IMPACT Registry Prepares to Launch Pilot

By Gerard R. Martin, MD

The IMPACT Registry (IMproving Pediatric Adult Congenital Treatments) will launch its pilot project in 14 hospitals (Table 1) in September 2009. The IMPACT Registry is the sixth registry within the American College Cardiology’s (ACC) National Cardiovascular Data Registry (NCDR) which has currently enrolled over 9 million patients in nearly 2,500 hospitals (Table 2).

IMPACT will be the first national registry to track in-hospital outcomes in all children and adults with congenital heart disease (CHD) undergoing diagnostic and interventional cardiac catheterizations. In this update, I will outline the development of IMPACT, provide an overview of the registry and the timetable for release to participating centers.

The impetus to develop the IMPACT Registry began at an ACC Adult Congenital/Pediatric Cardiology (AC/PC) Council breakout session on Quality Improvement held at the ACC ’06 Annual Scientific Sessions in Atlanta. During this session, pediatric cardiologists and adult

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<tr>
<th>Table 1. Pilot Sites for the IMPACT Registry</th>
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<tr>
<td>• Children’s National Medical Center, Washington, DC</td>
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<td>• Cincinnati Children’s Medical Center, Cincinnati, OH</td>
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<td>• Children’s Healthcare of Atlanta, Atlanta, GA</td>
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<td>• Children’s Hospital of Boston, Boston, MA</td>
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<td>• Children’s Hospital of Michigan, Detroit, MI</td>
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<td>• Children’s Hospital of Philadelphia, Philadelphia, PA</td>
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<td>• Columbus Children’s Hospital, Columbus, OH</td>
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<td>• Johns Hopkins Hospital, Baltimore, MD</td>
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<td>• Lenox Hill Heart and Vascular Institute of New York, New York, NY</td>
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<td>• Monroe Carell Jr Children’s Hospital of Vanderbilt, Nashville, TN</td>
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<td>• Rady Children’s Hospital - San Diego, San Diego, CA</td>
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<tr>
<td>• Rush University Medical Center, Chicago, IL</td>
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<td>• Tampa Children’s Hospital, Tampa, FL</td>
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<td>• Texas Children’s Hospital, Houston, TX</td>
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<th>Table 2. Registry Volumes</th>
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<tr>
<td>Registry</td>
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<td>---------------------------------------------</td>
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<tr>
<td>CathPCI Registry</td>
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<td>ICD Registry</td>
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<td>CARE Registry</td>
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<td>ACTION Registry-GWTG</td>
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The Melody® Transcatheter Pulmonary Valve and Ensemble® Transcatheter Delivery system have received CE Mark approval and are available for distribution in Europe. Additionally, a Medical Device Licence has been granted and the system is available for distribution in Canada. Products are not available for sale in the United States.

Providing new options for the lifetime management of patients with congenital heart disease

A nonsurgical breakthrough in treating RV to PA conduit dysfunction
CHD cardiologists expressed their desire to establish a national registry for CHD to better understand clinical practice and patient outcomes. The request was presented to ACC leadership and the AC/PC Council was directed to explore the feasibility of a registry with NCDR staff. Soon after, interested pediatric cardiologists and NCDR staff held a meeting at the American Heart Association's 2006 Scientific Session to increase each other's awareness of past and present registries in congenital heart disease, and to learn more about the ACC's NCDR. The discussion was positive, and given the expressed need for a CHD registry, as well as the success of the NCDR model, there was a consensus to continue to explore a potential CHD registry.

The president of the ACC, Dr. James Dove, and Dr. Ralph Brindis, chair of the NCDR Management Board formed a working group to write a concept and feasibility paper outlining the need and purpose of the registry. I chaired the committee and the other members included Drs. Kathy Jenkins, John Kugler, John Moore, and Rich Ringel. This group met at the Heart House in Washington, DC in January of 2007 and work began. The work was largely completed through a series of conference calls, but the committee decided to gather more input from the interventional cardiology community at the ACC '07 Annual Scientific Sessions in Chicago. At this meeting, all catheterization lab directors (American Academy of Pediatrics Directory), interested pediatric cardiologists from previous meetings and NCDR staff met to discuss a national catheterization registry for CHD. After an informational session on the NCDR, and due to a perceived need for a CHD registry, an informal vote of attendee's interest in participating in a national CHD registry was taken. There was near unanimous support for a registry of the nearly 30 hospitals represented. The concept and feasibility paper served as the basis of an eventual comprehensive business plan, which was completed and approved by the NCDR Management Board in May 2007 and by the ACC Board of Trustees in August 2007.

