you can imagine.

The first summer I was at Camp Odayin, I was overwhelmed by how much fun these children were having. There was nothing limiting them. Nobody was telling them they weren't allowed to do one of the activities because of their heart. Everyone around them had a similar medical history, and they could relate to each other without feeling judged. Nobody was staring at their surgical scars like they were an anomaly; almost every other kid there had one, so what was the big deal? And there were no adults around telling them to slow down. As stated by one former camp volunteer, "Kids only have one speed - kid speed." And it is incredible to see these kids with heart conditions find their "kid speed."

The second summer I was there, I began to notice a different benefit of Camp Odayin. Sure, the kids were having a great time. But the people most grateful to the camp and the staff were the children's families. Many of these parents had spent many years worrying on a daily basis about their child. Will they be okay at school? Can they play with the neighbors? Can they keep up with the other kids? Will they remember to take their medications? Many parents had not spent a night apart from their child before this camp. They, however, are quickly reassured when they hear about the medical capabilities of the camp. There is one nurse for each and every cabin. There are at least two and often three pediatric cardiologists on site at all times. There is a 24 hour health center, so that a physician and nurse are available at all times for any and every medical concern. Full cardiac monitoring is available on-site. Finally, each day of camp, over 250 pictures are taken and posted to the camp's website, so that parents can see their kids having the time of their lives. As physicians, we underestimate the psychological toll of taking care of a child with complex congenital heart disease for a lifetime. These parents don't often get breaks, where they know that somebody trustworthy is taking care of their child, with appropriate medical care available. I could see this summer how truly grateful these families were to know their kids would be taken care of.

This year, as the bus from camp arrived back home in the Twin Cities, the kids quickly swarmed their parents, excitedly telling about their adventures at camp. They were sad to leave their friends, but already talking about next year's camp. Camp Odayin is a special place, where kids can be kids, no matter their history. It is a place where nobody tells them they are different, and nobody says they need to slow down. It is a place where they can find their "kid speed."





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The University of Maryland Hospital for Children is developing a comprehensive Children's Heart Program to meet the cardiovascular healthcare needs of the children of Maryland. We are currently recruiting for a Director of Interventional Cardiology to work in our new Hybrid Catheterization Suite. We are also recruiting for Directors of Non-Invasive Imaging and Electrophysiology/Pacing.

Sub-specialty board certification or equivalent work experience is required for each position. The ideal candidates will have proven leadership and program development experience. Clinical duties will focus primarily in the respective subspecialty field of each faculty position, although all members of the program participate to varying degrees in the general pediatric cardiology and outpatient practices. The Children's Heart Program supports integrated quality enhancement and clinical research practices to improve patient outcomes and patient/ family experience.

The successful candidates will have faculty appointments in the Department of Pediatrics of the University of Maryland School of Medicine at academic levels to be determined by experience. The University of Maryland Medical Center is a major academic tertiary care center serving Baltimore, the state of Maryland, and the mid-Atlantic region. As the oldest public medical school in the United States, the University of Maryland School of Medicine has an established tradition of outstanding clinical care, education, and research. The Department of Pediatrics is deeply committed to promoting children's health in the community and across the state, while supporting innovative clinical programs and expanding research initiatives.

Located on the modern and urban campus of the University of Maryland at Baltimore, The School of Medicine is one of seven professional schools within the University of Maryland system. The campus is ideally located within walking distance to the Baltimore Inner Harbor, National Aquarium, Baltimore Convention Center, Hippodrome Theatre, Orioles Park at Camden Yards and Baltimore Ravens M & T Bank Stadium. The University of Maryland Hospital for Children is also close to historic Annapolis, the Chesapeake Bay, Washington D.C., and many residential communities with outstanding public and private schools. The area offers rich cultural fabric and many unique recreational opportunities.

The University of Maryland is an EOE/AA/ADA and encourages minorities to apply.

