

*Original Article***The improvement of care for paediatric and congenital cardiac disease across the World: a challenge for the World Society for Pediatric and Congenital Heart Surgery**

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**Abstract** The diagnosis and treatment for paediatric and congenital cardiac disease has undergone remarkable progress over the last 60 years. Unfortunately, this progress has been largely limited to the developed world. Yet every year approximately 90% of the more than 1,000,000 children who are born with congenital cardiac disease across the world receive either suboptimal care or are totally denied care.

While in the developed world the focus has changed from an effort to decrease post-operative mortality to now improving quality of life and decreasing morbidity, which is the focus of this Supplement, the rest of the world still needs to develop basic access to congenital cardiac care. The World Society for Pediatric and Congenital Heart Surgery [<http://www.wspchs.org/>] was established in 2006. The Vision of the World Society is that every child born anywhere in the world with a congenital heart defect should have access to appropriate medical and surgical care. The Mission of the World Society is to promote the highest quality comprehensive care to all patients with pediatric and/or congenital heart disease, from the fetus to the adult, regardless of the patient's economic means, with emphasis on excellence in education, research and community service.

We present in this article an overview of the epidemiology of congenital cardiac disease, the current and future challenges to improve care in the developed and developing world, the impact of the globalization of cardiac surgery, and the role that the World Society should play. The World Society for Pediatric and Congenital Heart Surgery is in a unique position to influence and truly improve the global care of children and adults with congenital cardiac disease throughout the world [<http://www.wspchs.org/>].

Keywords: Congenital heart disease; globalization; outcomes; complexity; complications; surgical outcomes; registry; database; cardiac surgery; results of treatment

**T**HE WORLD SOCIETY FOR PEDIATRIC AND CON-genital Heart Surgery is in a unique position to influence and truly improve the global care of children and adults with congenital cardiac disease throughout the world [<http://www.wspchs.org/>]. The care of the child and adult with congenital cardiac disease has undergone remarkable progress in the last 60 years. Even the most complex cardiac malformations can now be treated with real optimism for the future. In recent years, the focus has been on improvement of the quality of care, not only in the early period just after intervention, but also the long term outcome of the patients, with increasing focus on the adults with congenital cardiac disease.

Unfortunately, this progress has been largely limited to the developed world. Yet every year approximately 90% of more than 1,000,000 children born with congenital cardiac disease across the world receive either suboptimal care or are totally denied care. The World Society for Pediatric and Congenital Heart Surgery [<http://www.wspchs.org/>] was established in 2006.

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In this article, we present the following topics:

- an overview of the global epidemiology of congenital cardiac disease,
- the current and future challenges to improve care in the developed and developing world,
- the impact of the globalization of cardiac surgery and the opportunity it presents, and
- the role that the World Society should play in leading the way for the improvement of care for children and adults with congenital cardiac disease across the world and the education of the health care professionals providing that care.

### Global epidemiology of congenital cardiac disease

Globally, approximately 130 million babies are born every year. Of these babies, about 4 million die in the neonatal period, that is in the first 30 days of life. Of those deaths, 99% occur in low-income and middle-income countries.<sup>1</sup> According to various reports, about 7% of those fatalities are attributable to congenital malformations, most of them cardiac.<sup>2</sup>

It is said that congenital cardiac disease affects approximately 1 in 125 live births. Consequently, approximately 1 million babies are born each year with congenital cardiac disease. Nine out of 10 of those newborns are born in areas of the globe where appropriate medical care is either inadequate or unavailable. From the 280,000 babies who die each year from a congenital cardiac anomaly in the neonatal period, more than 250,000 are not offered the care that has been developed over the past 60 years and that has allowed cardiac surgeons and