“The IMPACT Registry (IMproving Pediatric Adult Congenital Treatments) will launch its pilot project in 14 hospitals (Table 1) in September 2009.”

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**Table 3. IMPACT Steering Committee Members and Representative Organization**

- Gerard R. Martin, MD, Chair, ACC
- Robert H. Beekman, MD, AAP
- Frank F. Ing, MD, SCAI
- Kathy J. Jenkins, MD, ACC
- John W. M. Moore, MD, ACC
- Richard E. Ringel, MD, ACC
- Jonathan J. Rome, MD, ACC
- Carlos E. Ruiz, MD, SCAI
- Robert N. Vincent, MD, SCAI
Following the approval to develop a CHD registry, later named the IMPACT Registry, a Steering Committee and Data Dictionary Workgroup were formed to begin the registry development process. The Steering Committee, which was tasked with establishing the strategic direction and scope of the registry, determined IMPACT Registry v1.0 would include all children and adults with congenital heart disease undergoing diagnostic or interventional cardiac catheterizations. They also agreed to pursue partnerships with several professional associations including the Society for Cardiovascular Angiography and Intervention, Society of Thoracic Surgeons and the American Academy of Pediatrics. The Workgroup was charged with selecting the actual data elements and metrics for reporting (Table 4). Upon launch of the registry, the Workgroup will no longer be necessary and two additional committees will be formed (Figure 1).

At each step in the process of developing the IMPACT Registry, we have had the opportunity to re-explore what IMPACT hopes to accomplish, the eligibility criteria for inclusion, and what key metrics are important to report to participating sites. Throughout the process

### Table 4. IMPACT Workgroup Members and Representative Organization

- Frank F. Ing, MD, Chair, SCAI
- Zahid Amin, MD, SCAI
- Robert H. Beekman, MD, AAP
- Thomas Doyle, MD, ACC
- Allen D. Everett, MD, ACC
- Thomas J. Forbes, MD, ACC
- Raif Holzer, MD, SCAI
- Jeffrey P. Jacobs, MD, STS
- Kathy J. Jenkins, MD, ACC
- Joshua P. Kanter, MD, ACC

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Quality Metrics

### ASD Quality Metrics

<table>
<thead>
<tr>
<th></th>
<th>Metric Description</th>
<th>Distribution of Data</th>
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<tbody>
<tr>
<td>1</td>
<td>Unadjusted mortality&lt;br&gt;The number of patients whose discharge status is deceased.</td>
<td><img src="image1.png" alt="Graph" /></td>
</tr>
<tr>
<td>2</td>
<td>Median fluoroscopy time&lt;br&gt;Median of fluoroscopy time in minutes</td>
<td><img src="image2.png" alt="Graph" /></td>
</tr>
<tr>
<td>3</td>
<td>Median fluoroscopy dose&lt;br&gt;Median of fluoroscopy dose in milligrays</td>
<td><img src="image3.png" alt="Graph" /></td>
</tr>
<tr>
<td>4</td>
<td>Median contrast dose&lt;br&gt;Median of contrast volume in milliliters</td>
<td><img src="image4.png" alt="Graph" /></td>
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<tr>
<td>5</td>
<td>Patients with an device implanted whose latest echo within 24 hours after device implant shows no/trivial residual shunt&lt;br&gt;Number of patients with an ASD device implanted whose latest echo within 24 hours after device implant shows no/trivial residual shunt</td>
<td><img src="image5.png" alt="Graph" /></td>
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<tr>
<td>6</td>
<td>Patients with a device implanted who have a device embolization&lt;br&gt;Number of patients with an ASD device implanted that have a device embolization</td>
<td><img src="image6.png" alt="Graph" /></td>
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### ASD Utilization Metrics

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<th></th>
<th>Metric Description</th>
<th>Distribution of Data</th>
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<tbody>
<tr>
<td>7</td>
<td>Median length of procedure time&lt;br&gt;Median of first catheter in and last catheter out date/time in minutes</td>
<td><img src="image7.png" alt="Graph" /></td>
</tr>
<tr>
<td>8</td>
<td>Post procedure median length of stay&lt;br&gt;Date difference in days of procedure date and discharge date</td>
<td><img src="image8.png" alt="Graph" /></td>
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Figure 2: IMPACT quality and utilization metrics
of creating the concept/feasibility paper to the business plan and eventual creation of committees, there has been the addition of new expert leaders with different perspectives on scope and design of the IMPACT Registry. The broader input these additional experts offered slowed the process a bit, but more importantly, has focused the project on developing a much more robust set of metrics and data elements that may more closely capture variations in clinical practice and patient outcomes among participating hospitals.