Interested applicants should send CV to:

Dr. Geoffrey L. Rosenthal Director, Pediatric & Congenital Heart Program University of Maryland Hospital for Children 22 S. Greene Street, N5W68 Baltimore, MD 21201 grosenthal@peds.umaryland.edu



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# The Children's Cardiomyopathy Foundation's (CCF) Second International Scientific Conference Keeps Cardiomyopathy at the Forefront of Pediatric Medicine and Research

By Renee Thekkekara

CCF's Second International Conference on Cardiomyopathy in Children, cosponsored by the National Heart, Lung and Blood Institute (NHLBI), the University of Miami Miller School of Medicine, the Myocarditis Foundation, and GeneDX was held May 13-14 in Bethesda, MD. The scientific workshop called attention to the critical issues related to cardiomyopathy in children. Manuscripts from the conference will be featured in three issues of Progress in Pediatric Cardiology. Plans are also in place for additional working group sessions that would focus on finalizing a research agenda and developing action plans for collaborative studies aimed at improving diagnostic methods and optimizing care for children with cardiomyopathy.

Sixty of the top clinicians and researchers from the US, UK, Canada and Australia convened to identify key research areas, share best practices and review new research data and findings on pediatric cardiomyopathy. A wide range of medical disciplines was present, including cardiologists, geneticists, molecular biologists and epidemiologists. Representatives from the NHLBI, the National Cancer Institute, and the National Institute of Child Health and Development also participated in the exchange of ideas and information.

"Cardiomyopathies result in some of the worst pediatric cardiology outcomes, as nearly 40% of the children who present with symptomatic cardiomyopathy receive a heart transplant or die within the first 2 years after diagnosis," said Conference Chair & CCF Medical Advisor Steven Lipshultz, MD. "This conference is a critical step in bringing together the best in the field to understand the molecular and genetic issues in cardiomyopathy and to identify the most critical and promising areas for clinical research efforts for this disease," continued Dr. Lipshultz.

CCF was the first to organize a conference dedicated specifically to pediatric cardiomyopathy. The first conference took place in January 2007 with conference proceedings featured in three dedicated issues of *Progress in Pediatric Cardiology*. Due to the general lack of information on the disease, these three issues became the most downloaded articles in the 20-year history of the scientific journal. Following the first conference, an additional \$1 million was committed to pediatric cardiomyopathy research by the Foundation.

The two-day conference was organized into six moderated sessions centered on topics of various interests. Panel moderators included: Jeffrey Towbin, MD; Wendy Chung, MD, PhD (Genetic Issues); Steve Webber, MBChB; Daniel Bernstein, MD (Molecular Mechanisms); Steve Lipshultz, MD; Michael Burch, MBChB (Biomarkers); Steve Colan, MD; Robert Weintraub, MBBS (Hypertrophic, & Restrictive Cardiomyopathy, Left Ventricular Noncompaction); Leslie Cooper, MD; Charles Canter, MD (Myocarditis); Daphne Hsu, MD; and Robert Shaddy, MD (Medical & Transplant Therapy). The conference also included five young investigators who are at the start of their medical careers and represent the future of cardiomyopathy research. These investigators outlined the findings of their work to date.

"An important part of CCF's mission is to provide accessible educational materials that are current. easy-to-understand, and offer practical guidelines for living with the disease for patients, parents/ caregivers and medical practitioners. CCF works with various healthcare organizations and medical societies to develop these materials in print and electronic formats. All materials have been carefully reviewed by CCF's medical advisors. and in most cases are offered free-of-charge.""

A new family panel was introduced this year in which attendees had the opportunity to hear from parents of affected children. Five parents from the Bethesda area shared their experiences of navigating the medical system and discussed the challenges of raising a child with a chronic illness. They also offered suggestions on which patient





Working Together to Develop a Better Tomorrow

resources and support services are most helpful and what physicians could do to further assist parents after a child's diagnosis.

CCF plans to organize another Scientific Conference within the next two years.

