

Cuba's National Pediatric Cardiology Program

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In the first two decades following establishment of the national public health system in 1961, Cuba's pediatric epidemiological profile was transformed. Mortality from malnutrition, acute diarrhea, acute respiratory infections, and infectious diseases steadily declined, as did the burden of these and other diseases associated with poverty and lack of access to health care. By 1980, infant mortality had dropped to 19.6 per 1000 live births, compared to 38.7 per 1000 live births in 1970.[1]

As infant mortality declined, however, congenital heart disease became increasingly predominant as a primary cause of death in infants under 1 year old. By 1970, congenital malformations in general were the number 3 cause of death in this age group, becoming the number 2 cause in 1980, and remaining so through 2008, with congenital heart disease the most frequent among these malformations.[1]

Specialized pediatric cardiology care was unavailable in Cuba until 1964 when a ward in the William Soler Pediatric Teaching Hospital in Havana was opened for patients with heart disease, and an outpatient service was created exclusively for children suffering heart damage from rheumatic fever. At that time, doctors had few options for treatment of very young children, limited in many cases to palliative care or so-called "closed-heart" procedures for less complex cases. Surgical techniques for early intervention in infants had not yet been developed, and prognosis for complex cases was poor. Between 1964 and 1984, over 1000 cardiovascular surgeries were performed in children under 14 years old by a small team of surgeons at this hospital, which received young patients from around the island.[2]

Beginning in the 1970s, the field of cardiology and cardiovascular surgery began a worldwide transformation with introduction of cardiopulmonary bypass (CPB); new techniques in anesthesia, surgery and intensive care; and development of more precise methods in echocardiography and hemodynamics. As a result, more surgical options became available for treating heart disease in newborns, infants and children, while the introduction and development of interventional catheterization provided a non-surgical option for a growing number of patients of all ages.[3–5]

In this context, in the early 1980s, Cuban pediatricians, cardiologists and government leaders focused attention on childhood heart disease and began creating conditions for providing comprehensive pediatric cardiology care on a national scale. In 1983, ground was broken for construction of the William Soler Children's Heart Center adjoining the hospital of the same name. The following year, a group of physicians began receiving advanced training at the Cardiology and Cardiovascular Surgery Institute (ICCCV, its Spanish acronym) in Havana and from specialists abroad, particularly Professor Milan Samanek of the Motol Hospital Cardiology Center in Prague, former Republic of Czechoslovakia.

The National Pediatric Cardiology Program was inaugurated in October 1986 with the opening of the new Children's Heart Center, the national referral center that oversees and coordinates the National Pediatric Cardiology Network. This nationwide public health program—unprecedented in the Americas and still unique today—integrates prevention, diagnosis, treatment, rehabilitation, research, and advanced professional training, providing complete coverage to children and adults with congenital heart disease or sequelae from childhood heart surgery.[2]

From a public health perspective, results of the Program can be seen in the decline in mortality from congenital heart diseases in children under 1 year old, from 3.0 per 1000 live births in 1985 to 0.5 per 1000 live births in 2008.[1,6] Incidence of congenital heart diseases in Cuba is 5–6 per 1000 live births, [7] within the international average of 4–8 per 1000 live births.[3] At the same time, incidence and severe cases of rheumatic fever—a primary cause of acquired heart disease in children and adults—has been significantly reduced over the last two decades, and there has not been a death from acute rheumatic fever in patients under 20 years old since 2005 through 2009.[1,8] The greatest impact, however, is in assuring families and communities that children affected by heart disease have access to specialized, comprehensive and continuous care, no matter where they live.

The National Pediatric Cardiology Network

The Network functions as a subsystem of the national public health system, linking community-based family doctors and polyclinics at the primary care level with municipal and provincial maternity, children's and rural hospitals and neonatal care units at the

Snapshot: Patients & Procedures, William Soler Children's Heart Center

Patients*	1986–2008	2008
Average annual admissions	2000	NA
Total admissions	NA	3643
Cardiovascular Surgery	1986–2008	2008
Total patients	6756	311
Total procedures	7488	332
Re-interventions	11.0%	6.3%
Total CPB procedures	56.26%	70.1%
Procedures in patients aged <1 year	30.0%	28.0%
CPB procedures in patients aged <1 year	NA	65.6%
Post-surgical survival	1986–2008	2005–2008
All ages	87.2%	94.3%
Aged <1 year, total	73.6%	87.2%
Aged <1 year, with CPB	67.9%	86.0%
Interventional Catheterization	1988–1990	2004–2007
Total patients	80	414
Total procedures	82	417
Complications, all ages	2.4%	0.5%
Survival, all ages	98.6%	99.5%
Cardiac Rehabilitation	1992–2008	2008
Total patients	3812	1012