cardiologists around the world to save millions of lives, very often with fairly simple measures.<sup>2</sup> One can also learn much and understand the consequences of this disparity in cardiac care when reviewing the natural history of frequent congenital cardiac lesions. For example, individuals with large atrial septal defects face a risk of mortality of 5–15% before the age of 30 years. Similarly, the presence of a patent arterial duct is associated with a 30% risk of mortality before the age of one year and a 42% risk of death before 45 years of age. Of all the individuals born with tetralogy of Fallot with pulmonary stenosis, 25% will die within their first year of life if left untreated. Respectively, 40%, 70%, and 95% will be dead by the age of 3, 10, and 40 years. Looking at more complex pathologies, transposition of the great arteries is associated, all varieties considered, with a 45%, 85%, and 90% mortality at one month, 6 months, and one year respectively. Finally, hypoplastic left heart syndrome, which is the fourth most common congenital cardiac defect, results in the mortality of most neonates within one to two weeks of birth, and survival beyond 6 weeks of age is unusual.<sup>3</sup> Those mortality rates are significant, but do not give an accurate description of the suffering children and young adults with congenital cardiac disease face in regions of the world where medical and surgical treatments are of difficult access. Indeed, the morbidity of unrepaired congenital cardiac disease has not been accurately assessed and quantified. Therefore, one must consider with equal importance the decreased quality of life they face with multiple potential complications:

- frequent pulmonary infections,
- a high risk of bacterial endocarditis,
- the impact of polycythemia for the unrepaired cyanotic lesions,
- the risk of neurological events, and
- the impairment and decreased functional status.

While we know that certain agents cause congenital cardiac defects, it is recognized that most cases are idiopathic or infrequently attributable to known genetic syndromes. In addition to the congenital malformations, low-income and middle-income countries have to deal with the significant burden of acquired cardiac disease in children. Indeed, while the mortality rates associated with rheumatic heart disease has dropped to just above 0% since the 1960s in developed countries, developing countries face a different situation. Chronic rheumatic cardiac disease is considered to exist in approximately 30 million children and young adults around the world. Estimates show that 90,000 patients die from this ailment each year.<sup>4,5</sup> Also, Chagas disease is endemic throughout much of Mexico, Central America, and

South America, where an estimated 8 to 11 million people are infected. During the chronic phase of the disease, about 30% of the infected individuals develop severe cardiomyopathy resulting in approximately 13,000 deaths per year worldwide.<sup>6</sup> Although there has been little focus on the global epidemiology of paediatric and congenital cardiac disease, it takes on increased importance if one is to improve care across the world.

### Improvement of quality of care in the developed world

As previously mentioned, cardiac surgery as a whole, and also congenital and paediatric cardiac surgery more specifically, have evolved greatly over the past 60 years. From its spectacular beginning, thanks to the courage and innovation of pioneers such as Alfred Blalock, John Heysham Gibbon Jr, C. Walton Lillehei, John W. Kirklin, and others, the development of the heart-lung machine and the refinements of surgical techniques have resulted in the ability to repair the vast majority of congenital cardiac malformations with significantly improved outcomes. From the early repairs of simple lesions such as atrial and ventricular septal defects, to the more complex repairs of tetralogy of Fallot and transposition of the great arteries, to the previously hopeless lesions such as hypoplastic left heart syndrome, the results have steadily improved, and patients previously facing either death or a life burdened by unrepaired congenital cardiac disease, can now look forward to a productive life of good quality.

These improvements have come from an accurate understanding of the anatomy and physiology of the various cardiac malformations, great advances in diagnostic modalities, vastly improved perioperative care by the paediatric cardiac anaesthetists and intensivists, and improvement of perfusion and monitoring techniques and equipment. The various health care professionals have ably supported the work of the paediatric and congenital cardiac surgeons in a spirit of cooperation and teamwork. This collaborative effort of multiple subspecialties has resulted in the dramatic decrease in surgical mortality in most programs to low levels even for the most complex cardiac malformations. Assessment and improvement of quality and outcomes has dominated discussions in the last decade, with multiple ongoing closely related projects:<sup>7–21</sup>