The Children's Cardiomyopathy Foundation (CCF) is a national, non-profit organization focused on pediatric cardiomyopathy, a chronic disease of the heart muscle. CCF is dedicated to accelerating the search for a cure by stimulating and supporting promising research on pediatric cardiomyopathy, by educating and assisting physicians and patients on the complexities of the disease, and by increasing awareness and advocacy on behalf of affected children and their families.

An important part of CCF's mission is to provide accessible educational materials that are current, easy-to-understand, and offer practical guidelines for living with the disease for patients, parents/caregivers and medical practitioners. CCF works with various healthcare organizations and medical societies to develop these materials in print and electronic formats. All materials have been carefully reviewed by CCF's medical advisors, and in most cases are offered free-of-charge. Materials include: Pediatric Cardiomyopathy Report (a report in collaboration with National Organization for Rare Disorders (NORD) that covers the disease forms, symptoms, affected population, causes, and standard and investigative therapies), Introduction to Pediatric Cardiomyopathies (a booklet of the most current facts about the disease put together in collaboration with the American Heart Association and NORD), Understanding Cardiomyopathy (a 14-page booklet that provides an overview of the disease and its various forms), and Secrets of the Heart (a 38-minute DVD that introduces the disease to newly diagnosed families).

For more information or to order these and other materials please visit CCF at www.childrenscardiomyopathy.org/site/pamphlets.php

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# Medical News, Products and Information

## Edwards Receives Approval to Begin US Clinical Trial of Next-Generation Transcatheter Valve

Edwards Lifesciences Corporation, a global leader in the science of heart valves and hemodynamic monitoring, announced in September that the US Food and Drug Administration (FDA) conditionally approved the first of two planned cohorts of the randomized, controlled The PARTNER II Trial. Building upon the learnings of the world's first randomized transcatheter heart valve trial -- Edwards' The PARTNER Trial -- the first cohort of The PARTNER II Trial will study the next-generation Edwards SAPIEN XT transcatheter heart valve. This trial includes the low-profile NovaFlex transfemoral delivery system, which broadens the number of eligible patients.

This cohort of The PARTNER II Trial will study up to 450 patients with severe, symptomatic aortic stenosis using two-to-one randomization, where for every two patients who receive the Edwards SAPIEN XT valve delivered transfermorally, one will receive standard therapy. The primary endpoint of the trial is a composite of death, major stroke and repeat hospitalization, with secondary endpoints that include valve performance and quality-of-life indicators.

Edwards anticipates a second patient cohort for the trial to compare traditional open-heart surgery with the Edwards SAPIEN XT valve delivered either transfemorally or transapically.

The Edwards SAPIEN XT valve is commercially available in Europe, where it received a CE Mark in March 2010. The Edwards SAPIEN XT transcatheter valve is an investigational device in the US, and not yet available commercially in this country. Additional information about the valve and Edwards Lifesciences can be found at www.edwards.com.

#### Clinical Trial Establishes Catheter-Based Aortic Valve Replacement as New Standard of Care for Patients Who Cannot Undergo Surgery

One-year data from the PARTNER clinical trial, published in September 2010 in the *New England Journal of Medicine*, demonstrated that transcatheter aortic-valve implantation, compared with standard therapy, resulted in significantly lower rates of death among patients who cannot undergo surgery for aortic stenosis. The results were presented as a Late Breaking Trial at the 22nd annual Transcatheter Cardiovascular Therapeutics (TCT) scientific symposium.

Transcatheter aortic-valve implantation (TAVI) is a new procedure in which a bioprosthetic valve is inserted through a catheter and implanted within the diseased native aortic valve. The Placement of AoRtic TraNscathetER valves (PARTNER) trial is a multicenter, randomized clinical trial comparing TAVI with standard therapy in high-risk patients with severe aortic stenosis. The co-principal investigators are Martin B. Leon, MD, and Craig R. Smith, MD, at New York-Presbyterian Hospital/ Columbia University Medical Center. The data published today reflect a prespecified cohort of patients who were considered to be unsuitable candidates for surgery.

