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THE GLOBAL BURDEN OF CONGENITAL HEART DISEASE

By Balu Vaidyanathan, MD, DM and
R. Krishna Kumar, MD, DM, FACC

Introduction:

Congenital heart disease, in a definition proposed by Mitchell et al [1] is "a gross structural abnormality of the heart or intrathoracic great vessels that is actually or potentially of functional significance." As a group, these abnormalities constitute a significant proportion (up to 25% in some studies) of congenital malformations that present in neonatal life.[2] With improvements in the standards of human development and health care infrastructure, preventable causes of neonatal and infant mortality like perinatal asphyxia, infections and diarrheal diseases have declined, especially in developed countries.[3] Recent studies from developing countries, like India, have shown decline in the prevalence of rheumatic fever and rheumatic heart disease, at least in certain geographic locations.[4,5] Congenital malformations and, in particular, congenital heart diseases are likely to become important contributors to infant mortality in the near future. Hence, it is important to determine the exact prevalence and case burden of congenital heart disease so that appropriate changes in health policies can be recommended.

In this article, the following issues relating to congenital heart disease in the developing world are discussed:

- The magnitude of the problem.
- Types of CHD at birth and survival patterns.
- CHD as a contributor to infant mortality: Global perspectives and perspective from the developing world.
- Resources for CHD treatment in the developing world.

Prevalence of CHD – A Global Perspective:

Several studies of the prevalence of congenital heart disease have been reported from the developed countries.[6-18] This includes very large registries like the Baltimore-Washington Infant Study,[6] New England Regional Infant Cardiac program,[7] etc. The prevalence of CHD reported in most of the earlier studies was remarkably constant at about 4 to 5 per 1000 live births.[6-16] More recent studies, reported after 1985, have reported higher incidences of 12 to 14 per 1000 live births.[17,18] The results of these studies have shown that the prevalence of CHD is constant across various geographic and ethnic backgrounds except for very minor exceptions.[19]

Factors Affecting Prevalence of CHD – Reasons for Higher Prevalence Reported in Recent Studies

Various factors determine the reported frequency of CHD in a given population. Very large population based studies are likely to miss some forms of CHD, particularly the minor ones without clinical significance, or the very major ones, because the baby may die in the first few days of life before it comes to medical attention.[20] More intensive studies done in tertiary care hospitals will pick up all the CHD including the critical ones, but will be inadequate in assessing the prevalence of uncommon forms of CHD. Availability of liberal echocardiography facilities for neonatal screening results in detection of minor structural abnormalities like small muscular ventricular septal defects, accounting for a much higher prevalence of CHD in recent studies.[17,18] The increasing use of fetal echocardiography also leads in certain communities to therapeutic abortion for complex heart diseases and can substantially reduce the incidence of specific lesions or total incidence.[21-23]

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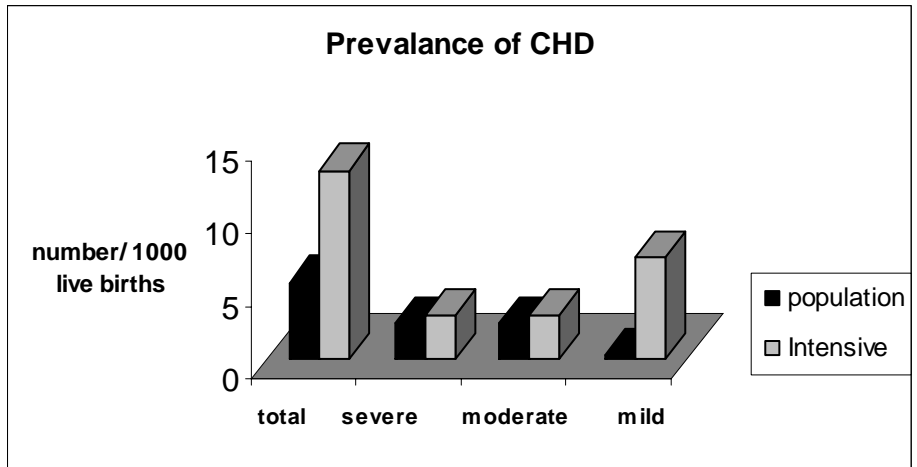


Figure 1. Prevalence of CHD at birth – comparison of Population-Based Surveys vs. Intensive Hospital Based Studies.

