



## Forming a Consortium to Promote Pediatric Cardiac Care in a Developing Country

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The Federation of Pediatric Organizations has identified pediatric global health care as 1 of its 5 priority areas for the next 5 years.<sup>1</sup> Consistent with this goal, there has been a growing effort to provide heart surgery for children in areas of the world where it has not yet been available. This usually takes the form of a medical group traveling to an underserved area and operating on small numbers of children. We describe a collaborative effort among 4 charitable organizations to provide these requisite surgical and medical services, train the local medical team to operate independently year round, and offer a global training experience to fellows and faculty based in the United States.

The Variety Children's Lifeline (VCL) was founded in 1982 under the executive directorship of Salah M. Hassanein, with the mission of sending teams to developing countries to perform heart surgery on impoverished children with no access to such care otherwise. Several other organizations provide care for children with congenital heart disease (CHD) in areas of need throughout the world. For example, the Association of Children with Heart Disease in the World sponsored 76 surgical missions in 12 developing countries and performed 412 operations over a 10-year period.<sup>2</sup> They stressed the importance of a concomitant educational program with a partnering institution that is committed to treating children with CHD over the long term. Likewise, the Save a Child's Heart Foundation was established to provide heart care to indigent children and is funded by both government subsidies and private donors.<sup>3</sup> This program, based in Israel, has sent teams to 5 countries in Africa and also to China. Their model is a regional center to which children can be sent that also serves as a training center for medical personnel from the host country.

The difficulties encountered when attempting to establish such cardiac care for children in the developing world have several common themes. First is the high cost of heart surgery and catheterization, with or without interventions. Most of these countries struggle to fulfill even the basic needs of large segments of the population who live in poverty. High incidences of infec-

tious diseases and malnutrition eat up meager health budgets, leaving few resources available for treating CHD.<sup>4</sup> But CHD is the most common birth defect, with an incidence of 0.8% worldwide. In countries with no access to cardiac surgery, large numbers of children with correctible lesions do not survive, and many who do survive have severe limitations.

In 2003, VCL began to support a team from Children's Hospital of Michigan to operate in Santo Domingo, Dominican Republic. The Department of Pediatrics at Children's Hospital of Michigan has embraced global health care for children and sends residents to China and Africa for educational and research purposes. This project has allowed the hospital to extend this global experience to fellows in both cardiology and intensive care medicine. In addition to actively honing their procedural skills, fellows evaluate older children with unrepaired heart defects who exhibit signs and symptoms not usually seen in the United States, where corrective surgery is performed at a much younger age.

Charitable organizations such as VCL reach out to potential donors for contributions to help further their work; thus, it is unusual for them to join forces with other groups that may be soliciting funds from the same donor pool. Despite this obstacle, however, in 2005, 4 such organizations—VCL, International Hospital for Children, Caribbean Heart Menders, and Heart Care International—convened in Santo Domingo to explore how collaboration could foster the common goal of best providing heart care to Dominican children. The local team was supported by a foundation called Health Care Dominicana, run by an adult cardiologist, Pedro Urena, MD, and a cardiothoracic surgeon, Freddie Madera, MD.

At the initial meeting, several areas of need were identified based on each team's experience in the Dominican Republic and elsewhere. These included a major initiative to train nurses in the postoperative care of children undergoing surgery for CHD, along with the recruitment of intensive care unit (ICU) doctors committed to the program. Consortium nurses with extensive teaching experience volunteered to lead the nurse training and put together a training manual in both Spanish and English. These efforts were led by Nancy Cole, RN, Assistant Dean of Nursing at Adelphi University, and supported by Gift of Life.

A full-time pediatric cardiologist from Santo Domingo, and a director of the ICU was eventually added. Likewise, an anesthesiologist, a pump perfusionist, and a second surgeon were recruited for the program. This surgeon was a Dominican general pediatric surgeon who was sponsored by the consortium to

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train in cardiac surgery for 2 1/2 years in Guatemala under the tutelage of Aldo Castaneda, MD. Several nurses also spent time in Guatemala, receiving specialized training in postoperative care.

Each group in the consortium committed to returning on a rotating schedule, so that every few months a team would be present to provide consistent training. Funding resources were pooled and matching grants were obtained, allowing the charitable organizations to cover the costs of medical supplies, housing of the teams, and other expenses. Fund-raising efforts in the Dominican Republic were intensified to ensure that indigent patients could continue to receive treatment free of charge. This was boosted by contributions from prominent Dominican-born Major League Baseball players wishing to give back to their country of origin.

Following each mission, a detailed report was provided to the entire group addressing areas of concern and proposing suggestions. An electronic system for distributing echocardiograms, purchased with donations, made the preparation for each trip more efficient. Catheterization data and images were forwarded when available. Early on, patients with surgically correctable defects who could be reasonably expected to recover completely during the 7- to 10-day mission were given priority; thus, children larger than 10 kg with septal defects, tetralogy of Fallot, and coarctation of the aorta were the prime candidates. Priority was given to the most symptomatic children. As the local team became more proficient, it was able to perform many of the operations independent of our teams' visits, and thus more-complicated surgeries were added to the mission trips. Catheterization-based interventions also were performed when devices were available through donations from the medical supply industry.

When a partnership is made, it is usually in an adult facility that recognizes the need to support care for the children in their country. It takes time and commitment from both the local medical community and the charitable groups to train the adult surgeons, anesthesiologists, ICU doctors, and allied professionals in the intricacies of caring for children with CHD. This is in the face of frequent loss of staff members, who often are paid very little and may leave for better opportunities, especially as their skills advance with the training provided.<sup>5</sup>

At the start of this program, only the US surgeons performed the operations, with the assistance of Madera. Since 2005, the year in which Madera and his team progressed to operating independently, this team has performed 143 operations with the same low mortality rate (< 2%) achieved by the US surgeons both in the Dominican Republic and at home (Table). The local medical center has supported this program such that space is reserved for 2 children to undergo surgery each week throughout the year.

A crucial person responsible for this success is the head coordinator of Health Care Dominicana. She volunteers her time and leads fundraising efforts in the Dominican Republic, including a gala at the National Theatre where the symphony orchestra donated their concert's proceedings. In addition, she coordinates all aspects of patient care, from organizing the patient's blood supply (obtained from family members) for surgery to arranging for follow-up care. The program would

**Table. Comparison of surgeries done by the consortium vs. those by Health Care Dominicana (HCD)**

Year	Number of consortium operations	Number of independent HCD operations
2003	126	0
2004	105	0
2005	80	3
2006	98	26
2007	77	48
2008	34	66

not function without her tireless efforts day in and day out. When starting a heart care program, it is essential to find the right person or people to play this central role with adequate resources to support the position.

The consortium continues to meet yearly, with frequent electronic communications throughout the year, and remains committed to supporting and growing the program in Santo Domingo. Many children have returned for completion of staged procedures or redilation of stented vessels. The local cardiologists have done a great job in following up with patients after discharge whenever possible. As in all developing countries, in the Dominican Republic, monitoring and follow-up of families from distant or rural areas often is challenging. A recent celebration reunited many patients with the care teams that performed their operations.

This experience demonstrates that quality treatment of significant numbers of children with CHD can be achieved in underserved areas abroad. This project is enhanced by the collaboration of multiple charitable organizations working together toward common goals in partnership with motivated and skilled local cardiology teams. Its success is made possible by the time and effort donated by the volunteers and the support from the medical centers. The benefits of training our fellows in these global health concerns are both the tangible experiences that they have and the hope that they will continue with these volunteer efforts after graduation.

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