The IMPACT Registry will include all children and adults with congenital heart disease undergoing diagnostic or interventional cardiac catheterization. The decision to include all children in the registry was based on the recognition of the importance of acquired heart disease in children. IMPACT will be able to provide outcome information from pediatric centers that perform procedures for Kawasaki Disease, cardiomyopathy, pulmonary artery hypertension and other acquired heart diseases. Including adults with CHD was determined important since many adult cases are now being performed in pediatric centers. There was also recognition of the importance of the lifelong burden of CHD on adults repaired in childhood. The only group excluded was primary electrophysiology studies.

IMPACT will record “some” data on all cases and “more focused” data on a select number of cases (ASD, PDA, Valvar PS, Valvar AS, Coarctation of the Aorta and PA Stenting). The Steering Committee considered the costs (time and money) of collecting all data on all cases and instead, focused on data elements critical for demographics, history and risk factors, procedure, hemodynamics, adverse events, and outcome and utilization statistics. The data entry will be via a web-based data collection tool by catheterization staff and warehoused at the ACC. Benchmark comparative reports that include quality and utilization metrics will be provided quarterly to each participating site (Figure 2 Example of ASD Metrics). Sites will use these reports to benchmark themselves with other “like” centers and national averages. Reported data will not include patient, physician, and participant identifiers.

IMPACT Registry data elements and definitions have been “harmonized” with the Society of Thoracic Surgeons, CHD Data Registry data dictionary which will:
• allow comparison with surgical procedures
• improve the ability to track patients between surgery and cath lab when the longitudinal module is available and
• reduce redundant data collection and data collection resources needed.

Much work has been done to date to create the IMPACT Registry. I am thankful for the vision of Ralph Brindis, who is now ACC’s incoming
president and James Dove, an ACC past president for supporting our CHD community and affording us the opportunity to realize the vision of the ACC’s AC/PC Council in 2006. NCIR staff has also been exceptionally supportive in providing the resources to bring us this far. In particular, two staff members have been instrumental in supporting all the meetings and telephone calls, Stephanie Mitchell and Joan Michaels, MSN, RN. It has been an honor working with a team of clinical and operational experts to create the concept/feasibility paper and the steering committee which has guided every step of this process. Kathy Jenkins’s expertise in registries and quality has been invaluable. We have also been fortunate to have tremendous leadership from our partner organizations: Society for Cardiovascular Angiography and Intervention, American Academy of Pediatrics, and Society of Thoracic Surgeons, in providing committee and workgroup members to design the program from its inception. It has been particularly satisfying to see our community come together on the project.

The IMPACT Registry will be a more robust registry because of the contributions of Lisa Bergersen, C3PO, Tom Forbes, CCISC, and Allen Everett, MAGIC, each of whom has participated in the registry development process. I am not an interventional cardiologist, but a customer of their services and I have been moved and humbled by the enthusiasm of the community in identifying the need and

**Related Resources to the IMPACT Registry**

Video Presentation of the “American College of Cardiology Impact Registry at PICS-AICS” by Dr. Gerard Martin

Dr. Peter Block, CVN Chief Cardiologist, Video Interview of Gerard Martin on “The Launch of the IMPACT Registry”
Recap of PICS-XIII

By Ziyad M. Hijazi, MD

PICS-XIII was held this year in collaboration with the 5th World Congress of Pediatric Cardiology & Cardiac Surgery in Cairns, Australia June 21st-23rd, 2009. The meeting attracted over 450 attendees from around the globe.

On the first day, Sunday June 21st, the meeting started with a session on the branch pulmonary arteries. This session included talks on the evaluation of patients with peripheral pulmonary artery stenosis, including angiographic and other diagnostic tools; another talk was on balloon angioplasty, including cutting balloons; another talk on stent implantation for this condition and the long-term outcome of such patients and, finally, two surgical talks on the surgical management of branch PA stenosis and on the hybrid implantation of stents.

After this session, live case transmission started with demonstrations from Saudi Arabia, where Dr. Tarek Momenah, who had Shakeel Qureshi, MD as a guest operator performed their first live case. This was followed by a case from Cochin, India, where Dr. Krishna Kumar performed device closure of a challenging atrial septal defect. The third case was transmitted from Kuala Lumpur, where Dr. Mazeni Alwi, who hosted Dr. Omar Galal as a guest operator, performed an interesting case of PDA stent. These live cases generated a lot of discussion between the operators, moderators, panelists and audience.

The didactic sessions continued at lunch with the traditional session “My Nightmare Case in the Cath Lab,” where eight speakers demonstrated various cases. At the end of the session, Dr. Gil Wernovsky, the chair of that session, announced the winner was Dr. Kasemi from Iran, who presented a case of aortic rupture.