Prevalence and Fate of Different Types of CHD Detected at Birth:

Depending upon the severity, CHD presenting at birth can be categorized into 3 groups – severe, moderate and mild categories.[20] Severe CHD includes all cyanotic lesions as well as acyanotic lesions (Large VSD, Large PDA, Critical AS, Critical PS, Critical Coarctation, and AVSD), which require intervention early in life. Moderate CHD (Mild-Moderate AS or PS, Non-critical Coarctation, Large ASD) are those that require expert care, but less intensive compared to severe CHD. Mild CHD (Small VSD, PDA, ASD, Mild AS or PS) are those that are asymptomatic and often undergo spontaneous resolution. The prevalence of various types of CHD at birth is given in Table 1.

The prevalence of the severe and moderate types of CHDs has not changed significantly, being around 2.5 to 3 per 1000 live births respectively.[20] The reported higher prevalence of CHD in recent, more intensive studies compared to older population-based surveys, is due to higher pick-up of the minor forms of CHD due to increased use of routine echocar-

diography. These comparisons are shown in Figure 1.

CHD as a Contributor of Neonatal and Infant Mortality – Global Perspective

On a global perspective, about 7% of all neonatal deaths are attributable to major congenital malformations of which at least 25% are due to severe forms of CHD.[3] With decline in mortality due to preventable causes like sepsis, the contribution of major congenital malformations will be much higher (> 25%). Patients born with severe forms of CHD are at approximately 12 times higher risk of mortality in the first year of life, particularly if they are missed in the neonatal period.[24,25] Recent studies from developed countries have shown very poor sensitivity of routine neonatal examination for detection of CHD in the neonate with sensitivity of clinical examination less than 50%.[26] Wren et al reported 18% mortality in the first year for all CHDs that are diagnosed in infancy.[27]

Prevalence of CHD – The Situation in the Developing World

It is difficult to estimate the actual case burden of CHD in developing countries



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Atrial Septal Defect	0.564	0.372	1.059
Atrioventricular Septal Defect	0.34	0.24	0.396
Pulmonic Stenosis	0.532	0.35	0.835
Aortic Stenosis	0.256	0.16	0.39
Coarctation of Aorta	0.356	0.29	0.49
Tetralogy of Fallot	0.356	0.29	0.58
D Transposition of Great Arteries	0.3	0.23	0.39
Hypoplastic Right Heart	0.16	0.1	0.22
Tricuspid Atresia	0.09	0.02	0.1
Ebstein's anomaly	0.04	0.04	0.16
Pulmonary Atresia	0.08	0.07	0.15
Hypoplastic Left Heart Syndrome	0.22	0.15	0.28
Truncus Arteriosus	0.09	0.06	0.14
Double Outlet Right Ventricle	0.13	0.08	0.25
Single Ventricle	0.08	0.05	0.14
Total Anomalous Pulmonary Venous Connection	0.09	0.06	0.12
All Cyanotic	0.127	0.1	0.15
All CHD	7.7	6.0	10.5
Bicuspid Aortic Valve	9.2	5.3	13.8

Table 1. Prevalence of various types of CHD at birth (number per 1000 live births (Ref: Hoffman JIE et al. [20])

since systemic population based surveys for detection of CHD have not been conducted in these parts of the world. Khalil et al in a hospital based study from New Delhi, India reported a CHD prevalence of 3.9 per 1000 live births with PDA and VSD being the commonest lesions.[28] Population-based studies[29-32] done on school children reported a CHD prevalence of approximately 4 per 1000

(Table 2). Population based surveys in older children will not give a true picture of CHD prevalence because many children with severe forms of CHD would have undergone attrition in early life.

Extrapolations on the disease burden can be made to determine the approximate magnitude of the problem of CHD. For example, based on prevalence of

CHD estimates at birth from previous studies, it can be estimated that approximately 130,000 – 270,000 infants with CHD are added to the total pool every year in India.[33] Another 37,000 cases are diagnosed during childhood.[34] About 25% (around 50-80,000) of these patients will require intervention in infancy. Three to 10% of the infant mortality in India can be attributed directly to CHD.[33] Every year, about 121,000 children with CHD reach the age of 15 years. Of these, 425 extra cases of CHD per 100,000 live births every year will require adult follow-up.[34] At present, 24% of all cardiology admissions in a typical tertiary care cardiology center in India are constituted by CHD (third most common after RHD and CAD).[35]

Within the developing world and indeed within countries, considerable variations exist in the standards of living, literacy and availability of health care facilities. [36] To give a better indication of the state of development of a country, the United Nations Development Program has initiated two indices: the Human Development Index (HDI) and the Human Poverty Index (HPI).[37] HDI incorporates gross domestic product, literacy and life expectancy and is considered to be a sensitive indicator of a nation's development status. Certain states in India, like Kerala, have achieved very high standards of human development, so that the demographic statistics like Infant Mortality Rate have reached standards of selected developed countries.[38] In

Author	Hospital/Community	Total Patients Studied	Age Group	No. of CHD/1000 Population Studied
Khalil et al	Hospital	10,964	Live births	3.9
Gupta et al	Community	10,263	6-16 years	0.8
Chadha et al	Community	11,833	< 15 years	4.2
Thakur et al	Community	15,080	5-16 years	2.25

Table 2. Indian studies on prevalence of CHD.

