

Save a Child's Heart: We Can and We Should

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Background. Congenital heart disease (CHD) causes the death of thousands of children in developing countries. At the Wolfson Medical Center (WMC), a prototype program has been developed to address this issue.

Methods. Since 1996, indigent children have been referred to the program, with the cooperation of partners in developing countries. The project's aims are to (a) train their medical personnel at WMC, (b) travel to participating countries to teach, evaluate patients, operate, and promote the development of local centers, and (c) treat children with CHD, at WMC, who lack a local option for care either due to prohibitive costs or unavailability. The project's personnel are state employees who volunteer to treat additional patients within the framework of their salaries, and community volunteers.

Results. The program has seven partner sites in six

countries, including two provinces in China (Hebei and Gansu), Ethiopia, Moldova, Nigeria, the Palestinian Authority, and Tanzania. Five physicians and 10 nurses have been trained from five participating countries. Over the past 4 years, 11 teaching trips have been made abroad, and operations have been performed at four partner sites. A total of 386 patients have been operated on—360 at WMC and 26 at other sites. There have been 17 (4.3%) acute deaths. Follow-up is 92% complete with 3 late deaths reported.

Conclusions. Hospital-based regional centers can be created to promote the care of children with CHD in developing countries. Good results and follow-up care can be provided with appropriate planning.

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Congenital heart disease (CHD) occurs in newborns at an incidence of 8 per 1,000 live births [1]. Symptomatic CHD is found in 2 to 3 per 1,000 live births [2]. The incidence of pediatric cardiac disease due to infectious diseases, such as rheumatic fever and Chaga's disease, is even greater [3, 4]. Many advances in this field have occurred over the past 20 years. Many resources have been expended in North America and in Western Europe to create the sophisticated infrastructure necessary to treat these problems [5].

Over the last decade, the advent of single-stage early complete repair, prenatal diagnosis, improved prenatal care, and the advancement of invasive pediatric cardiol-

ogy, and parts of Asia, the incidence of CHD is the same; however, the infrastructure is inadequate to treat these children [3, 5, 8–10]. In these areas, we estimate hundreds of thousands of children are born annually with surgically treatable CHD. Millions are living with untreated, correctable CHD [5, 11]. Most of these children will die by the age of 20 from the effects of prolonged cyanosis, pulmonary hypertension, and increased left ventricular pressure [12–14].

Modern medicine has the resources and potential to help many of these children. Today, hundreds of these children are assisted as isolated pro bono cases in many centers around the world [5, 11]. In addition, surgical teams travel to regional sites where they treat children locally [5, 11]. However, to date, there has been no organized, sustained effort to improve treatment capabilities in local communities for these patients or provide direct care for large numbers of these children.

At the Wolfson Medical Center (WMC), the pediatric cardiac division in cooperation with Save a Child's Heart Foundation has dedicated most of its resources to develop a prototype center that would address these problems. The primary goal of this project is to improve care for children with CHD and increase the number of children receiving adequate care within the region.

We report on the first 4 years of this experience.

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ogy have resulted in a significant decrease in the number of children requiring surgical treatment for CHD in the developed world, as well as a decrease in the number of procedures required per child [6, 7]. This trend has resulted in consolidation of surgery programs, and the elimination of programs in Western Europe and in North America.

In other parts of the world, such as Africa, the Middle

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Material and Methods

Hospital and Staff

The Save a Child's Heart project was established at the WMC to promote cardiac care for indigent children with heart disease. The WMC is a 700-bed, tertiary care, government hospital in Israel whose workers are state employees. The staff of Save a Child's Heart is composed of hospital employees who volunteer to treat additional patients within the framework of their monthly salaries, as well as volunteers from the community. The primary professional medical staff includes pediatric specialists in cardiac surgery, cardiology, intensive care medicine, anesthesiology, and general pediatrics. Consultation is available when needed in all pediatric subspecialties. The nursing and paraprofessional staff includes intensive care nurses, pediatric surgery nurses, operating room nurses, respiratory therapists, and physical therapists. Overall, the Save a Child's Heart staff includes 72 personnel from the hospital and 35 in the community.

