



Cardiac Services



Little
Hearts - A Project by the Community

to Save the Children of Sri Lanka

Samarasinghe, D.¹
1Lady Ridgeway Hospital
Corresponding author Samarasinghe, D.
Email: dsamarasinghe@gmail.com

Preamble

Paediatric cardiac services have rapidly advanced in Sri Lanka over a period of a few years. At the beginning of this millennium, facilities for treatment of children with Congenital Heart Disease (CHD) were limited and most of the patients succumbed to their illness or became inoperable due to development of pulmonary hypertension. A dedicated paediatric cardiac clinic was established in 1998 with the appointment of Dr. S. Narenthiran as the Cardiologist at Lady Ridgeway Hospital (LRH) which is the tertiary care referral centre for children. Considering the need to develop the field, Postgraduate Institute of Medicine introduced Paediatric Cardiology as a subspeciality in Paediatrics in 2004. At the LRH, a dedicated paediatric catheterization laboratory was commissioned in December 2005 and paediatric cardiac surgery was commenced in January 2007. Expansion progressed with the addition of a four-storey building and the first ever human heart valve and tissue bank in the country to provide homografts and other tissues needed for paediatric cardiac surgery. With the improvement in infrastructure and manpower our current capacity is to treat 1600 children with CHD, 900 cardiac surgeries and 700 catheter-based interventions. However, this is only about 50% of the need. Our requirement, calculated on population-based estimates, is to treat 3000 patients with structural heart lesions every year. In order to reach that target, we need to improve our infrastructure, manpower and supply of consumables. Reaching this level of care is an immense task for a middle-income country like Sri Lanka. Most of the countries in the region could not reach even 20-30% of the requirement. Financial burden is the main obstacle to such development in middle-income countries. However, Sri Lanka is ranked as the fifth most giving nation in the World Giving Index indicating the generosity of our people. When combined, we have a need to develop a field

to save the children of Sri Lanka and a possible source of funding through our own population. If we could take the “need” to the “source”, we should be able to reach that target. Little Hearts Project is the path to bridge the “need” and the “source”.

The Need

The incidence of CHD is around 8 per 1000 live births(1). According to national statistics around 365,000 live births occur in Sri Lanka every year. Therefore, the number of children born with CHD is approximately 3000. Only 60-70% of them need a cardiac surgery or a catheter-based intervention to rectify their lesion. However, patients with more complex lesions like Univentricular hearts and Tetralogy of Fallot would need multiple surgeries and most of these redo complex surgeries take the surgical time of 2 or 3 usual surgeries. In addition, we need to leave some allowance for children with acquired heart diseases like Rheumatic heart disease and endocarditis needing surgery for their cardiac complications. Therefore, to provide treatment to all patients with structural heart diseases, we need to target 3000 patients per year. Considering the current trend, locally and internationally, the most logical division would be 2000 surgeries and 1000 catheter-based interventions every year. However, to reach this level we need to spend billions of rupees on infrastructure, manpower and consumables. Is it cost effective for a middle-income country like Sri Lanka?

Cost Effectiveness of Interventions

Different countries have different cut off levels for cost-effectiveness of medical interventions.



It is expressed as the cost per Quality Adjusted Life Year (QALY) that the patient gets after the intervention. In the USA it is 50,000 USD per QALY and in the UK it is 20,000 GBP(2). According to the World Health Organization, an intervention which costs less than the per capita GDP of that country per a QALY is very cost-effective for developing countries. Per capita GDP of Sri Lanka is around 3800 USD according to the World Bank report. As the average cost of our interventions varies between 1000- 4000 USD and almost all our surgical and catheter interventions provide many decades of normal life to the patient, all our interventions fall under the very cost-effective category.

In a country with a free health care service, finances for new developments are limited as it is a double burden to the economy. First the establishment cost and then the cost involved in maintenance and provision of services. However, if we are to bring down our infant mortality rate (IMR) any further from the current figure of 8 per 1000 live births, we need to invest in improving services for CHD, as in any country once the IMR drops to below 20, it becomes a major contributor for infant deaths. The most cost effective and practical way of further improvement is through a public and government partnership where the general public contributes to the establishment and the government provides the maintenance and services. This is the concept in the Little Hearts Project.

Plan for Expansion of the Paediatric Cardiac Services

Plan for expansion of paediatric cardiac care had three main components, short term, intermediate term and long-term plans. The long-term plan is to develop the Paediatric Cardiac Centre at the Lady Ridgeway Hospital to a national centre where all children with heart diseases can be provided timely and appropriate treatment.

This was decided after considering scientific evidence on provision of paediatric cardiac care, geography of the country, availability of manpower and cost of services.