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1	A well-defined birth cohort.
2	All deliveries should be medically supervised, ideally in a hospital.
3	All the hospitals in the area should be included.
5	A well-defined clinical protocol for screening CHD among newborns.
6	Complete referral of all suspected newborns with CHD to a pediatric cardiology facility.
7	Remaining newborns of the birth cohort should be followed up at specified intervals and referred whenever CHD is suspected.
8	A reliable echocardiogram for confirmation of CHD.
9	A post-mortem facility for all infants or newborns dying without a clearly specified cause.

Table 3. Estimation of prevalence of congenital heart disease among live born infants: Requirements of an ideal study.

these developed pockets of the country, deaths due to preventable causes like infections have declined considerably and congenital malformations have become significant contributors to infant and neonatal mortality. In the All India Institute of Medical Sciences database, congenital malformations accounted for up to 32.5% of neonatal mortality.[39]

Children's HeartLink, a voluntary organization from Minnesota, USA, recently compiled estimates of prevalence of CHD in the developing world. According to their review, there are nearly one million children with CHD in the developing world.[40]

Current Status of CHD Treatment in the Developing World

The current state of CHD management in India (Table 4) is similar to the typical situation found in the third world countries.[41] Logistic and infra-structural hurdles exist in every step. Pediatric cardiologists and cardiac surgeons in developing countries are often forced to resort to indigenous technology and utilization of re-sterilized hardware due to financial constraints.[42] The problem starts with the fact that pediatricians in most parts of the developing world are not familiar with the presentation of severe CHD at birth or early infancy. Hence, only a small fraction of the CHD at birth is detected. Most centers do not have facilities for

echocardiography, especially in rural areas. Therefore, diagnosis is not confirmed, even if it is suspected. This leads to significant delays in referral to a tertiary center, which has the capability to manage these sick patients.

The problem is compounded by the fact that very limited facilities exist for high quality pediatric cardiac care in the developing world. In many developing countries there are no pediatric cardiac centers. Apart from a few centers in North and South Africa, there are no centers for all of Africa. There are no centers performing infant cardiac surgery in Afghanistan, Bangladesh, Nepal and Bhutan. Facilities are only just being established in Pakistan, but neonatal surgery is yet to commence. Only selected countries in Southeast Asia have comprehensive pediatric cardiac surgery facilities. These include Singapore, Malaysia, Thailand and the Philippines. The large populations in Indonesia and Myanmar have little pediatric cardiac coverage.

Only 12 institutions support an infrastructure for neonatal and infant heart surgery in India, which has a population of over 1 billion. In most Indian centers, pediatric cardiology services just "piggy-back" onto a busy adult cardiology program. In many centers, adult cardiologists who are unfamiliar with managing critically ill neonates and infants, provide pediatric cardiology services. There are less than 25 trained

pediatric cardiologists in the country and only around 10 cardiac surgeons are exclusively practicing pediatric cardiac surgery. Dedicated pediatric intensive care is available only in 5 institutions. Most of the institutions involved in cardiac care have invested time, money and manpower for treatment of adults with coronary artery disease since it is lucrative and financially viable. The pharmaceutical industry also shows very little interest in development of pediatric cardiology infrastructure. At present, the pediatric cardiology services in the country are provided by few government institutions and selected private, semi-private and charitable institutions. These institutions can cater only to a very tiny fraction of the affected population.

What are the fallout of these shortcomings? For example, of the estimated 80,000 children born with critical CHD (fatal unless they receive attention in infancy) every year in India, only around 1,000-2,000 cases (1.6%-3.2%) are receiving treatment in Indian centers. Congenital heart disease remains either undiagnosed or untreated in the rest and a vast majority of these will undergo attrition in the first year of life itself. This will include several patients who can be potentially cured by treatment. The actual impact of CHD on infant mortality in India is likely to be higher since there is no data about what happens to the affected patients on follow-up.