The facilities within the hospital include two dedicated cardiac operating rooms, a 7-bed pediatric intensive care unit (ICU), a 4-bed pediatric intermediate unit, and a 20-bed pediatric surgery ward. The Save a Child's Heart project shares these facilities with the local patient population.

Program Function

Save a Child's Heart functions in conjunction with a partner in each of the participating countries. The partners include either nongovernment organizations or university departments. The requirements to establish a partnership include:

1. a qualified cardiologist or pediatrician with an interest in cardiology,
2. access to an echocardiography machine,
3. capability to establish a clinic that can identify and focus on children with CHD,
4. capability to follow-up postoperative children and dispense medicine, and
5. laboratory capability to test for human immunodeficiency virus, hepatitis, and monitor coumadin.

Once a partner has been established, the personnel of Save a Child's Heart will interact with the partner in the following manner:

First, a team travels to participating sites on an annual basis. At a minimum, this trip includes a series of lectures, a preoperative clinic to evaluate children with CHD, and a follow-up clinic for postoperative children. In addition, requirements for training and equipment needed to expand and improve local sites are agreed on. When possible, the Save a Child's Heart team will operate in conjunction with local personnel at the partner site.

Training is provided for doctors, nurses, and paraprofessionals at WMC in Israel. The training periods last between 3 and 15 months, and are aimed at providing training to personnel who will expand and improve the partner sites. Once the personnel are properly trained,

Save a Child's Heart assists the local site in procuring equipment needed to expand their services.

For children who cannot receive treatment in their local communities, Save a Child's Heart offers treatment at WMC. The children to receive treatment at WMC are screened at the preoperative clinics held at the partner sites. The priority and number of children to come for each clinic are determined in cooperation with Save a Child's Heart and partner site personnel. Once children have been selected for treatment at WMC, they travel to Israel in groups of 3 to 6 children. Each partner site provides personnel who stay in Israel and care for the children at the Save a Child's Heart facility close to the hospital. These personnel are either social workers or nurses who speak English, and have a long-standing relationship with the partner sites. Once a child's hospital course is complete, he or she is discharged to the Save a Child's Heart facility where he or she stays an additional 2 weeks before returning home. In the hospital, care is provided for the children by Save a Child's Heart personnel and trainees from participating countries.

Finances and Administration

The financial and medical burden for treating children is shared between Save a Child's Heart and its partners. Partner sites are responsible medically and financially for establishing a clinic where the children are evaluated and screened. The partner team is responsible for screening candidates for human immunodeficiency virus, hepatitis, and endemic diseases such as tuberculosis and malaria, where appropriate. Partner groups are also responsible for the round-trip transport of the patients, and all follow-up care, procurement of medicine, and distribution of donated medication. The patients' families contribute whatever they can toward the cost of operation. The remainder is financed through the Save a Child's Heart foundation.

Save a Child's Heart is supported by the Health and Foreign Ministries of the State of Israel. As such, all travel and other documents for patients and trainees coming to Israel and Save a Child's Heart personnel traveling to partner sites are expedited. A significant part of the training of partner site personnel is accomplished through the Israeli government Foreign Aid programs. The remainder are supported by training grants from private companies in the medical field.

The Health Ministry has allowed WMC to treat these children at a reduced cost, which in turn allows Save a Child's Heart to use its resources to help as many children as possible. The funds to pay for the children's hospitalization are raised from foundations, individuals, and medical-related companies.