The afternoon included live cases from the above centers. Each site transmitted two more cases that afternoon. Again, the diversity of such cases created great interest, with lively interaction between the operators and the attendees/moderators/panelists.

The last session in the main hall was about percutaneous pulmonary valve implantation where indications were discussed and then the Melody and Sapien valves were discussed separately. This was followed by a surgical talk on the technical and results aspects of valve replacement.

On Sunday, there was one breakout session geared towards nurses and technologists who work in the cath lab. This session was well-attended, and the speakers discussed various topics including: understanding hemodynamics and calculations; obtaining vessel access and closure in the cath lab; complications and other hazards in the cath lab; family involvement in procedures in the cath lab and ECMO in the cath lab-how to get patients in and out safely.

Monday was as busy. The morning started very early in the morning at 6:30 AM with two excellent workshops: one was devoted to ICE in the cath lab, and the other session was “how to.” In the “how to” session, various topics were discussed including: “how to” do trans-septal puncture; “how to” perform pericardiocentesis; “how to” perform transhepatic access and, finally, “how to” be most efficient with limited resources. In the ICE breakout session, topics included: simple ICE use for ASD/PFO guidance, another one on advanced ICE use for percutaneous valves repair/implantation and, finally, a comparison between ICE and TEE.

The general session then started at 8 AM with a comprehensive workshop on the atrial septum. In this session, Dr. Paul Weinberg presented an anatomic correlation for ASDs that can and can’t be closed in the cath lab with videotape of actual specimens. Then an echo talk on the septum by Dr. Craig Fleishman followed. The topic of device erosion was discussed by Dr. Zahid Amin, and then we had a parade of all available “approved and non-approved” devices for closure of ASD: the BioStar device; the Cardia device; the Helex
device; the Occlutech device; the pfm device and the Amplatzer device. Finally, this session concluded with Dr. Masura, who presented a talk about long-term outcome of ASD device closure. Live cases then began from Seoul, Korea, where Dr. Jae Young Choi, who hosted Dr. Frank Ing, did two live cases; Dr. Teiji Akagi, who hosted Dr. Evan Zahn, also did two very interesting live cases. Finally, Drs. Felix Berger and Peter Ewert performed three live cases from Berlin. All of these cases were very educational, and the attendees interacted very well with the operators.

Other sessions on Monday included a lunch session on percutaneous valve therapies for the aortic and mitral valve, as well as the LAA closure devices and heart failure monitoring devices. This was a well-received session from the pediatric cardiologist point of view. Later on, other sessions included the ventricular septum where, again, Dr. Weinberg showed videotaped specimens of VSDs; echocardiographic assessment of VSDs and then a surgical debate on PmVSDs. Finally, Dr. Jo De Giovanni discussed closure of muscular VSDs, and Dr. Masura the perimembranous closure of VSDs.

The last day of the meeting was as busy, and live transmission took place from Melbourne, where Dr. Geoff Lane hosted the PICS course director, Dr. Ziyad Hijazi. Three excellent and challenging live cases were performed and the attendees interacted very well with the operators who encountered various complications.

Didactic sessions on Tuesday morning included a workshop on embolization therapy and another one on the aortic arch. The lunch session was divided between talks on the sick neonate and also on PDA management. During the lunch session, Dr. William Hellenbrand, a course director, presented the PICS Achievement Award to Dr. Mario Carminati. Unfortunately, Dr. Carminati could not be there due to family obligations. His partner, Dr. Butera, accepted the award on his behalf.

The afternoon session included talks on PA/IVS; hybrid management of HLHS. In this session, Dr. Weinberg presented a videotape of specimens of HLHS and then, Dr. Simone Pedra presented the echo evaluation of babies with HLHS and, finally, Drs. Galantowicz and Schranz presented their experience in this area. In the late afternoon, Drs. Kavinsky and Nakanishi talked about coronary arteries assessment and Kawasaki Disease respectively. A new session that was about new imaging techniques in the structural heart lab, took place in the afternoon. This session was organized by Dr. Evan Zahn. Various imaging modalities were discussed, including: CT angio; MRI in the cath lab; 3D echo and 3D angiography.

PICS ended in the evening with a PFO symposium, which was very well-attended with over 250 attendees. In this symposium all aspects related to PFO were discussed including stroke, migraine and have course various devices for PFO.

The three days of PICS were very busy, and attendees enjoyed interaction with the faculty. The World Congress began on Wednesday morning.

We hope that you will join us for PICS-XIV, which will be back in Chicago after 5 years on the road...so save the date of July 18-21, 2010 Chicago, Sheraton Hotel. It promises to be the best and largest ever. We hope you will come and enjoy what Chicago can offer from the social point-of-view. Summer is beautiful in Chicago, and there is a lot to do for families.