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Requirements	Shortcomings in India	Reasons
Detection of CHD	Only a tiny fraction of CHD detected at birth and during infancy.	Limited access to health care. Adequate supervision by a pediatrician is available for only a small proportion of births and subsequent care. Limited ability of most pediatricians to detect heart disease because of limited exposure of pediatricians to pediatric cardiology during their postgraduate training.
Diagnosis	Inaccurate diagnosis in a sizable proportion.	Very limited specialized pediatric echocardiography expertise.
Referral	Delayed referral of many infants and children.	Limited knowledge of natural history of CHD resulting in delayed referral. Lack of awareness about the developments in the specialty. Lack of awareness about what is available within the country.
Treatment	Small proportion of referred infants and newborns actually receive definitive treatment for CHD.	Few institutions with good standards of care. Care too expensive for most people.
Prevention	Very few termination of pregnancies because of diagnosis of CHD. Very few families adequately counseled.	Very limited fetal echocardiography expertise. Very few centers with infrastructure for chromosomal analysis and genetic studies.
Health Care Planning	No national policy for CHD treatment.	No data on CHD prevalence at birth. Very little information on CHD prevalence later in life. No information on proportional mortality from CHD.

Table 4. Shortcomings in Pediatric Cardiac Services in the Developing World.

Why is CHD Not a Health Care Priority in the Developing World?

The reasons for this include:

- There is no data on the magnitude of CHD or its contribution to infant mortality and morbidity. It is assumed (without data) that the proportion of CHD deaths is small and hence, should not be a child health priority.
- Pediatric cardiology is not adequately addressed in pediatric

training programs. Most pediatricians have had very little exposure to pediatric cardiology and are, therefore, not comfortable with early diagnosis and referral of children with CHD.

- There is no data regarding the morbidity due to undiagnosed and untreated CHD in older children, adolescents and adults.
- Treatment for CHD requires ex-

pensive infrastructure and cannot be afforded by most government-sponsored institutions.

- There are no systems for providing health insurance for treatment of CHD in the developing world; in most cases the families themselves have to generate the entire resources required for treatment. Hence, treatment becomes prohibitively expensive for the people who actually need it most.

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In view of these reasons, there is no national policy for CHD in most developing countries. The governments have provided only very limited infrastructure for care of children afflicted with CHD, and these facilities are clearly not adequate to cater to the entire affected population. As human development indices improve, CHD management will become a priority due to decline in deaths from other common childhood illnesses. Hence, more infrastructure for CHD management and changes in policy and attitude are required, sooner than later.

Suggested Action Plan

Obtaining Accurate Information on CHD Prevalence and Mortality:

This can be accomplished by a survey of all live births in a well-defined population for prevalence in CHD. The birth cohort needs to be followed up for at least one year to pick up cases missed at birth. The requirements of an ideal study are given in Table 3. Such a study can be undertaken by a tertiary care pediatric cardiology program with the back up of a national body/government.

Educating Pediatricians and Primary Health Care Staff about CHD:

Pediatric cardiology training needs to be incorporated in all pediatrics post-graduate training program. Pediatricians should be educated regarding the clinical signs of CHD in the newborn. Since clinical evaluation for CHD in the newborn is very insensitive, routine use of pulse oximetry to screen for CHD in the newborn should be encouraged.[43] Perhaps, creation of a clinical screening system incorporating pulse oximetry also to screen for CHD in the newborn will enable easy and early recognition of CHD by pediatricians.

Improvement in Infrastructure for CHD Management:

This is the more challenging task. The first step is to train more pediatric cardiologists who are exclusively involved in managing children with heart disease. For example, a fellowship-training program in pediatric cardiology has been initiated by the National Board of Examinations in 5 different institutions in India to train pediatricians for this purpose. This program will result in the generation of around 10 trained pediatric cardiologists in the country every year, and is a step in the right direction. The more difficult steps are to increase the number of centers offering pediatric cardiac care, and to improve facilities and standards in the existing ones. These will require enormous investments in terms of money and personnel. Perhaps, there is a role for non-government and charitable organizations to provide logistic and financial supports in this endeavor.

Creation of a National Policy for CHD Management:

The absence of a national policy perhaps reflects the prevailing attitudes about CHD in that it is quite uncommon, it is mostly fatal and, therefore, not worth the effort and expense. Demonstration of significant improvement in the natural history in a sizable proportion of children with CHD through treatment is required to bring about changes in existing attitudes.[44] For this purpose, tertiary centers practicing pediatric cardiology services should generate data about the impact of CHD treatment on immediate as well as long term outcomes, particularly on issues like mortality, nutrition and long term neurodevelopment.