Results

Save a Child's Heart currently has seven partner sites in six countries (Table 1). Four other sites are being considered. Five doctors and 10 nurses have been trained from four of the participating countries (Table 2). Training will include all partner sites by 2001. Since its establishment,

Table 1. Participating Partners with Save a Child's Heart

Country	Partnership Time (years)
China	2
Ethiopia	5
Moldova	4
Nigeria	2
Palestinian Authority	4
Tanzania	1

Save a Child's Heart has made 11 trips abroad (Table 3). In four of these sites operations have been performed (Hebei and Gansu Provinces in China, Moldova, and Ethiopia). Three hundred eighty-six patients have been treated by the program. The annual case load and age distribution of the children operated on through the project are shown in Table 4; 360 were operated on at WMC and 26 at partner sites. The diagnoses of the children treated are shown in Table 5. Three hundred fifty-one children underwent primary repair, and 35 underwent palliation. Follow-up is available for 92% of our children through our yearly clinics and partner-site personnel.

There were 17 (4.3%) perioperative deaths, which we defined as occurring within 30 days or before returning to country of origin (Table 6). There have been 3 late deaths. One was a 14-year-old boy from Ethiopia following mitral valve replacement. Due to inclement weather, he could not get to the hospital to receive coumadin. He died suddenly, most probably from thrombotic complications. Two children died in Gaza. One, a 17-month-old infant, died suddenly at home 6 weeks after ventricular septal defect repair. She had a postoperative pericardial effusion that had been treated and resolved before discharge. The second was a 14-month-old girl with trisomy 21 after closure of an atrial septal defect and large patent ductus arteriosus. She died from septic complications 8 months after her operation. She had been evaluated in our clinic 1 week before her death, at which time she was clinically thriving. Echocardiogram showed good repair and moderate pulmonary hypertension.

Six children have died while waiting to come to Israel. We have no data on children seen in the clinic but not included on the list to come to Israel.

Table 2. Personnel Training at the Save a Child's Heart Center

Country	Physicians	Nurses
China	...	4
Ethiopia	2	2
Nigeria	2	2
Palestinian Authority	1	1
Tanzania	...	1

Table 3. Save a Child's Heart's Medical Team Traveling Clinics

Year	Country	Purpose
1995	Ethiopia	Preoperative clinic and surgical treatment
1996	Moldova	Preoperative clinic
1997	Ethiopia	Preoperative and follow-up clinic
1997	Moldova	Preoperative clinic and surgical treatment
1998	Ethiopia	Preoperative and follow-up clinic
1998	Nigeria	Preoperative clinic
1998	China	Preoperative clinic and surgical treatment
1999	Ethiopia/Nigeria	Preoperative and follow-up clinic
1999	China	Preoperative clinic and surgical treatment
1999	Tanzania/Zanzibar	Preoperative clinic
2000	Ethiopia	Preoperative and follow-up clinic

Comment

Children with CHD in developing countries continue to have difficulty gaining access to adequate treatment [1, 9, 10]. A neonate with complex heart disease born in a developed country will benefit from massive resources even when the best final result will be only palliation [15]. In contrast, many children born in developing countries succumb to simple lesions that can be repaired with a high success rate, single hospitalization, low morbidity, and low cost [9]. Although health professionals are happy to treat these children, the logistic problems related to such an endeavor are significant [11]. Even though the number of children that the Save a Child's Heart center affects will not impact significantly on the total problem, the fact that such a center can be operated successfully as a prototype is encouraging.

Our experience dictates that the most successful model to build such a project is one that is hospital based. Thus, the "project hospital" serves as a regional center that provides care for children as well as training to participating personnel. The primary goal of the regional center must be the promotion of improved conditions at the partner sites.

The choice of a partner is critical to the success of the project. In most countries, the population is too vast for a project hospital to deal with the problem on a national level. Thus we found that partners the size of a university program to be ideal. We have also had success with

Table 4. Pediatric Cases per Annum and Age Distribution

Year	Cases	0-6 months	6-12 months	12-36 months	3-10 years	>10 years
1996	69	5	5	8	37	14
1997	80	10	9	20	24	17
1998	105	10	9	19	50	17
1999	132	26	18	13	42	33

Values are numbers of patients.