- international efforts to standardize the scientific language for congenital cardiac disease and the establishment of the International Pediatric and Congenital Cardiac Code [<http://www.ipccc.net/>],
- the establishment of continental multi-institutional databases, such as the Databases of The

Society of Thoracic Surgeons [<http://www.sts.org/>] and The European Association for Cardio-Thoracic Surgery Congenital Heart Surgery [<http://www.eacts.org/>],

- the development of complexity stratification and risk assessment for congenital cardiac disease with the Risk Adjustment for Congenital Heart Surgery-1 method and the Aristotle Complexity Score [<http://www.aristotleinstitute.org/>], and
- data verification and validation processes.

Those efforts have been very helpful for the analysis and improvements of our surgical outcomes and for the assessment of quality.

All this progress in the developed world has resulted in a much lower rate of mortality for paediatric and congenital cardiac surgery to approximately 4 percent, with as many as 96 percent of the children born with congenital cardiac disease now surviving and looking forward to a fruitful life. The low rate of mortality in most programs in the developed world has resulted in a shifting focus towards better understanding of complications following procedures, either surgical operations or percutaneous interventions. The decrease of complications, particularly those that leave residual and long-term disabilities, is becoming the increasing focus of research about outcomes in paediatric and congenital cardiac surgery and related specialties, and is the topic of this historic supplement produced by The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease.

### Improvement in quality of care in the developing world

For obvious reasons of lack of resources, the development of paediatric and congenital cardiac surgery has been late, slow and erratic in most developing countries. Many reasons exist to explain this unfortunate situation:

- competing priorities,
- poor structural organizations,
- lack of financial resources,
- lack of trained personnel, and
- absence of stable training and education infrastructure.

While some countries have succeeded in developing surgical programs to treat congenital cardiac disease, most children born with a cardiac malformation still do not have access to appropriate medical and surgical care.

The sporadic provision of care in developing countries has been through multiple approaches. Some regions have benefited from "surgical missions" of fully trained congenital cardiac surgeons, cardiologists,

anaesthesiologists, intensivists, perfusionists, nurses, and other professionals, providing on-site care at various intervals. Others received medical attention through the pro-bono treatment of patients transported from their countries of origin to developed countries in the Americas or Europe. Finally, some areas have seen the establishment of cardiac centres after the local training of their healthcare professionals or their return from instruction abroad. By and large these efforts have so far had a minimal impact in the numbers of children treated compared to the overall needs.

Innovative unique solutions are required. An example is the Walter Sisulu Pediatric Cardiac Centre for Africa which, through local philanthropy and the involvement of Nelson Mandela as its patron, has managed to provide cardiac operations for several hundred children from Africa. The Centre's mission is not only up-to-date delivery of care, but also training and education of health care professionals for the continent of Africa.

The best model of international collaboration is unknown, but it seems that, in terms of sustainability, the optimal strategy should involve the training and education of the local teams. Surgeons, cardiologists, anaesthesiologists, intensivists, perfusionists, nurses, and other professionals trained abroad infinitely enrich their countries upon their return. However, a serious problem is the lack of retention due to the poor local infrastructure and the absence of a critical mass of health care professionals, which further exacerbates the vicious circle. The various models of international collaboration that exist need to be evaluated for their efficiency. The best models need to be supported, encouraged and expanded. Models of cooperation that are inefficient, waste resources, and do not result in the sustainable education and training of the local teams, need to be discouraged and discontinued. The global improvement of care for patients with paediatric and congenital cardiac disease will require the systematic mobilization of health care professionals in a spirit of cooperation and teamwork.