Role of Fetal Echocardiography:

Routine cardiac scanning as a part of the obstetric scan has become a common practice in all developed countries.[45] This has led to the early detection of many complex CHD in early or mid ges-

tation. This will give the family an option of therapeutic abortion in the event a complex, difficult-to-treat and poor prognosis CHD is detected. This option, perhaps, may be preferable in the setting of a developing country with limited resources than continuing with the pregnancy and opting for complex multi-staged surgical procedures after the birth of the baby. Hence, it is increasingly important to train obstetricians in the country about ante-natal cardiac scanning and to establish more fetal echocardiography referral set-ups for confirming the diagnosis. Ideally, all tertiary level pediatric cardiology centers should have a fetal echocardiography unit as well.

Conclusions

Pediatric cardiology is a developing specialty, especially in developing countries like India. The magnitude of the CHD problem is considerable and is largely unrecognized, understated and underestimated. For a child born with congenital heart disease in most parts of the world, there is really no facility available for treatment. It is perhaps appropriate to state that the vast majority of world's children born with critical congenital heart disease do not survive. The focus in most of the countries in the developing world is on more readily treatable pediatric health problems. However, with advances in care of children and decline in preventable mortality, CHD is likely to assume increasing importance in near future. Hence, there is an urgent need to improve pediatric cardiac care infrastructure enabling early diagnosis, prompt referral and subsequent care of children with significant CHD. The encouraging results of treatment for most forms of CHD from developed countries should prompt more clinicians to take up the challenge of managing these complex problems and also governments to establish a national policy for management of CHD.



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EXPERIENCES IN CENTRAL AMERICA AND THE PEDIATRIC
CARDIOLOGY PROGRAM IN NICARAGUA
OR WHY WE NEED TO TEACH FISHING

By Elaine M. Urbina, MD

The population of Nicaragua in 2003 was nearly 5.5 million people.[1] As in many developing nations, their 'dependency ratio' is high with 41% of the population under the age of 15.2 The average income is \$740 per year and the gross domestic product is only 4.1 billion compared to the nearly 11 trillion produced in the US.[1] Unfortunately, only \$60 is spent annually per person for health care as compared to \$5274 in the US.[2] Recent data from the World Health Organization demonstrate that the neonatal mortality rate is triple that seen in our country.[2] However, the highest mortality rate is actually for atherosclerotic cardiovascular disease, not infectious causes such as pneumonia and diarrhea. [2] This pattern is, unfortunately, becoming more common in countries undergoing 'nutritional transition' from fresh food and manual labor to fast food and mass transportation.[3] Since congenital heart disease has a prevalence of less than 1% per year per live birth, the Ministry of Health allocates few resources to the three pediatric cardiologists that work in this country. Therefore, they are forced to rely on the charity of medical volunteers from around the world.

My first experiences with medical missionary work actually took place in Honduras during my fellowship in Pediatric Cardiology. I worked in a small clinic in a remote mountainous area two hours from San Pedro Sula. The only doctor in Concepción del Norte was the 'intern' sent by the government for her one year

of service. We were impressed as we watched her suture a wound, neatly cutting close to the knots, conserving every inch of the only supply of cat gut she had for the entire year. It is hard to imagine many of us surviving a year as the only physician in town with no supervision, limited supplies and only a telegraph as your contact with the rest of the world. In this clinic with no running water and intermittent electricity, no specialized care could be delivered. We did offer transportation to the bigger city hospital, but our patients knew they would have to wait for care they could not afford. Few took us up on the offer. As a primary care mission, however, we were well aware of the conditions and were able to offer consultations and a full pharmacy free of charge. A prescription without the means to purchase it is just another piece of scrap paper. The most memorable gift of thanks that I received was a bag of star fruit that one of my patients proudly presented to me, exclaiming that they were very fresh as he had just descended from the tree where he had picked them. What we learned from this experience was how resilient people can be even in difficult situations. As Americans, we had more trouble adjusting to life in a house without electricity or hot water than the women who came every morning at 5 am to cook us fresh tortillas in an adobe oven with a wood burning stove. Despite the roosters that crowed at 4 am, the mosquitoes and the heat, I longed to return.