Table 5. Distribution of Pediatric Cases per Annum

Type of Surgery	Surgical Procedure	1996	1997	1998	1999
Closed	PDA	5	5	4	12
	Aortic coarctation	5	4	4	5
	Vascular ring	1	1
Open-simple	ASD/PAPVD	13	3	7	13
	VSD	16	12	31	24
	DSS	5	1
Open-moderate	VSD with PHT	...	1
	TOF	7	12	16	18
	A-V canal	2	4	4	1
	Univentricular palliation	5	11	6	10
	Diffuse SAS	1	1	1	4
	Valve repair or replacement	2	9	13	19
	Ventricular aneurysm	1
Open-complex	TAPVD	...	3	2	3
	Transposition of great arteries	3	7
	TOF, pulmonary atresia	1	1
	Double outlet right ventricle	2	...	3	2
	Anomalous LAD from PA	1	...
	Interruption of aortic arch	2	2
Other		3	13	8	11
Total		69	80	105	132

Values are numbers of patients.

ASD = atrial septal defect; A-V = atrioventricular; LAD = left anterior descending artery; PA = pulmonary atresia; PADVD = partial anomalous pulmonary venous drainage; PDA = patent ductus arteriosus; SAS = subaortic stenosis; TAPVD = total anomalous pulmonary venous drainage; TOF = tetralogy of Fallot; VSD = ventral septal defect.

nongovernmental organizations in Ethiopia, Nigeria, and Tanzania. The advantages of partners at this level are twofold: first, training is very effective, as trainees from different disciplines all come from the same hospital, and return to work together. This method makes it feasible to train the needed personnel for such a program in a reasonable period of time. Second, by working with a specific hospital, expensive equipment is concentrated in one center where people are trained. This both reduces costs and makes sure the equipment is utilized maximally.

The location of the partner has a significant impact on direct care of the child. A center should try to form partners with groups as physically close to the project hospital as possible. Such proximity allows adequate treatment of younger children and infants as well as emergencies. Follow-up is more frequent and effective.

It is vital that the project hospital and the participating organization both view themselves as equal partners. The project hospital will bear most of the financial burden. However, organization of clinics, proper screening of candidates for clinics, and follow-up care are needed for such a program to be successful. This endeavor can be accomplished only with an active, equally participating partner. Further, candidates for training can be chosen only by the participating partner. Proper choice of their personnel is needed for success and the development of the evolving center.

Clinics, held in participating countries by the project hospital personnel, are important. Clinics enable the proper selection of patients to travel to the project center,

as well as provide the opportunity to teach and evaluate on site. Initial attempts to receive patients without prior screening resulted in children being inoperable or not requiring operations on arrival in Israel. Screening clinics have almost eliminated this problem. Another major advantage of these clinics is that they allow personnel from both teams to work within the limited capabilities of the clinic. This strategy provides for thorough understanding of the problems faced by the partner program and good working relationships to form between the teams. Further, the presence of the Save a Child's Heart personnel helps make the public in these countries aware that children with CHD can be helped; a fact unknown among the public in a number of locations before the Save a Child's Heart project began.

Ideally, Save a Child's Heart personnel will be able to operate with local teams at each site. This design is currently possible in four sites, and is the goal for all the sites. This design should not be started, however, until personnel are adequately trained and facilities are available. This preparation may take years, which should be underscored at the beginning of any partnership.