* aged ≤19 years, unless noted otherwise
 NA: Not available
 CPB: Cardiopulmonary bypass

secondary level. Tertiary care is provided at three children's heart centers across the country—one in Villa Clara in central Cuba, one in Santiago at the eastern end of the island, both opened in 1988,[2] and the William Soler center in Havana—as well as the Cardiology and Cardiovascular Surgery Institute (ICCCV), the Ameijeiras Hospital, and the Medical-Surgical Research Center (CIMEQ, its Spanish acronym), all in Havana.

The primary aim of the network is to make integral cardiology services available to patients in or near their communities, relying on multidisciplinary teamwork and emphasizing early detection, follow-up, and lifetime monitoring and care, if necessary. Prenatal screening and diagnosis for congenital heart disease is currently 80% effective, consistent with levels obtained in developed countries, and systems are in place to plan for and provide specialized neonatal care when required and to transport critically ill patients to the Heart Center as quickly as possible by plane or specially-equipped ambulance.[5,9]

Provincial pediatric cardiology teams include neonatologists, intensive care specialists, obstetricians and gynecologists, pathologists, family doctors and nurses, ultrasound technicians, and other allied health personnel. In each municipal and provincial health service, a cardiologist, pediatrician or pediatric cardiologist is responsible for coordinating care of all pediatric heart patients in their service area. A pediatric cardiologist team in each province regularly monitors patients in the polyclinics closest to their homes and refers them for more specialized diagnostic testing and evaluation when necessary or, in the case of newborns with detected heart disease, hospital admission to pediatric cardiology, neonatal, or intensive care units.

Adults with congenital heart disease, regardless of age at detection, type of treatment or stage of rehabilitation, also come under the care of the provincial pediatric cardiology team and may be referred to tertiary care for surgical procedures or re-implantation, interventional catheterization, arrhythmia treatment, or pacemaker implantation. The Villa Clara and Santiago Children's Heart Centers are equipped to perform surgery and interventional catheterization in adults with congenital heart disease, and less complex surgeries in children, while all cardiovascular surgery in children under 3 years old and complex pediatric surgery, as well as all interventional catheterization in children and some adults with congenital heart diseases, is done in Havana at the William Soler Children's Heart Center. Certain complications of childhood heart surgery that present in adults, such as arrhythmia, are generally treated in collaboration with the ICCCV in Havana.

Network coordinators are in permanent communication with the William Soler Children's Heart Center electronically and by telephone. In 2005–2006, the Heart Center opened an internet portal (www.cardiows.sld.cu), and a computer network was set up linking coordinators around the country with the three heart centers. Since 2009, heart center specialists have access to the Internet, simplifying information retrieval and exchange, and the Center has begun exploring telemedicine opportunities for exchanging medical images using software developed at Cuba's Information Sciences University.

Prevention is also a major focus of Network activity through participation in the National Program to Reduce Infant Mortality, the National Rheumatic Fever Prevention and Control Program, and

the National Program for the Detection of Congenital Malformations. Through these multisectoral programs, the Network also coordinates with the National Maternal-Child Care Program, the National Genetics Program, the Ministry of Public Health, scientific societies, biomedical research centers, and other national and international entities.

William Soler Children's Heart Center

In addition to heading the National Pediatric Cardiology Network, the William Soler Children's Heart Center provides cardiovascular surgery, diagnostic and therapeutic catheterization, and post-surgical rehabilitation services for patients referred from throughout Cuba and from other countries, primarily in Latin America. As the National Referral Center for Pediatric Cardiology and Cardiovascular Surgery, it also combines patient care with research and advanced specialist training.

Located in Boyeros municipality in Havana, the Center is a 100-bed facility with 3 operating rooms; intensive care unit; hemodynamics laboratory; clinical laboratory; transfusion service; and diagnostic radiology, echocardiography, stress test, arrhythmia and electrocardiography services. The staff of 400 includes 223 medical specialists and paramedical personnel, 66% of whom are women.