That chance came when Violetta Chamorro defeated Daniel Ortega in the first democratic elections conducted in

Nicaragua since the 1930s (although these were during the occupation of Nicaragua by the U.S. Marines). After years of dictatorship under the Somozas, and then the lost idealism of Sandinistas as that regime crumbled into corruption, the country finally had a chance for a new start. My first trip there with a group from the International Hospital for Children (www.theihc.org) based in New Orleans was a fact-finding mission. We found the main children's hospital in Managua in disarray and disrepair. The few surgeries we performed were simple and used outdated equipment. A visit to the medical school in Leon did nothing to change my view that the children of Nicaragua had suffered under the Sandinistas. In Granada, my husband's home town, the X-ray equipment from Soviet Russia sat unshielded in a hallway and the operating room had leaks in the roof. At first I was sad and overwhelmed but then I saw this as an opportunity to make a difference and I embraced it. The dedication of the doctors there was inspiring. With IHC we were able to send multiple 40 foot containers of equipment including OR lights, suction machines, anesthesia machines and laboratory equipment. I sent the first ambulance that Granada had since the 1960s via ship from New Orleans. It still functions today.

With the victory of Arnaldo Alemán, in the mid-1990's confidence was building in the country's ability to sustain the democratic process and foreign investment increased. The stores that had few products on their shelves suddenly were fully stocked. Big corporations like ESSO (and unfortunately MacDonald's) came



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on the scene. Sadly, medical care did not improve. The upper classes traveled to Miami or Houston for their care and felt little impetus to invest in the medical system in Nicaragua. Again, I was given the opportunity to perform medical charity work, but this time as the director. Once again, rural primary care was our objective. With little infrastructure in place in the Ministry of Health, we were on our own in identifying clinic locations and interfacing with the local physicians and community leaders who assisted in triage. I also found myself performing many non-medical tasks, such as arranging housing in farm houses, purchasing food for all of the meals, and scrounging for transportation. My favorite vehicles were a Russian IFA artillery truck and an ox-cart. I also managed the payroll of native cooks, cleaners, drivers, guards and other helpers. This was in addition to the headaches of getting the \$25,000 of medicines shipped from the U.S. and out of customs in Nicaragua with the taxes exonerated, a task that took from 3 to 5 days including trips to the Ministry of Health, Taxes, Customs and Agriculture (for the veterinary supplies). Although we pre-packed medications (with labels translated in Spanish and with pictures for non-literate persons), in an effort to support the local economy, we also purchased additional drugs from pharmaceutical firms in Managua. Although slow improvement in medical care has been seen, from the early 1990s to now, I have dealt with over half-a-dozen ministers of health. Obviously, the political process complicates the delivery of health care to the poor of Nicaragua. Despite the headaches and heartaches, the rewards we received were incalculable. I was given the gift of learning about the charity work of my husband's family back in the 1960s from the communities that benefited. I also had the great fortune (or misfortune?) to be working in a remote area during Hur-

ricane Mitch. Despite the devastation, the outpouring of support from both the local government and the US was inspiring.

Unfortunately, in recent years, not only has the former president been accused of corruption, but one minister of health (Maria Ángeles Arguello) fled the country under a cloud of suspicion. So where does this leave Pediatric Cardiology in Nicaragua?...Harried, but hopeful. Our colleagues were well trained in Mexico and Spain. They push on despite the outdated equipment and limited resources. When I first started work in Nicaragua, there was no catheterization laboratory at all! Today there is a single plane lab that has not received the necessary maintenance and is in danger of falling into disrepair. The echocardiogram machine with a phased array transducer (they only had a 3 mHz mechanical array) that I sent to the children's hospital years ago, has been damaged by dust and heat.

But what can a concerned physician do to improve conditions? I once brought a child to the US for surgery. However, I believe that the \$25,000 spent on one child could be better utilized equipping and training physicians in their own country. Therefore, I have continued to work with the IHC in New Orleans and have formed connections with the Lions and Rotary clubs in Cincinnati, who do similar work. REMEDY (recovered medical equipment for the developing world www.remedyinc.org/) is another organization that can give any individual doctor the framework and instructions needed to start charity work. Many countries do not have gas sterilizers. Collecting clean but unused plastic items like ET tubes, Foley and cardiac catheters and re-sterilizing them is a great way to support our colleagues around the world. Your hospital will receive a tax benefit from donations to a certified charitable organization. My

current project includes replacement of the echo machine in Managua (*I have made some progress...wish me luck*).

Technology transfer also includes teaching. Send equipment then invite the physicians to visit you or better yet, go to the receiving country yourself. Give lectures, teach young doctors, give them hope. Most of all, be one of the 'thousand points of light' spreading your vision as far as the eye can see. Take a young American physician with you on your travels. Inspire them to teach a man to fish, not just give them one. You have no idea what gifts you will receive in return.

¡Dios te bendigas! (God blesses you!)