### The globalization of cardiac surgery

The world is shrinking. This fact is true in multiple areas: trade, technology, culture, media, economics and politics. Medicine is not escaping this trend towards globalization. Due to the technological revolution, it is easier than ever to communicate at anytime of the day or night with a colleague from across the world. This ease of communication obviously promotes opportunities for networking and exchanges of ideas that were not available until recently. This globalization is also materializing through the increasing uniformity of surgical

approaches and techniques. This development has been allowed partly through the creation of large cross-continental databases. This trend is far from its apogee and will likely be part of the solution to the inadequacies of congenital and paediatric cardiac surgical care in large areas of our world.

In his Presidential Address to the American Association for Thoracic Surgery in 2006, Richard A. Jonas presented an overview of the impact of the globalization of cardiac surgery, and talked about the risks, rewards, and responsibilities in that process. We encourage everyone to read this very timely and inspiring Presidential Address published in the *Journal of Thoracic and Cardiovascular Surgery*.<sup>22</sup> The fact of the matter is that the global improvement of care for children and adults with congenital cardiac disease is the shared responsibility of both the developed and the developing world.

### **The role of the World Society for Pediatric and Congenital Heart Surgery**

The World Society for Pediatric and Congenital Heart Surgery was established in 2006. The Vision of the World Society is that every child born anywhere in the world with a congenital heart defect should have access to appropriate medical and surgical care. The Mission of the World Society is to promote the highest quality comprehensive care to all patients with pediatric and/or congenital heart disease, from the fetus to the adult, regardless of the patient's economic means, with emphasis on excellence in education, research and community service. The World Society held a highly successful inaugural meeting in Washington, D.C., in May 2007, which was attended by 385 delegates from 61 countries. During the Presidential Address, the President of the World Society, Christo I. Tchervenkov, from Montreal, Canada, presented his vision for the role of the World Society, and talked about the key elements for the global improvement of care. President Tchervenkov coined the phrase "Medicine of RESPECT" or "Medicine of Responsible Education Sustained through Partnership, Empowerment, Care and Commitment, and Teamwork and Trust" as the basis of the necessary paradigm shift for the 21st century.<sup>23</sup>

The World Society for Pediatric and Congenital Heart Surgery is in a unique position to truly improve care for paediatric and congenital cardiac disease across the world. Indeed, the World Society is the largest society for paediatric and congenital cardiac surgery in the world with more than 500 members from close to 70 countries and its potential for playing a defining role in the global improvement of care is significant. The vision and mission of the World Society are being pursued by

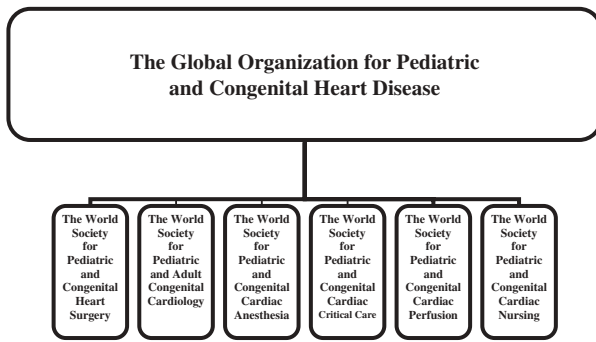
working towards clearly defined objectives in the following domains:

- patient care,
- training and education,
- research, and
- community service.

In the area of patient care, the World Society hopes to promote the professional and educational development of surgeons specializing in, and practicing, paediatric and congenital cardiac surgery across the world, as well as the dissemination of informational support to patients, parents of patients, families of patients, and health care professionals, working in collaboration with societies such as The International Society for Nomenclature of Paediatric and Congenital Heart Disease (ISNPCHD) [<http://www.ipccc.net/>]. It also wants to develop global standards for the training and education of paediatric and congenital cardiac surgeons, and for the practice of paediatric and congenital cardiac surgery across the world. Finally, its members, originating from all areas of the globe, will form a forum for the respectful exchange of knowledge in the form of scientific meetings and publications across the world. In terms of research, the World Society wants to encourage basic and clinical research in paediatric and congenital cardiac surgery across the world with emphasis on long-term and regional outcomes and to organize and maintain a global database on operations and outcomes built upon extant continental databases. This database should be multi-disciplinary and all-inclusive, containing data on preoperative parameters, interventional procedures or surgeries, as well as long-term follow-up.