It is proven that high volume centres have better outcome in paediatric cardiac surgery. To achieve this, a plan was laid to have four cardiac operating theatres, a 40 bedded cardiac intensive care unit

, a dedicated paediatric cardiac catheterization laboratory, 48 bedded wards for Paediatric Cardiology and Cardiothoracic Surgery, areas for outpatient services and other services like electrophysiology, advanced cardiac investigations, staff training and research. This included three four storey buildings. Foundation for the first phase building was laid in 2007, ground floor was occupied in 2010 and the building was completed in 2016. The second phase was planned in 2011, funds allocated from the budget, but construction has not yet commenced. The third phase, where the operating theatres and most of the other facilities are housed, was extended from a four-storey cardiac complex to a ten storey cardiac and critical care complex to address the other needs of the hospital. Cost estimate for the third phase was Rs. 2billion. Even though there was an extensive plan, there was no significant progress. If calculated at this rate of progress, it will take another 30years to reach the optimum level of care. How many children will succumb during this period? Considering this need, a group of likeminded people gathered and drew a plan to expedite the process. That was the birth of Little Hearts.

Birth of Little Hearts – The Inception

The target of Little Hearts was to construct the third phase building as the most crucial services that mainly determine the outcome are confined to the third phase. However, raising two billion was an unthinkable target which has not been achieved by any charity in Sri Lanka. The question was whether to give up or go ahead. Many brainstorming sessions were conducted by a handful of people interested in the project and many facts and figures were analysed.

There are over 10million mobile users in Sri Lanka. If 10% of them donate Rs. 100 every month for 2years, we can raise 2.4 billion rupees.

365,000 live births occur every year in Sri Lanka. Based on this, there should be at least 300,000 school children in each grade in Sri Lanka and 3.6million in 12 grades. If 10% of them could donate their till (piggy bank) we could raise over one billion as each piggy bank has around Rs. 2000 to 4000.



There are over 90,000 registered companies in Sri Lanka. They engage in various activities through Corporate Social Responsibility (CSR) projects mostly outside Colombo. Out of this 90,000, if 2000 companies donate one million each, for a project which provide services to children from all districts of the country, we can reach our target.

The building, when fully functional, will treat a minimum of 10,000 patients every year. As all these are critically ill children with either heart diseases or critical illnesses it is equal to saving 10,000 lives per year and 200,000 in 20 years. When the cost of construction, Rs. 2billion is divided by the number of lives saved, the cost to save a life is only Rs. 10,000. Will it be impossible to find 200,000 donors who could donate Rs. 10,000 each?

When these facts and figures were analysed in detail, in a country ranked 5th in the World Giving Index, a project deemed impossible, became possible. That was the inception of the project Little Hearts.

The Way Forward

Success of a fund-raising project, where massive crowd attendance is expected, depends on many factors. There should be a scientifically proven need which can be felt by the masses, a reliable organisation to move it forward and permission from legislative organisations and the government. The need was scientifically proven, and the project proposal was approved by the Department of National Planning in December 2015. Ministry of Health has considered it as a top priority and granted approval for a fundraising campaign in May 2016.

The planning was done by the Central Engineering Consultancy Bureau and land was allocated within the premises of LRH. Bank accounts were opened as instructed by the Ministry of Health. KPMG, one of the leading audit firms in the world, agreed to do the annual audit to maintain transparency of the fund-raising activities. A constitution was laid down as a guide and a clear statement was made that all donated funds will be utilised only for construction of the building.

The project was designed to attract public attention, a positive theme was created and a way to take the message to the public was arranged.

Infrastructure needed for smooth operation was completed by November 2016. All this was achieved thanks to the untiring effort of the four main organisations involved in the project, the guardians of Little hearts.

The Guardians of Little Hearts

Little Hearts could come this far because of the strength of the organisations that supported it. Mr. Sushena Ranathunga and his team at Creative Software Solutions was involved in the project from the first discussion onwards and took the responsibility of providing financial support, establishing and managing infrastructure like websites and payment gateways. These are integral components for smooth sailing of the project. Creative Software Solutions was the main driving force behind the project.

A project of this magnitude needs to be structured properly before it is launched. A negative message had to be converted to a positive message to raise public funds. The problem of 3000 children dying every year before reaching their first birthday due to heart diseases and critical illness had to be highlighted in a positive way so that that the society would donate rather than criticise the system. There was a need for an attractive name, logo and a theme for the project. Mr. Subash Pinnapola, one of the leading Chief Creative Officers in Sri Lanka volunteered to provide his services free of charge. The theme, "I have a beautiful heart", the name Little Hearts and the logo were all his concepts. His teams at TBWA and Storybook were responsible for creating the outlook of Little Hearts.

Sri Lanka College of Paediatricians(SLCP) is the apex professional body concerned about the healthcare needs of children of Sri Lanka. When the proposal for Little Heart project was tabled at the council meeting, the council unanimously decided to support the project and also to take it forward as it's own project. The support of a professional body is a great strength to the project.

Taking the message to the masses and delivering it within the limits of medical and media ethics was a herculean task. Manusath Derana at Derana TV agreed to come on board as the principle digital media partner of the project.



The project was launched on 20th November 2016 through an eight-hour TV program – a Telethon (Television Marathon) organised by the Derana TV, generating an unprecedented public response to the project.

These four organisations; Creative software solutions, Mr. Subhash Pinnapola and his team at TBWA and Storybook, Manusath Derana and Sri Lanka College of Paediatricians are the four pillars of success and hence called the guardians of Little Hearts.