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~CCT~



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REPORT OF THE 1ST ANNUAL TORONTO SYMPOSIUM

By Andrew N. Redington, MD

The 1st Annual Toronto Symposium "Contemporary Questions in Congenital Heart Disease," was held from May 29 through May 31 in the Four Seasons Hotel, Toronto. The meeting followed immediately after the Adult Congenital Heart Symposium, held in the same venue. I am sure many of us would agree that there may already be too many meetings within our field. For that reason, the Toronto group felt that our meeting should be a little different. As a result, we chose to frame every lecture in the form of a question. It was interesting to see how the various speakers handled this slightly different approach. It certainly led to a more focused presentation, dealing with

many of the issues of clinical paediatric cardiac practice that we face on a daily basis. Each lecturer was given a simple mandate: "answer the question!"

Despite our concerns regarding potential "meeting fatigue" the symposium was extremely well supported with registrations selling out prior to the meeting. Next year we will increase the size of the venue accordingly. We also chose to partner with just 3 major sponsors (Phillips, Siemens, and GE-Vingmed) in order to maximize their exposure to the delegates. Hopefully the companies were happy, and it was their generous support that made the meeting possible.

The only exceptions to the 'answer the question' rule were our state-of-the-art lectures. The meeting was kicked off

with a wonderful presentation from Dr. Jane Newburger, "Kawasaki's Disease:

"...the Toronto group felt that our meeting should be a little different. As a result, we chose to frame every lecture in the form of a question.... Each lecturer was given a simple mandate: 'answer the question!'"

from description to prevention." Other highlights from the first morning, which was uniformly well received and of high quality, were Dr. Rob Gow's discussion of the topic 'How much tachycardia justifies ablation?', Professor John Deanfield's outstanding lecture, 'Hyperlipidemia: Who should be treated and with what?' and a lecture from our newly appointed head of Toronto's Paediatric Heart Failure Service, Dr. Paul Kantor, "Drug treatment: Should we treat children according to data from adult heart failure trials?" The latter two lectures emphasized two new areas of responsibility and subspecialization for pediatric cardiologists, and reminded us that we don't just deal with structural heart disease.

The afternoon session included a breakout meeting to discuss the impact of genetics and developmental biology on our understanding of congenital heart malformations. Bob Anderson discussed, "Can embryology guide our understanding of congenital malforma-



Some of the attendees at the 1st Annual Toronto Symposium at the Four Seasons Hotel.

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tions?" It was interesting to hear him chronicle his conversion from sceptic (albeit justified on the basis of earlier presumptive embryology) to convert, based on the elegant developmental biology science that now underpins investigations of the developing embryo. Some of this work has been performed by one of our rising stars, Benoit Bruneau, who discussed, "Genes, environment or both ... What factors regulate cardiac development?" And, one of our surgeons, John Coles, gave an excellent review of our increasing knowledge of genomic responses as analyzed by gene expression studies. While microarray techniques are necessarily hypothesis generating, it does not seem too far-fetched to suggest that we will soon be gene-profiling our patients prior to surgery, and perhaps modifying their treatment accordingly. At the same time, an imaging session gave us state-of-the-art expositions regarding whether all echocardiographers should now routinely be performing three dimensional echocardiography (Dr. Jeff Smallhorn), how we decide who should have a CT scan rather than an MRI scan (Dr. Shi Joon Yoo), and a typically space age presentation from David Sahn regarding, "What extra do we learn from tissue Doppler echocardiography?"

The end of the first day was a sad affair. Some three weeks previously, Dr. Bob Freedom had passed away close to his home in Nova Scotia. Our first day reception, therefore, became a tribute to him, organized by Dr. Lee Benson. Four hundred and fifty friends, colleagues, and family members were present to hear reminiscences from Lee, Jane Somerville, and Bob Anderson, hospital colleagues, Bob's stepson, and ex-fellows. The reminiscences were at times amusing,

often emotional, but always recognizing Bob's Freedom immense contributions to our field. This was a perfect way of celebrating Bob's life. I am sure he would have appreciated such an event being held at a symposium in Toronto, at the end of a wonderfully academic day, and followed by copious amounts of wine and food!

The following two days built upon the success of the first. Gil Wernovsky gave our second state of the art lecture, 'Beyond Mortality: Central Nervous System Dysfunction in School Age Children with CHD – How can we improve outcomes?', followed later by his contribution to a debate with Gus Mavroudis regarding the presence of parents at the bedside during cardiopulmonary resuscitation. Unfortunately, Dr. Mavroudis agreed with Gil that parents should be at the bedside....so an easy win for Gil!! Pedro Del Nido and John Finley gave a more spirited debate regarding the optimal size of cardiac surgical programs, the proposal being that those with less than 200 pumps per year should be closed. This is, of course, an old chestnut, but it was no less compelling for that. All of our debaters performed with great aplomb, making it a very popular session. Less controversial was Dr. Mavroudis' lecture regarding his group's amazing results with Fontan

"There are indeed many pediatric cardiac meetings. Nonetheless, the first Toronto symposium worked on all levels."



