Every Heartbeat Matters
Report 2017-18

Nepal Heart Foundation

Edwards LIFESCIENCES FOUNDATION

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Caring the Underserved Children

A Report on Heart Screening of School Children funded by Edwards Lifesciences Foundation 2017/18

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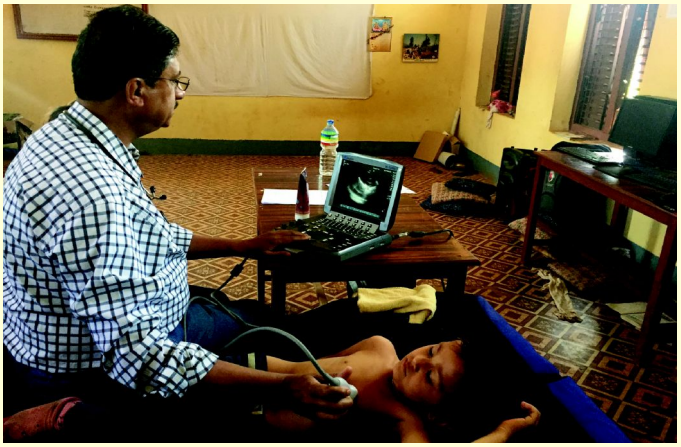
Rheumatic Heart Disease in Nepal

Nepal is a landlocked country bordered with China and India. Nepal has population of some 28 million people of which 80% lives in rural areas and 35% of population are under the age of 15. According to the UNDP Human Development Index, Nepal ranks in 144t^{h} position. More than a third of all Nepalese children are chronically undernourished and 47% of Nepalese women are illiterate. Three distinct geographical bands transverse the country: plains (bordering India), the hilly region, and the mountain region (bordering China). The country is prone to natural disasters including earthquakes, landslides and flooding, and is still recovering from a devastating earthquake that occurred in 2015. Poor roads and transport infrastructure and mountainous terrain leave many parts of Nepal extremely isolated.

Although the incidence of RHD has declined as living standards and access to health care have improved in many areas of Nepal (especially the urban areas), the disease remains common in many areas that are isolated and poor. Available data shows prevalence of RHD in Nepal that varies from 0.9 to 6.9 per 1000 children of age 5-15 yrs. There are around 100,000 existing RHD cases, every year 7500 new cases are added. There are 3000 deaths due to RHD annually and of them 35% are children.



Nepal Heart Foundation

The Nepal Heart Foundation (NHF) was formed in 1988 with aims to ensure a better life, free of heart disease, in Nepal. It helped the government establish Nepal's first center for advanced cardiac care.With a focus on prevention and public awareness, NHFworks to: strengthen health services for the prevention, diagnosis and treatment of heart diseases; help people with heart disease get the treatment they need; promote cardiac rehabilitation and lifestyle management; raise

public awareness about heart disease; advocate for policies that prevent it; and train health and community workers to recognize and treat it effectively.

With over 5,000 members and branches in almost all 77 districts across the country, NHF's current activities include: prevention and control of rheumatic heart disease; raising public awareness of risk factors for heart disease; promotion of rehabilitation for those with CVD; help to poor patients for covering costs related to heart surgery. It is advocating for establishment of regional heart hospitals in Butwal, Nepalgunj and Biratnagar. NHF District Unit Heart Clinics offer affordable outpatient health services in 4 districts to over 50,000 heart patients a year, and NHF mobile heart camps provide diagnostic services for over 10,000 heart patients yearly often in isolated areas. Nepal Heart Foundation belongs to the Nepal Heart Network and Nepal NCD Alliance, and is a member of the Asia Pacific Heart Network and the World Heart Federation.

NHF is registered with the government of Nepal as a not for profit organization and is affiliated to the Nepal Social Welfare Council.

NHF in RHD Control

Some of the founders of NHF were RHD suffers who had repeated valve surgeries in India. At the time, rheumatic heart disease was the most common heart problem in the country, but there were no facilities for surgery in Nepal, so NHF focused on helping patients

with advanced RHD to get over the border for life-saving surgery, and advocated with the government to establish advance cardiac care in country. It worked with the government to help establish ShahidGangalal National Heart Center.