Ziyad M. Hijazi, MD
On behalf of all PICS Directors.
This is the second edition of Dr. S. Bert Litwin’s “Color Atlas of Congenital Heart Surgery.” Dr. Litwin is a superb technical surgeon and an outstanding medical photographer. Since the beginning of his career, Dr. Litwin has photographed virtually all of his operations as a means to document the pathologic anatomy and the type of repair. Many of the photographs in this atlas are unique. The book is divided into 23 chapters, there are no references and few eponyms are utilized. The index is comprehensive, making it possible for the reader to quickly locate operative photos of a specific entity. In the brief Preface, Dr. Litwin explains his photographic techniques. In the Introduction and Techniques section, a few paragraphs are devoted to technical considerations. In this section, Dr. Litwin describes the techniques utilized for cannulation and the conduct of cardiopulmonary bypass at the Herma Heart Center in Milwaukee, Wisconsin.

The atlas does not attempt to define the history, physical findings, and diagnostic evaluation for each defect. For some diagnoses, appropriate angiograms are provided. In each case, the angiograms are superb and they fit very well with the operative photos.

The chapters are arranged by diagnosis. Similar abnormalities are clustered together which makes comparison of the anatomic pathology and the surgery quite easy. Dr. Litwin usually photographed the surface anatomy of the heart after the pericardium was opened and retracted. All students, residents and practicing cardiothoracic surgeons will benefit from reviewing these superb photographs of the anterior surface anatomy of the heart. There is quite a difference when the reader compares the appearance of the living heart with pictures of fixed specimens from other texts. This atlas would be worthwhile if it only contained the photographs of the surface anatomy of the heart for each defect. The intracardiac repair pictures are well labeled and easily understood.

Since Dr. Litwin’s career spans more than 35 years, some of the techniques depicted are different from those utilized at the present time. For example, most surgeons do not utilize Dacron for patching the atrial septum. In this atlas, the use of Dacron or Goretex patches is quite helpful, because the contrast between the synthetic patch and the cardiac structures highlights the surgical anatomy. In this atlas, the pathology is demonstrated as it appears in “real life.” Most successful pediatric cardiovascular surgeons have spent a considerable number of hours examining specimens in cardiac registries. Studying a formalin fixed specimen can be quite useful in preparing to perform a complex surgical procedure. The photographs in this atlas are equally helpful in defining the anatomy and the surgical techniques necessary to achieve a proper repair. The photographs complement the information derived from the study of fixed specimens. Some congenital heart defects occur relatively rarely, for example, consider supravalvular mitral ring. The photographs in this atlas clearly demonstrate the anatomy and the surgical technique necessary to achieve an excellent result when resecting a supravalvular mitral ring.

Chapter 4, entitled “Endocardial Cushion Defect” is particularly useful for the student attempting to understand the various forms of an atrio-ventricular septal defect and the repair techniques that are currently in use for these defects. In some chapters, the terminology may be a bit confusing, but the photographs are never confusing.

Chapter 18 is dedicated to aortic root anomalies. The pathologic anatomy depicted in this chapter is strikingly real and the surgical techniques are clearly depicted.

In summary, this atlas is not a textbook of pediatric cardiology, nor is it a textbook of pediatric cardiac surgery. The text is limited. The pictures are marvelous. The second edition of the Color Atlas of Congenital Heart Surgery expands and updates the excellent photographic documentation found in the first edition. Now that more than half of the patients living with congenital heart disease are over the age of 18, surgeons in training must be aware of historic operations that were state of the art 20 or 30 years ago. Serious students of congenital heart surgery will benefit from reviewing the photographs of classic operations that are rarely performed today, e.g. the Waterston shunt, the classic Blalock-Taussig shunt, formalin injection of the ductus arteriosus and others.

This compendium of operative photographs illustrates the evolution of pediatric cardiac surgery in a graphic and striking manner. At the same time, the atlas clearly depicts virtually all established operations in use today. This atlas should be a key reference in the library of all children’s hospitals, especially in those institutions where pediatric cardiology and cardiac surgery fellows are in training.

In the second paragraph of the preface, Dr. Litwin states, “the congenital heart surgeon is a student during his or her entire career because he or she encounters so many different anomalies. Learning from the experience of others should always be part of the clinicians’ education; this is best done by personally observing an operation performed by another. Otherwise, the best record of the procedure is a good operative photograph.” I concur completely with Dr. Litwin’s thoughts about the career-long learning curve that all students of congenital heart disease must experience. This atlas can provide useful information to any student of congenital heart disease at any point in his/her career.