Center of Toronto with the CN Tower. Photograph courtesy of João Estevão A. de Freitas.

conversion, ("Who should have a Fontan conversion and when?"), and another visiting lecturer, Dr. Anthony Chang, answered the question, "How close are we to permanent implantable mechanical support in children?" The short answer being, close, but not close enough. The day ended with Pedro Del Nido giving an outstanding surgical state-of-the-art lecture, in which he described extremely novel methods of modifying ventricular growth in the hypoplastic left heart syndrome.

The final day was kicked off by the Disenhouse lecture. Bob Anderson, who was with us in Toronto for a month as visiting professor, gave an outstanding lecture that proved to be a salutary lesson to us all: Learning from Bristol, how we should organize and monitor paediatric cardiac services," he chronicled one of the more unfortunate episodes in the history of our specialty. On the more positive side, however, Bob Anderson described how this scandal, which led to a media frenzy, led to the development of a nationwide review system, which while imperfect, changed the way in which we think about surgical results and governance.

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No meeting would be complete without a discussion of new catheter intervention techniques, and our session concentrated on new paradigms in intervention, particularly forms of hybrid procedures. "Should we be building combined OR/Catheter laboratories?" "Who should have their VSD closed with a device?" "When should we perform transcatheter pulmonary valve replacement?" "Fontan completion in the cath lab: Who, how, when?", were all discussed in the final session. Increasingly the edges between surgeon and interventionalist are being blurred, and already many procedures are being performed with them standing side by side (pulmonary artery banding/ductal stenting for HLHS, periventricular closure of VSD, etc). Not only was there a resounding "yes," to the question of need for combined OR/cath labs, but a qualified "yes" to the question from the floor as to whether cardiac surgical trainees should learn interventional catheter techniques, and interventional fellows should learn how to put a child on bypass!

Modesty forbids an over indulgence in terms of the performance of our guest faculty and 'home' contributors (including our outstanding lecturers from other Canadian units in Ottawa – Rob Gow, Edmonton – Patti Massicotte, and Halifax – John Finley), but the scores from the evaluations from the course were truly outstanding. "Contemporary questions" will remain a theme for the Toronto symposium in the future, which will be held on an annual basis. Next year (June 10th-13th, 2006), it will incorporate the proefschrift for Dr. Bill Williams, but the title of the meeting will be, "Contemporary Questions in Congenital Heart Disease: The Right Heart" (www.sickkids.ca/cardiology).

This will be a follow-on meeting from the very successful "Right Heart" meeting organized by myself, Bob Anderson and others in London in the mid-nineties. Just as with this year's symposium, a DVD will be provided to all delegates, providing live video of all the lectures with the synchronised PowerPoint presentations. Furthermore, it is envisioned that next year's symposium will lead to a second edition of the textbook, "The Right Heart in Congenital Heart Disease (Greenwich Medical Media 1998)", to be edited by Glen Van Arsdell, Bob Anderson and me.

There are indeed many pediatric cardiac meetings. Nonetheless, the first Toronto symposium worked on all levels. It was financially viable (just!), academically rewarding, and the more social aspects allowed for establishing new friendships, collaborations, and exchange of ideas. We are looking forward to next year with great anticipation.

~CCT~



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NEW ORGANIZATION

The Inter-American Society of Cardiology is organizing a Women in Cardiology Network

Some of the objectives to be accomplished with this Network are:

- To establish initiatives that will make the field of cardiology more appealing to other female physicians
- To enhance the professional development of female cardiologists
- To address issues that are of concern to members
- To improve networking among members

The charter members of the Network met during the First Latin-American Symposium of Cardiovascular Diseases in Women, which took place at the Condado Plaza Hotel in San Juan, Puerto Rico from April 29th to May 1st, 2005. This meeting was led by Drs. Geida Segarra from the Association of Women Cardiologists of Puerto Rico and Ruth L. Collins-Nakai current president of the Inter-American Society of Cardiology (www.soinca.org/index.htm).

The next activity will be a luncheon panel, during the XX Inter-American Congress of Cardiology from November 19th - 23rd, 2005, in Cancun, Mexico.

For more information, contact Dr. Geida Segarra: office (787) 721-3200, geidasegarra@msn.com or the Association of Women Cardiologists of Puerto Rico; tel: (787) 850-1720; fax (787) 852-7275.



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