In 2007, working closely with the Nepal Ministry of Health (MoH), the NHF founded Nepal's National Rheumatic Fever and Rheumatic Heart Disease Prevention and Control Program. Overall, the program has three objectives:

- To increase health system capacity for prevention, early identification and control of RHD.
- To raise public awareness on prevention and control of RHD.
- To identify, educate, counsel and refer people affected by RHD so that they can obtain needed measures of control or treatment.

To achieve these objectives, the NHF RHD program:

- Ensures Benzathine Penicillin G (BPG) supply to 39 RHD units in 25 districts located in all 7 of the newly-established states of Nepal
- Maintains a disease register
- Trains health workers in RHD prevention, identification, control and treatment
- Raises community awareness on RHD and how to prevent it
- Screens school pupils to identify the disease in early stages.
- Promotes primary prevention of RHD

Cardiac surgery is performed by three government hospitals in Kathmandu and the Government of Nepal covers the costs of surgery. Patients still must pay for diagnostic tests, medications and other expenses, as well as travel and accommodation for caregivers. The NHF offers small grants to help cover additional hospital costs for under privileged patients who receive cardiac surgery.

NHF RHD Screening Procedure

Since the earthquake in 2015, the NHF has screened over 75,000 children in more than districts of Nepal. In each district, a team of 6-8 (health professionals and staff of the Nepal Heart Foundation) make a 2-3 day visit to combine screening for case-finding of RHD and Congenital Heart Disease (CHD) in schools with awareness-raising among students, teachers and community members. These visits "connect the dots" of services for heart care in Nepal so that they function effectively and are accessible to those who need them. The visits are organized by the district branches of the Nepal Heart Foundation. Activities in school screening visits include:

- Auscultation of all students to identify those with murmurs (physicians & cardiologists)
- Echocardiography for all students with murmurs (cardiologists)
- 30-60 minute training in RHD for teachers and Health Professionals (Cardiologists and Physicians)
- 90-minute education session on RHD to students from grades 6-10 (RHD educator)
- Distribution of posters, pamphlets and stickers on RHD (NHF staff)

When students are identified with RHD or CHD, the team calls their parents or caretakers (who, if available, often come in to the school); the student, his/her parent, and teacher are given one-to-one counselling about the seriousness of the disease, its causes, the importance long-term secondary prophylaxis or other treatment needed (particularly for

RHD) and how to obtain it. The family is given a referral slip which is filled for the nearest RHD unit, heart clinic or heart hospital whichever is appropriate. When the screening is finished, the NHF team contacts the RHD unit to give the names and details of new RHD cases identified. The RHD cases are entered into the RHD register and they are followed up by telephone as are CHD cases.

After school visits are finished, the team usually makes one or more community education sessions on heart health in general (with RHD integrated). It may also, in parallel, organize heart camps for adults wishing to be screened for risk factors.

Edwards-funded activities 2017-2018

Screening visits to

Chitwan, Rupandehi, Arghakhanchi, Lalitpur, Kathmandu, Tanahun, Parsa, Jajarkot and Kavrepalanchok districts.

Chitwan District is situated in western region of Nepal at a distance of 98 Km from Kathmandu, which is remote and under developed challenged. Some 58.2% of land in lower tropical zone, 32.6% are in upper tropical and 6.7% are in subtropical zone. The place chandibhangyang of Chitwan where screening was conducted has 398200 population with 8.9% people living under poverty. The region has limited basic services and complex Socio-economic structures along with widespread gender and caste-based discrimination.

Rupdandehi District is on the southern and western part of Nepal with a population of 880196 and covers and area of 1360 Km2. It is the birthplace district of Lord Buddha and is touristic place. Some 16.1% of area lies in Churia range and rest in Terai region. Average Literacy rate is 72% while as of female is only 62%. 37.7% of children under the age of 5 are malnourished and 17.3% people living in rural areas are under the margin of poverty line.

Arghakhanchi District is on the southern part of Kathmandu with a distance of 227 Km from Kathmandu. 68% of land is mountainous in Arghakhanchi making it difficult to reach the development. 28.8% of population are under the poverty range, having them difficulty accessing health needs. All total of 13825 people lives in Sandhikharka VDC of Arghakhanchi of which 73% of people are literate.