A major concern about patients returning to less-developed regions after heart operations has been adequate follow-up care. This project has demonstrated that, with proper partner selection, close follow-up care is possible. To minimize acute problems after operation, children are left in Israel in the Save a Child's Heart facility for an additional 2 weeks for observation after they have been discharged from the hospital. This time

Table 6. Summary of Mortalities

Patient No.	Diagnosis	Age	Surgical Procedure	Cause of Death
1	TOF	2 y	Repair	Sepsis
2	Holmes heart	1.2 y	Band	Pulmonary hypertension
3	TOF, PA	5 days	Shunt	Shunt occlusion
4	TOF, PA	4 days	Shunt	Aspiration on postoperative day 7
5	TAPVD, VSD, juxtaposed atria	2 days	Repair	Failure to wean off bypass
6	Univentricular connections, PA	5 days	Shunt	Intraoperative VF
7	TAPVD	2 days	Repair	Failure to wean off bypass
8	TOF, PA, discontinuous PAs	2 y	Unifocalization of PAs + central shunt	Intracranial hemorrhage
9	A-V canal	7 mo	Repair	Severe MR. Death occurred during repeat attempt at repair
10	TGA, single coronary artery	6 weeks	Repair	CHF on postoperative day 3
11	Rheumatic mitral valve disease	13 y	Mitral valve replacement	Massive pulmonary hemorrhage on postoperative week 4
12	Multiple VSDs	1.7 y	Repair	Pulmonary hypertension, sepsis
13	Multiple VSDs	7 mo	Repair	Acute respiratory failure, residual VSDs
14	TAPVD, univentricular connections	4 days	Shunt	Intraoperative VF
15	TOF, PA	2 days	Complete repair	Heart failure postoperative day 2
16	Shone's syndrome	4 m	SAS resection, mitral valve replacement	Pulmonary hypertensive crisis night of surgery
17	PA, unbalanced A-V canal, DORV, PDA	4 days	Central shunt, PDA ligation	Intraoperative VF

A-V = atrioventricular; CHF = congestive heart failure; DORV = double outlet right ventricle; IAA = interruption of aortic arch; MR = mitral regurgitation; PA = pulmonary atresia; PDA = patent ductus arteriosus; SAS = subaortic stenosis; TAPVD = total anomalous pulmonary venous drainage; TGA = transposition of great arteries; TOF = tetralogy of Fallot; VF = ventricular fibrillation; VSD = ventricular septal defect.

permits the treatment of any late infection, effusion, or other unforeseen complication in the project hospital before returning patients to their home countries.

There is 92% follow-up on all of our operated patients. Of particular note are the 43 patients with prosthetic valves; 41 of these patients were alive and in follow-up at the time this report was written. All of these patients require medication and follow-up. All patients are undergoing anticoagulation therapy and are being monitored. The monitoring does not meet the standard of care in developed countries [16]. Prothrombin time is monitored on the average of four times a year; however, only 1 patient has died, and there have not been any other major hemorrhagic or embolic complications.

Several limitations should be recognized at the outset of such a project. First, financial and physical constraints do not allow us to treat all the patients presented to us at screening clinics. The need to deny certain patients is traumatic to both the families and the staff. To minimize this process, there is an understanding between the two cooperating staffs as to how many children will be accepted for the clinic before it is held. Second, because of the needs for airplane flights sometimes requiring 2 days of travel, our ability to treat neonates with complex

lesions is limited to the Palestinian Authority. Neonates with complex diseases located in other regions are not accepted into the program. Finally, children with complex lesions who require conduits or who can only be palliated pose a tremendous strain on the system and its resources. The two notable exceptions to this are children with univentricular hearts and pulmonary stenosis in whom a Glenn shunt is performed without eliminating forward flow (we have operated on 10 such children with minimal early and late complications), and children from the Palestinian Authority where the proximity allows for close follow-up and rehospitalization when necessary. Again, these differences between the Palestinian Authority and other sites emphasize the need to choose partners as close as possible to the project hospital.