The primary end point was the rate of death from any cause over the duration of the study. A total of 358 patients with aortic stenosis who were considered to be unsuitable candidates for surgery underwent randomization at 21 centers, including 17 in the United States. Patients randomized for standard therapy received a combination of watchful waiting, medications, and balloon aortic valvuloplasty, which can provide transient clinical benefit, but does not alter long-term outcomes.

At one year, based on the Hazard Ratio of 0.55, patients who underwent TAVI showed a reduction in mortality from 50.7% to



#### **Topics will include:**

- Clinical syndromes associated with risk of sudden death
- Use of automated external and implantable defibrillators in the young
- Arrhythmias in the young
- Screening, with an emphasis on defining levels of evidence and areas of controversy in management decisions

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www.choc.org/cardiacconference or call (800) 329-2900

#### JANUARY MEETING FOCUS

#### Sudden Cardiac Arrest in Children -2 Day Conference January 14-15, 2011 Disney Grand Californian 1600 S. Disneyland Dr., Anaheim, CA USA www.choc.org/cardiacconference

This conference will present the current state-of-the art on topics related to the diagnosis, therapy and prevention of cardiac arrest in young people. Topics will include:

- clinical syndromes associated with risk of sudden death.
- · arrhythmias in the young.
- use of automated external and implantable defibrillators in the young.
- and screening, with an emphasis on defining levels of evidence and areas of controversy in management decisions.

The intended audience is pediatricians, pediatric cardiologists, residents and fellows-in-training, electrophysiologists and affiliated professional involved and interested in the care of young people.

**Overview:** A comprehensive meeting on sudden cardiac arrest in children, designed specifically for physicians, nurses, and other healthcare professionals. Featuring a distinguished faculty consisting of nationally recognized leaders well-known for their clinical expertise and teaching abilities.

Clinically focused lectures and debate panels, case discussions, Q&A, and extended informal faculty interactions. At the conclusion of the course, the participant should be able to:

- Recognize the causes of sudden cardiac arrest in children.
- Differential diagnosis of patients who are at risk for sudden cardiac death based on age.
- Recognize common arrhythmias and describe the management for children who are at risk for sudden cardiac death
- Recognize the indications for screening modalities to identify causes of sudden cardiac arrest in children.
- Prescribe secondary prevention modalities for sudden cardiac arrest in children.

30.7%. In addition, there was a reduction in the combined endpoint of death from any cause or repeat hospitalization from 71.6% with standard therapy to 42.5% with TAVI. Among survivors at one year, the rate of cardiac symptoms was significantly lower among patients who had undergone TAVI, as compared with those who had received standard therapy (25.2% vs. 58.0%).

"Based on the reduction in mortality during the first year of the study, balloon-expandable TAVI should be the new standard of care in patients who are not suitable candidates for surgery," said Martin B. Leon, MD, Professor of Medicine and Director of the Center for Interventional Vascular Therapy at New York-Presbyterian Hospital and Columbia University Medical Center. Dr. Leon, founder and chairman emeritus of the Cardiovascular Research Foundation, is the co-principal investigator of the study.

At 30 days, TAVI, as compared with standard therapy, was associated with a higher incidence of major strokes (5.0% vs. 1.1%) and major vascular complications (16.2% vs. 1.1%). In the year after TAVI, patients had no deterioration in the functioning of the bioprosthetic valve, as assessed by evidence of stenosis or regurgitation on an echocardiogram.

"This study shows that transcatheter valve replacement is a safe and effective option for this life-threatening illness in patients unsuitable for surgical valve replacement," said Dr. Smith, study co-principal investigator and Surgeon-in-Chief at NewYork-Presbyterian Hospital/Columbia University Medical Center. Dr. Smith is also the Valentine Mott Professor of Surgery, the Johnson & Johnson Distinguished Professor of Surgery, and Chair of the Department of Surgery at Columbia University College of Physicians and Surgeons. "Additional studies are needed to examine the increased incidence of stroke following TAVI."