Proximity to the William Soler Pediatric Teaching Hospital and the Hematology Institute at the same site facilitates ongoing consultation and collaboration among specialists in different fields, as well as shared computerized axial tomography (CAT), bacteriology, special blood tests and some logistical services with the hospital.

Since its inauguration, the Center has prioritized care for children under 3 years old. In newborns presenting heart disease, 20%–40% of cases are critical and potentially fatal, requiring highly specialized care. With advances in surgery, interventional catheterization and other techniques, treatments have become increasingly more successful at ever younger ages. Of 7488 surgical interventions performed between 1986 and 2008, 30% were in children under 1 year old. During the same period, mean post-surgical survival of children under 1 year old was 73.6%. Even as more complex pathologies in ever younger patients are being treated with surgery, survival continues to improve. Mean post-surgical survival of children under 1 year old in 2005–2008 was 87.2%, and 86.0% in those operated on with CPB, compared to 67.9% mean survival in the latter group over 22 years since 1986.

National Pediatric Cardiology Program

William Soler Children's Heart Center, Havana, Cuba

- National referral center for pediatric cardiology and cardiovascular surgery
- Coordinator, National Pediatric Cardiology Network
- Post-graduate specialist training in pediatric cardiology and cardiovascular surgery
- In-service training and continuing education in pediatric cardiology

National Pediatric Cardiology Network

Primary Care: 169 municipal service areas throughout Cuba

- Ensure early detection and timely referral of all new patients with suspected heart malformation or disease
 - Pre- and postnatal care
 - Prenatal ultrasound testing of all pregnant women with risk factors or any suspicion of fetal heart malformation
 - Genetic testing and counseling in coordination with the National Genetics Program
 - Follow-up and continued monitoring of all children with heart disease
 - Routine pediatric care
 - Screening to detect asymptomatic disease, discrete symptoms, and undiagnosed hypertension
- Prevention and control of rheumatic fever
- Prevention of infectious endocarditis
- Ensure adequate preventive dental care for heart patients
- Prevention of exposure to teratogenic agents

Secondary Care: hospital service areas in 14 provinces and the Isle of Youth Special Municipality

- Follow-up and continued monitoring of each patient, including case registration and risk stratification, with or without surgery or other interventional procedure
- Pre- and postnatal care
 - Confirmation fetal diagnostic ultrasound testing
 - Early postnatal diagnosis of critical or complex heart malformations
 - Prompt referral of patients to tertiary care
- Specialist care in provincial health services
- Stage II and Stage III post-surgical rehabilitation
- Active implementation and monitoring of the Rheumatic Fever Prevention and Control Program
- Prevention of infectious endocarditis, emphasizing dental care in children with some risk who need anesthesia or in-hospital care in case of complications
- Supervision and support of primary care functions

Tertiary Care:

- **William Soler Children's Heart Center, Havana, Cuba**
 - Surgical treatment of congenital heart malformations, all ages, including re-interventions
 - Surgical treatment of acquired heart disease, children aged ≤19 years
 - Interventional catheterization, children aged ≤19 years and adults with congenital heart diseases
 - Stage I post-surgical rehabilitation
 - Prevention of infectious endocarditis, emphasizing dental care in high-risk children requiring anesthesia or in-hospital care for complications
- **Villa Clara and Santiago de Cuba Children's Heart Centers**
 - Surgical treatment of some cardiac non-complex congenital heart diseases

In 2008, mean post-surgical survival in patients under 1 year old operated on without CPB was 90%, compared to a 22-year mean of 74.9%. These survival rates are comparable to those of similar institutions, taking into account case volume, complexity of procedures, and morbidity and mortality rates.[10-12]

Due to the accumulated waiting list of operable cases combined with incidence of new cases, more surgeries were performed in the Center's first 5 years than at any other time—over 450 per year between 1987 and 1991. As the waiting list shrank and interventional catheterization techniques improved,[13-15] along with the center's capacity to perform these procedures, the number of patients requiring surgery declined, freeing up resources for treatment of more complex cases, particularly in newborns and infants under 1 year old.

During the economic crisis of the 1990s, however, the heart center was forced to cut back all but the most critical services and adopt emergency measures to conserve resources. Waiting periods for surgery were extended for patients who could wait. As a result, in 1993–1996, only half as many surgeries were performed per year as in 1987–1991, and of those, fewer with CPB and fewer in children under 1 year. Since 1997, conditions have steadily improved, and there is currently no waiting list for surgery. Interventricular communication, Tetralogy of Fallot, and functional single ventricle heart are the congenital heart conditions most frequently treated with surgery at the Center, followed by atrioventricular septal defect, transposition of the great arteries, ventricular outflow tract obstructions, and mitral valve disease.