Whereas one might argue that these children are the responsibility of governments and world organizations, the governments and large organizations working in the developing world are dealing with much more basic problems, such as hunger, vaccinations, and infections [3, 9, 10]. They have neither the resources nor the expertise needed to solve the problem of children with CHD. The World Health Organization report did not include cardiovascular disease on its list of priorities [3]. On the other hand, the world of thoracic surgery has the expertise to solve this problem, and

the medico-industrial complex that supports these surgeons has the resources to help. We have demonstrated that a hospital-based project can be effective in promoting care of children with CHD within a region. In addition to the humanitarian value of the project, we have demonstrated that such programs are administratively and economically feasible.

For more than 50 years, thoracic surgery has led medicine in revolutionizing medical technology and advancing knowledge in cardiorespiratory physiology [17]. This challenge offers us the opportunity to lead a social revolution, and help children in need whom we have been trained to heal.

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Appendix. Organizations Dedicated to Pediatric Cardiac Care in Developing Nations

Name	Mission	Address	Fax/E-mail
Caribbean Heart Menders	Children's heart surgery in the Caribbean area	3090 Venice Way, Miramar, FL 33025, USA	954-436-0726 (Telephone)
Chain of Hope, UK	Provides medical and surgical therapy to children suffering from heart disease in developing countries	South Parade, SW3 London SW3 6NP, UK	+44-20-7351-1978
Children's HeartLink	Treatment of heart disease in needy children	5075 Arcadia Ave, Minneapolis, MN 55436, USA	612-928-4859 info@childrensheartlink.org
Cleveland Clinic Foundation	Surgery for needy children in the United States	The Children's Hospital-M41, 9500 Euclid Ave, Cleveland, OH 44915, USA	216-444-2200
Deborah Heart and Lung Center	Surgery for needy children in the United States	200 Trenton Road, Brown Mills, NJ 08015, USA	609-893-6611
Gift of Life, Inc.	Surgery for needy children abroad and in the United States	505 Northern Blvd, Suite 102, Great Neck, NY 11021, USA	516-504-0828 golman@msn.com
Global Healing	Help for needy children with heart disease	3 Scenic Court, Danville, CA 94506, USA	
Healing the Children	Treatment of children with heart disease in developing countries	PO Box 9065, Spokane, WA 99209-9065, USA	509-327-4284 national-Hte@worldnet.att.net www.northwest.net/HTC
Heart Care International	Treatment of needy children; training for personnel	139 East Putnam Ave, Greenwich, CT 06830, USA	203-552-5344 heartcarei@aol.com

Appendix. Continued

Name	Mission	Address	Fax/E-mail
Heart to Heart International	Surgery in the US for needy children	318 Lyons-Harrison Research Bldg, 701 South 19th St, Birmingham, AL 35294-0007, USA	205-975-6535 www.uab.edu/hearttoheart/mission.htm
International Children's Heart Foundation	Treatment of needy children with heart disease	The Variety Heart House, 756 Jefferson Ave, Memphis, TN 38105, USA	901-432-4243 www.babyhearts.com
Medical Outreach for Armenians	Support cardiac center in Armenia; supply treatment abroad	PO Box 1333, Paramus, NJ 07653-1333, USA	201-934-6577
Project Hope	Medical treatment overseas	International Headquarters, Health Sciences Education Center, Millwood, VA 22646, USA	540-837-1813 www.projhope.org
Project Open Hearts	Share medical technology and expertise with partnered countries	13600 Highway 285, Pine, CO 80470, USA	Rital.enz@poh.org www.poh.org
Samaritan's Purse	Provide surgery for children in the US	Box 3000, Boone, NC 28607, USA	828-266-1053 usa@samaritan.org www.samaritanspurse.org
Save a Child's Heart	Promote cardiac care in developing countries	9 Habanium St, Holon 58213, Israel	+972-9-5019006 sach@barak-inline.net
Variety-Children's Lifeline	Provide medical treatment to needy children	514 Via de la Ville, Suite 209, Solana Beach, CA 92075, USA	619-509-0708

Information courtesy of Children's HeartLink. More details available on www.heart-net.org.