By John J. Lamberti, MD

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China California Heart Watch Needs Your Help

By Robert Detrano, MD

The China California Heart Watch

The China California Heart Watch (China Cal) is a not-for-profit public charity whose purpose is to increase awareness of the need for better health care, particularly cardiac care, in China’s western rural areas. Bob Detrano, its President and Clinical Director is an adult cardiologist and a Professor at the University of California, Irvine, and a visiting professor at Peking University in Beijing. China Cal is embarking on a moving and fascinating project. We need your help.

Background

The impact of recent Chinese economic reforms has had enormous positive effects on Chinese society: the development of agricultural production and of industry, the creation of wealth in the industrial and banking centers, and the creation of a Chinese middle class. However, vast regions of the Chinese countryside have been left behind by economic reform. Many western rural villages have no running water, no paved roads and no well-trained doctors, no well-equipped clinic, nowhere to turn when illness strikes. Median family incomes in many villages in western China are less than $150 per year, yet a day in the hospital can cost $15; and when medicines, procedures and other services are added, this can exceed $50. Health insurance in the western provincial countryside is inadequate.

The mission of the China California Heart Watch is to research the extent of heart disease in rural Yunnan province, to provide care for those who are too poor to afford care and to provide training for Chinese and American students and medical trainees, and to provide free cardiac and preventive care to impoverished farmers and their families. The Heart Watch provides free care at its home clinic in Kunming, in nearby Kunming slum hospitals for migrant farmers and in rural villages in Yunnan. Heart Watch doctors and students work closely with the Village Doctors Training program of Yunnan province, with local health departments and local leaders, and with physician specialists of the Saint Johns International Heart Hospital of Kun Ming. The Heart Watch provides all care free of charge and provides grants to help cover the costs of surgeries and procedures for children with congenital heart disease.

Programs of the China California Heart Watch

Grants for Kids Program

There is one published report regarding the distribution of congenital heart disease in rural Yunnan province. This cross-sectional study, Jiang LH, Duan CQ, Ma ZQ, Zhu LJ, Yin WJ, Zou HL, Li P, Wu J, Wei J, Na ZH, Chen WM, Epidemiological investigation on congenital heart disease in several regions of Yunnan province Zhonghua Liu Xing Bing Xue Za Zhi. 2005 Mar;26(3):182-6) was carried out among 48,638 children from seven regions of the province using stratified, clustered sampling. The overall prevalence was 5.08 per thousand with 5.09 per thousand in males, and 5.07 per thousand in females. This is similar to that seen in Western countries. However, prevalence rates in different regions varied from 3 per thousand in the sub-tropical state of Xishuangbanna to 17 per thousand in Luxi Wuchalu. More importantly, in the same region, rates were different among different residents; for example, in Gejiu farming areas the rate was 3 per thousand in Gejiu, but in the nearby tin mining area of Gejiu, prevalence was 9 per thousand. Prevalence among ethnicities also differed greatly from 0 per thousand in the Hani minority to 8 per thousand in the Bai

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minority. There are, thus, significant regional and ethnic differences in congenital heart disease prevalence in Yunnan.

In 2008, China Cal started a program to assist impoverished families with children who have congenital heart disease. The program provides financial assistance to help cover the cost of surgeries and nonsurgical procedures. So far, eight children have benefitted from this program. We plan to expand the program and to assist more in 2009 and 2010. We need the assistance of a volunteer pediatric cardiologist who is willing to spend at least two weeks with us screening, diagnosing and treating these children. Children are referred to our colleagues at Yan An Hospital and at Saint Johns Heart Hospital in Kunming for surgery and percutaneous interventions.

Along with this program, China Cal is running mission trips to rural villages in Yunnan to screen thousands of children for heart disease, to diagnose and to refer and provide financial assistance for families of children with heart defects. We are inviting pediatric cardiologists to attend these trips and to teach both local health care workers and American college student interns.

This Grants for Kids program has received enthusiastic support from the cardiology community and from industry. The AGA Corporation, maker of Amplatzer occlusion devices has given us a grant of equipment worth $30,000. The company is considering another equipment grant now. Last February, ten year old child prodigy pianist, Marc Yu, donated his time and talent to a two hour concert in Irvine, California that raised over $8000 for Grants for Kids.

Student Internship Program

In 2008, the China California Heart Watch started its student internship program for medical, pre-medical and public health students in the United States. This program allows American students, aspiring to a career in medicine or public health, to spend two to five weeks learning first hand the basics of Chinese health care and health problems, especially cardiovascular problems. This year, 2009, we are conducting six clerkships. The first clerkship in April was attended by five students, the second by one student, and the third by six students. We expect another 22 students to attend clerkships in August, September and December this year, and a similar attendance in 2010.