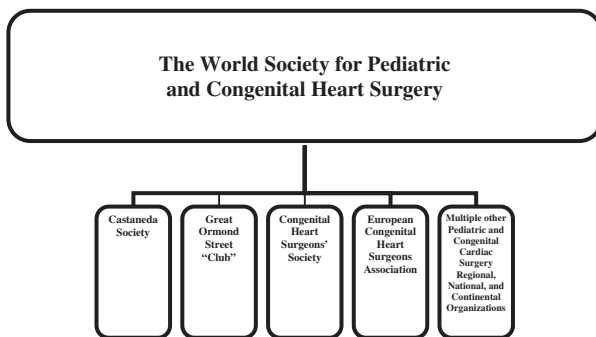
Finally, and maybe most importantly, the World Society aims to promote collaboration across medical and surgical subspecialties and is working hard to facilitate the establishment of a multi-societal Global Organization for Pediatric and Congenital Heart Disease. In Figures 1 and 2, we demonstrate the logical hierarchical structure and relationship between various related organizations.

The World Society wants to establish and maintain an accurate database of paediatric and congenital cardiac surgeons and programs across the world and facilitate mentorship between surgeons and centres. It will also work towards facilitating fundraising across the world for paediatric and congenital cardiac surgery in order to achieve its goals, particularly in areas of need. This fundraising will be done partly by sensitizing governments and public organizations to the necessity to support and adequately fund paediatric and congenital cardiac surgery programs across the world. The World Society is also in a unique position to provide professional advice to global organizations regarding



**Figure 1.**

*The possible logical hierarchical structure and relationship between various related specialty organizations in a multisocietal Global Organization for Pediatric and Congenital Heart Disease. The Global Organization for Pediatric and Congenital Heart Disease can potentially function as an umbrella organization.*



**Figure 2.**

*The possible logical hierarchical structure and relationship between various related regional, national, and continental organizations, and The World Society for Pediatric and Congenital Heart Surgery. The World Society for Pediatric and Congenital Heart Surgery can potentially function as an umbrella organization.*

issues pertaining to paediatric and congenital cardiac surgery, and interact as well as cooperate with existing continental organizations in the pursuit of its mission and its objectives.

The objectives and roles that the World Society for Pediatric and Congenital Heart Surgery has given itself are numerous and broad, and will likely have a real impact on the remaining 90% of children born with congenital cardiac disease who are not offered treatment. However, the process we have embarked on will be long and arduous and may be filled with many frustrations. It will not be a sprint, or even a marathon, but perhaps more of a long arduous triathlon. Nevertheless, we have taken the first few steps on this challenging and exciting journey.

## Conclusion

Pediatric and congenital cardiac surgery was born about 60 years ago and now has matured to a point

where it enjoys unprecedented successes with results barely conceivable only a few decades ago. Unfortunately, this success has been almost exclusively confined to the developed world. More than 90% of the 1 million children born with congenital cardiac disease in the world do not receive adequate care or are totally devoid of care. It is time to foster a major paradigm shift in the care for patients with paediatric and congenital cardiac disease and to extend a hand to those in the developing world. While continuing to make new scientific advances, a great portion of our efforts should now also be directed to extend the care to the rest of the children born with congenital cardiac disease in the remainder of the world. Such improvement in care can only come through the systematic organization of all health care providers across the world, based on Medicine of RESPECT, or the Respectful Education Sustained through Partnership, Empowerment, Care and Commitment, and Teamwork and Trust.<sup>23</sup> The World Society for Pediatric and Congenital Heart Surgery is in a unique position to lead the way in this seemingly daunting task.

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