The Public Response

The initial response, as expected, was from middle and low-income society. On the day of the launch, many donors came to Derana TV station and donated. A three-wheeler driver came at 4pm, in heavy rain, and donated all his earnings for the day. To encourage the school children to contribute to the project, a “Till Parade” was organised on 4th of December 2016. There was a continuous flow of donors, mainly children, who came to donate their till to save another child. We could raise over four million rupees in one day. The way people responded to the request was astounding. Donation of one day to one month salary, donation of what they have saved for years, donation of money after selling land and donation of their one month’s pension are to name a few.

Prison inmates of Welikada prison donated the cost of their one-day meal and Sri Lanka Army donated a half a day salary which amounted to Rs. 70 million. Even now, many companies including MAS holdings, Cambio software solutions are organising fundraising activities to contribute to Little Hearts.

Many organisations came forward to support Little Hearts. Shradha TV organised fund-raising walks to support Little Hearts. Green electric, Gamma Pharma, Maxis tyre, Kodomo toothpaste and ESoft came forward to share a percentage of their profits with Little Hearts. Dialog Axiata, one of the leading mobile service providers have opened up their loyalty points – Star Point donation to Little Hearts. DSL Stationaries joined hands with Little Hearts to market a pen and a pencil dedicated to Little Hearts.

A group of volunteers gathered around Little Hearts to support its fund-raising activities. An organisation named “Big Hearts for Little Hearts” was formed to formalise its activities. Their main target is to promote consumer items and gift items in aid of Little Hearts. A badge, a T shirt and a gift pack with a pen, pencil and a bookmark were their initial products.

These are only a few examples which show the public interest for a positive project to save the children of the nation.

The Project Progress

For a project to be a success, it needs a multifaceted approach. Fund raising is only one facet and there are many other facets to the big picture. Permissions, land allocation, construction, managing public opinion, maintenance of transparency and auditing are some of them. After many brainstorming sessions and considering opinion from many experts in the field, Sri Lanka College of Paediatricians have made a request to His Excellency the President to allocate the Civil Engineering division of Sri Lanka Navy for construction. The request was granted, and the Navy commenced ground preparation on 28th of April 2017. The corridors were relocated, and the ground was cleared, and foundation stone was laid on 2nd of October 2017. Tender for pile construction was advertised on 2nd of February 2018 and is in the process of evaluation and award. Hopefully, pile construction will commence in June 2018. A Memorandum of Understanding was signed among the Ministry of Health (MOH), SLCP and National Health Development Fund (NHDF) to define the responsibilities of each agency. Cabinet approval was granted and Rs. 300 million was allocated from the 2018 budget. This multifaceted approach is the main reason for success in the little hearts project.

Key Features of Success

Even though it is too early to comment on success, the distance that Little Hearts has travelled with the support of all segments of society is in itself is a success. There are key elements to this success. First and foremost is the magnitude of the problem and the reason for the problem.



Drive is easy if it is witnessed by everyone like Tsunami or floods but is difficult when it is restricted and hidden like congenital heart disease. The main task is to take the message to the society and to create an impact of a Tsunami in the society. The message needs to have the correct impact as otherwise it can generate a negative impact in the society. The second is the solution. It should be the best possible solution to the problem and should be a feasible and a viable solution in the long run. There shouldn't be a better alternate solution to the problem. The third and the most important is the methodology used to implement the solution. It should be a cost effective, transparent and fool proof method where accountability is maintained at every level. The fourth is the progress. The project should progress steadily with growing commitment from the community. Any negative remarks should be immediately attended to, with an explanation or rectification. The impact that Little Hearts has made up to now in the community is thanks to these key elements, which were meticulously planned right at the commencement of the project.

The Future of Little Hearts

Little Hearts has made a significant impact in the society up to now. However, to reach its ultimate goal, there is a long way upfront. Even though it appears to be a simple fund-raising campaign, it has much more to it. Scientifically, it is a project to bring down the infant mortality rate from the current 8 per 1000 live births to 4 per 1000 live births which falls within the Sustainable Development Goals set by the United Nations.

Socially, it is a project which helps the society think about the wellbeing of their own children and an opportunity to donate whatever they donate to a project that will remain and serve future generations. Morally, it helps healthy children to realise the value of the healthy heart they have received at no cost. When engaged in the project and having witnessed the effort taken by the parents and children with heart diseases, they will start to appreciate the value of their healthy heart. Society should realise the value of healthy lives we lose every day, due to suicide, road traffic accidents and domestic accidents which can be prevented at no cost.

Therefore, Little Hearts is not only a project to raise funds to construct a building. It is a project, with the support of all agencies concerned, that can change the mindset of the people to generate a better society in Sri Lanka.

References

1. Hoffman, J.I. and S. Kaplan, *The incidence of congenital heart disease*. *J Am Coll Cardiol*, 2002. **39**(12): p. 1890-900.
2. McCabe, C., K. Claxton, and A.J. Culyer, *The NICE cost-effectiveness threshold: what it is and what that means*. *Pharmacoeconomics*, 2008. **26**(9): p. 733-44.