Students participate in clinical research, teaching of village doctors and clinical care of farmers. Some internships focus on screening for congenital heart disease among children under the age of 13 years. Some focus on studying hypertension among rural farmers near Li Jiang City in northern Yunnan Province. We are looking for a pediatric congenital expert to accompany us for two pediatric clerkships next year in May and June/July. We offer all expenses paid for such an expert, including round-trip airfare from Los Angeles to Kunming. Students who attend internships are asked to make tax deductible donations, and to pay for round-trip airfare and local expenses. Dr. Detrano and other faculty personally teach them cardiac epidemiology, physical diagnosis and public health.

What Can You Do?

We need the assistance of the pediatric cardiology community in the United States. If you wish to volunteer in Yunnan or in California, contact Dr. Detrano at robert@ChinaCal.org. We especially need pediatric cardiology experts to assist us in screening and diagnosing congenital heart disease in children. We need donations to support our programs. By donating equipment or money to the China California Heart Watch, a 501 c (3) public charity, you obtain a 100% tax deduction and the satisfaction of helping others much less fortunate than ourselves. Use our Paypal secure web page at www.ChinaCal.org.

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Society of Cardiovascular Computed Tomography Announces the Winners of The 3rd Annual Young Investigator’s Award

The Society of Cardiovascular Computed Tomography (SCCT), the leading international professional society dedicated to research, education and clinical excellence in cardiovascular computed tomography (CT), has named Dr. Chirapa Puntawangkoon and Dr. Thananya Boonyasirinant the winners of the 3rd Annual Young Investigator Award’s. Drs. Puntawangkoon and Boonyasirinant were announced as the winners at SCCT’s 2009 Annual Scientific Meeting in Orlando, FL.

"The Young Investigator Award cultivates pioneers, who will ultimately enhance the safety, comfort and effectiveness of diagnostic imaging," said Dr. Daniel S. Berman, president, SCCT. "In today’s economic environment, SCCT’s and Toshiba’s support of this award is all the more critical in finding tomorrow’s medical imaging leaders.”

Thananya Boonyasirinant, MD, from the Cleveland Clinic in Cleveland, Ohio won for her submission titled, “Elliptical Geometry of Left Ventricular Outflow Tract (LVOT) Results in Underestimation of LVOT Geometry of Left Ventricular Outflow Tract.”

Chirapa Puntawangkoon, MD, from the Wake Forest University School of Medicine in Winston-Salem, N.C. was named a winner for her submission titled, “Comprehensive Multidetector Computed Tomographic Assessment for Noninvasive Coronary Sinus Imaging and Myocardial Infarction Correlation in Ischemic versus Non-ischemic Cardiomyopathy: Implications for Cardiac Resynchronization Therapy.”

Five finalists presented their work at the SCCT Annual Scientific Meeting on July 16-19, 2009 in Orlando, Fl. An independent panel of five editorial advisors reviewed the submitted papers for scientific accuracy, as well as originality, creativity and writing style. Drs. Puntawangkoon and Boonyasirinant were awarded the Young Investigator Award, which includes a $2,500 cash prize, trophy, an opportunity for priority peer-reviewed publication in the JCC and recognition at a Toshiba-sponsored dinner.

"During my career in diagnostic imaging, I have continually been impressed by the way physicians can see new ways to use imaging equipment, especially CT, to improve protocols and patient care,” said Doug Ryan, Denior Director, CT Business Unit, Toshiba. "Toshiba is leading innovation in equipment development, and we believe the industry's young investigators are the ones who are going to continue to develop new applications that will make significant differences within healthcare.”

Sponsored by Toshiba America Medical Systems, Inc. through an unrestricted educational grant, the Young Investigator Awards are awarded to two residents or fellows in either radiology or cardiology for their patient care research in the categories of technical and clinical advancement of cardiovascular CT.

Study finds virtual doctors visits satisfactory for both patients and clinicians

BOSTON – Travelers book plane tickets online, bank customers can check their accounts at any computer, and busy families can grocery shop online. Someday, even doctor visits could be among the conveniences offered via the Internet. Researchers considering the feasibility and effectiveness of virtual doctors visits report that patients and physicians found that evaluations done through videoconferencing were similar to face-to-face visits on most measures, according a study published in the May issue of the Journal of Telemedicine and Telecare.

"There is growing evidence that the use of videoconferencing in the medical environment is useful for a variety of acute and chronic issues," says Ronald F. Dixon, MD, an internist at Massachusetts General Hospital and the study's senior author. "Videoconferencing between a provider and patients allows for the evaluation of many issues that may not require an office visit and can be achieved in a shorter time."