Interventional catheterization was introduced in the heart center in 1988, and 1328 procedures were performed over the next 20 years. Today, interventional procedures make up more than half of all catheterizations and are expected to surpass 70% in the near future. As with surgery, despite increased complexity of these procedures, survival has improved while complication rates have consistently declined, comparing favorably with results in the most advanced countries in the field (See Snapshot).[13] The top five interventional catheterization procedures performed at the heart center are atrioseptostomy, valvuloplasty, angioplasty, stentotherapy, and occlusion devices.

National Program for Cardiac Rehabilitation in Children

The William Soler Cardiac Rehabilitation Center opened in 1992 as the hub of the national three-stage Program for Cardiac Rehabilitation in Children, based on American Heart Association recommendations and similar programs in other countries.[16–22]

In Stage I Rehabilitation: Hospitalization, patients begin a progressive individualized physical conditioning program immediately after surgery, led by a multidisciplinary team made up of a cardiologist, physiatrist, psychologist, physical therapist, and rehabilitation nurses, taking into account the patient's age, primary cardiovascular disease, type of surgery and immediate post-operative complications.

Stage II Rehabilitation: Convalescence begins when the patient is discharged from the Heart Center and returns home as an outpatient under the care of a family doctor with continued rehabilitation at the physical therapy services in their community-based polyclinic. Six months to 1 year after surgery, the patient returns to the Heart Center for re-evaluation, and as often as necessary until he

or she is ready for Stage III Rehabilitation: Daily Life. Stage III is geared toward attaining a level of social, educational and occupational activity as close to normal as possible, considering the individual's functional capacity and intellectual and physical abilities.

Under the Congenital Heart Disease Work Program, rehabilitation includes coordination with the Labor Ministry to place adult patients with physical limitations due to congenital heart disease in jobs appropriate for their health status and abilities. Of 3812 rehabilitation patients in 1992–2008, 316 are currently enrolled throughout the country. Stage III also includes a subprogram for pregnant women who have undergone surgery for congenital heart disease, which includes medical counseling about risks associated with pregnancy and childbirth, and specialized prenatal and delivery care if required. As of 2008, patients in this program had given birth to over 100 babies with no negative outcomes.

Scientific Research and Professional Training

Advanced specialist training is a cornerstone of Cuba's pediatric cardiology program, made possible initially through collaboration with the Motol Hospital Cardiology Center in Prague, mentioned above, and continued through scientific collaboration with national and international clinical and research institutions. The William Soler Children's Heart Center currently has collaborative relationships with some 16 hospitals and research centers worldwide, including Guys Hospital in London (Great Britain), Johns Hopkins University in Baltimore (USA), University of Kiel (Germany), and the Latin American Pediatric Cardiology Hospital in Caracas (Venezuela).

Cuba's first pediatric cardiovascular surgery residency program opened at the Heart Center in 1995. Nine specialists (8 Cuban,

1 international) have since graduated and 3 more (2 Cuban, 1 international) are currently in training. In 2003, the Ministry of Public Health approved a second residency program—in pediatric cardiology—which has graduated 2 specialists with another 2 now in their third year. The Heart Center also conducts certificate courses in pediatric cardiology for health professionals working in the national pediatric cardiology network, and recently initiated a master's program in pediatric echocardiography.

Heart Center staff includes 63 professors of pediatric cardiology in Cuban medical universities (28 in Havana and 35 throughout the country), most of whom are involved in institutional or public health research projects.

Challenges and Assets

The primary challenges facing the program are economic, given the high cost of equipping and maintaining the level of surgical, intensive care and other therapeutic facilities required to provide opportune, life-saving, quality care for children with heart disease. [14] Obtaining specialized equipment and supplies is made particularly difficult due to commercial restrictions imposed against Cuba by the US government. These difficulties are offset, however, by highly qualified staff at all levels throughout the country, combined with continued structural and programmatic support from the Ministry of Public Health and other Cuban institutions, such as the National Medical Sciences Information Center and the Information Sciences University. The William Soler Children's Heart Center is also particularly fortunate in its collaborative relationships with some of the world's leading pediatric cardiology programs. 

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