According to the study authors, research is already under way on the next generation of TAVI devices that researchers hope will address the vascular complications encountered in the trial.

In clinical practice, at least 30% of patients with severe symptomatic aortic stenosis do not undergo surgery for replacement of the aortic

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#### **Pediatric** LOYOLA Stritch Cardiology **Faculty Position**

School of Medicine

The Division of Pediatric Cardiology at Loyola University Chicago (LUC) Stritch School of Medicine's Department of Pediatrics is seeking a pediatric cardiologist to join its growing practice. The position requires excellent clinical skills in general pediatric cardiology. The ideal candidate should be BE/BC in pediatric cardiology with demonstrated expertise in multimodality noninvasive imaging of congenital and structural heart disease. Candidates should have excellent judgment, good work ethic, and interact well with peers, other medical and support personnel, and community physicians. Faculty also have important roles in student and resident education and have the opportunity to conduct research.

Based in the western suburbs of Chicago, Loyola University Health System (LUHS) is a quaternary care system with a 61-acre main medical center campus and 14 off-site facilities in Cook, Will and DuPage counties and the Gottlieb Memorial Hospital campus in Melrose Park. On the medical center campus is Loyola University Hospital, a 570-bed licensed facility; it houses a Level 1 Trauma Center, a Burn Center and the Ronald McDonald® Children's Hospital of Loyola University Medical Center. Also on campus are the Cardinal Bernardin Cancer Center, Loyola Outpatient Center, Center for Heart & Vascular Medicine, and Loyola Oral Health Center as well as the LUC Stritch School of Medicine, LUC Niehoff School of Nursing and a fitness center. LUHS is a nationally recognized leader in providing specialty and primary health-care services as well as in conducting groundbreaking research in treatment of heart disease, cancer, organ transplantation and neurological disorders.

Loyola's Ronald McDonald Children's Hospital, located in Loyola University Hospital, is a "hospital-within-a-hospital" and is comprised of 36 general inpatient, 20 newborn nursery, 14 pediatric intensive care, and 50 neonatal intensive care beds. The hospital is staffed by a full complement of pediatric subspecialty services and a 46-member residency program.

Please send a letter of interest and CV to: Joel Hardin, MD, Division Director of Pediatric Cardiology, Jhardin@lumc.edu, or Holly Nandan, Director of Faculty Recruitment, hnandan@lumc.edu.

#### www.LoyolaMedicine.org

#### www.stritch.luc.edu

The Loyola University Health System is an affirmative action/equal opportunity educator and employer. The University undertakes affirmative action to assure equal employment opportunity for underrepresented minorities, women, and persons with disabilities.



valve because of advanced age, left ventricular dysfunction, or the presence of multiple coexisting conditions.

The replacement valve used in the PARTNER trial is made of pericardial tissue leaflets hand-sewn onto a metal frame and implanted via a catheter into the left ventricle. It is then positioned inside the patient's existing valve using a balloon to deploy the frame, which holds the valve replacement in place. The procedure is performed on a beating heart, without the need for cardiopulmonary bypass and its associated risks.

The transcatheter valve procedure takes about 90 minutes, compared with four to six hours for open-heart surgery. In open-heart surgery, the surgeon cuts through the breastbone, stops the heart, removes the valve, and replaces it. Open-heart surgery can require a two- to threemonth recovery period, compared with only a few days for the transcatheter approach.

The multicenter PARTNER trial, which has more than 1,000 patients, began in 2007 and will be completed in 2014. The results reported in late September 2010, reflect only the cohort of patients who are not considered candidates for surgery. The other arm of the trial, which compares transcatheter valves with surgically implanted valves, is ongoing. The executive committee of the trial includes two academic coprincipal investigators, three interventional cardiologists, and three cardiac surgeons.

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