The healthcare delivery model in the United States is under scrutiny. Reduced access to providers, rapidly increasing costs and an aging population represent major challenges for the healthcare system. Telemedicine projects, including virtual visits (a patient-physician real-time encounters using videoconferencing technology) are being examined to evaluate their capacity to improve patient access to care and lower healthcare costs.

This study, the largest trial of virtual visits versus face-to-face visits done to date, randomized patients to one of two arms. In the first arm, the patients completed a visit (virtual or face-to-face) with a physician; they then completed a second visit via the other modality with another physician. In the second arm of the study, subjects had both visits face-to-face with two different physicians. All physicians and patients completed evaluation questionnaires after each visit.

Patients found virtual visits similar to face-to-face visits on most measures, including time spent with the physician, ease of interaction and personal aspects of the interaction. Physicians scored virtual visits similar to face-to-face visits on measures including history taking and medication dispensing. Though they were less satisfied on measures of clinical skill and overall satisfaction, those ratings were still in the good to excellent range.

The diagnostic agreement between physicians was 84 percent between face-to-face and virtual visits; it was 80 percent between the two face-to-face visits.

"The tradition of medicine is to lay hands on the patients, which has always been considered paramount to patient care in the minds of physicians," says Dixon. "However, these findings suggest that virtual visits could be a viable option in circumstances where patients need to be monitored routinely for chronic conditions like diabetes, hypertension, obesity or depression, and where self-management strategies are not working. Virtual visits may also be effective for triage of acute,
Among the benefits of virtual visits are reduce overhead costs for a physicians’ practices by reducing the space and resource requirements. For patients, a virtual visit can minimize time taken away from work and transportation costs. The study suggests that both patients and physicians could benefit if virtual visits were used as an alternative method of accessing primary care.

Comprehensive Cardiogenetic Testing for Families of Sudden Unexplained Death Victims can Save Lives

Vienna, Austria: Relatives of a young person who dies suddenly should always be referred for cardiological and genetic examination in order to identify if they too are at risk of sudden death, a scientist told the annual conference of the European Society of Human Genetics, 26 May 2009. Dr. Christian van der Werf, a research fellow at the Department of Cardiogenetics, Academic Medical Centre, Amsterdam, The Netherlands said that, although his team’s research showed that inherited heart disease was present in over 30% of the families of sudden unexplained death (SUD) victims, the majority of such relatives were currently not being referred for examination.

When an individual aged 1-50 years dies suddenly, autopsy reveals an inheritable heart disease in the majority of the victims. But in approximately 20% autopsy does not reveal the cause of death. "We thought that cardiological and genetic examination of surviving first degree relatives of these SUD patients might reveal an inherit heart disease", said Dr. van der Werf.

In the largest such study to date, the team looked at the outcome of first degree relative screening in 127 families who had suffered an SUD and where either there had been no autopsy (53.8%), or the autopsy did not reveal a cause of death. "At present we are conducting a study to stimulate general practitioners and other involved physicians to request autopsy and DNA-storage for SUD patients and to refer relatives to a cardiogenetics department after a case of sudden death at young age. We hope this will lead to identification of more families at risk of sudden cardiac death, in which preventive measures then can be taken" said Dr. van der Werf.

"Relatives of young sudden death victims are often referred to cardiologists for cardiological examination. We believe relatives should instead be referred to cardiogenetics departments, where clinical geneticists, cardiologists and psychosocial workers cooperate. These professionals specialise in inherited heart diseases and their clinical and psychosocial implications, and can provide a better quality of care. Additionally, cardiologists should receive more education in inherited heart diseases. By taking these measures we can save lives and avoid further distress for families who have already suffered enough," he said.

The researchers found inherited heart disease in 36, or 32% of the families. These results meant that doctors were able to treat affected relatives and try to prevent their succumbing to sudden cardiac death. "The scale of heart disease that we found in such families underlines the necessity for general practitioners to refer first degree relatives of SUD victims to a specialised cardiogenetics department as soon as possible", said Dr. van der Werf. "Currently we estimate that only 10% of SUD families are being examined for inherited heart conditions.

The study is the second report from the registry of families who attended the Amsterdam centre’s cardiogenetics department because of unexplained sudden death of a relative aged 1-50 years. The scientists intend to continue to report the yield of family screening in an increasing number of families.

Do you or your colleagues have interesting research results, observations, human interest stories, reports of meetings, etc. that you would like to share with the congenital cardiology community?

Submit your manuscript to: RichardK@CCT.bz

The final manuscript may be between 400-4,000 words, contain pictures, graphs, charts and tables.
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