Lalitpur District is major city of Nepal with population of 468132, area of 385 Km2 of area and poverty rate of 7.6%. 16.2% of children of below age 5 are malnourished. As it is a major city of Nepal, people across the cities of Nepal migrate to this region, making them vulnerable to endemic diseases. Migration of people has direct effect on health system and literacy of people.

Kathmandu District is capital city of Nepal with area of 395 sq. Km and with a population of 1744240, making one of the high-density cities. Poverty rate is 7.6% and literacy rate is 86%. Being a capital city is of major attraction to migrants from other cities of Nepal.

Tanahun District is on the Western developmental region of Nepal with a population of 323288. It is 110 Km west of Kathmandu. 14.8% of people are living under the poverty rate. Over 80% of population lives in the rural areas. Altitude of Tanahun district varies from 350 meters above sea level of 2325 meters.

Parsa District is on the central development region of Nepal with population of 601017 and having an area of 1353 sq. Km. Birjung is the headquarter of Parsa district and is major part of the Terai region of Nepal. Some 29.2% of people living in rural area of central Terai live below the poverty line. Madhise and Dalit comprises of 41% of total population of Parsa district is considered to be people with low income status people and those with low literate rate. Only 56 percent of population of Parsa is literate as per the census provided by Nepal. Though it is in the Terai best still it is considered underdeveloped areas of Nepal.

Jajarkot District is one of the hilly regions of Nepal which is underdeveloped and difficulty accessing areas of Nepal. Khalanga is the headquarter of Jajarkot and easily accessing via motor vehicle but farther away from, roads are still devoid of black tarred. Off road and mountainous geographical distribution has made people less accessible to health facilities, even the basic needs. 171304 number of people are living in Jajarkot. Poverty rate is of maximum of 37.7% and literacy rate is of 57%. Some 51.3% of children under the age of 5 are reported to be malnourished.

Kavrepalanchok District lies on the east of Kathmandu valley with a population of 381937. It is in the mid-hilly region and lies in the altitude of 280 meters to 3018 meters. Being an attraction place for the tourist, it has poverty rate below 13.9% and literacy rate is of 70%. Dhulikhel is the headquarter and is easily accessible by motorway.

Caring the Underserved

In Nepal, nearly all families with any discretionary income send their children to private schools; because of this, public school students are exclusively from the poorer, underserved populations, and new cases of RHD are still common there. In the private schools, which represent less than 10% of the children screened by NHF, RHD is uncommon and is largely from indigent students on scholarship; screening there is justified by an unchanged rate of Congenital Heart Disease.

Even those who have benefitted from a rise in living standard can still be considered underserved by the health system if they are living outside of Kathmandu: for most, to get to a facility offering valve surgery, or the systematic follow up that is required to ensure good outcomes for surgery (INR monitoring), or sometimes even having regular access to a trained cardiologist requires long travel of many hours, sometimes days, under difficult circumstances. As living standards rise and the disease declines, new cases of RHD come almost exclusively from the underserved and are a marker of poverty and exclusion. In New Zealand RHD is being tackled as a whole government priority as a marker of health inequality. So, worldwide nearly all new cases of RHD are underserved and any program targeting RHD prevention targets the underserved. NHF extends its activities to provide heart care services to the underserved.

Activities Performed (2017/18)

S.N.	District	Screening/Echo				Training			Advanced support		Public Awareness			
		Children Screened	Echos	Cases detected		Clinicians	Health workers Trained	Teachers Trained	Medical	Surgical	Students	Teachers	Lecture (approx.)	Media (approx.)
				RHD	CHD									
1.	Chitwan	307	145	4	6									
2.	Rupandehi	1527	171	3	4	47								
3.	Arghakhanchi	2590	225	2	8		38							
4.	Lalitpur	761	52	1	3									
5.	Kathmandu	3225	208	0	4		24							
6.	Tanahun		77	6	7									
7.	Parsa	6573	658	17	15									
8.	Jajarkot	6147	602	45	18		17							
9.	Kavre	2391	87	4	9									
10.	Morang						25							
11.	Palpa							59						
12.	Gulmi						16							
13.	Dhanusha						22							
14.	Surkhet						35							
Total		23521	2225	82	74	47	254	59	40	9	2535	321	1400	10000

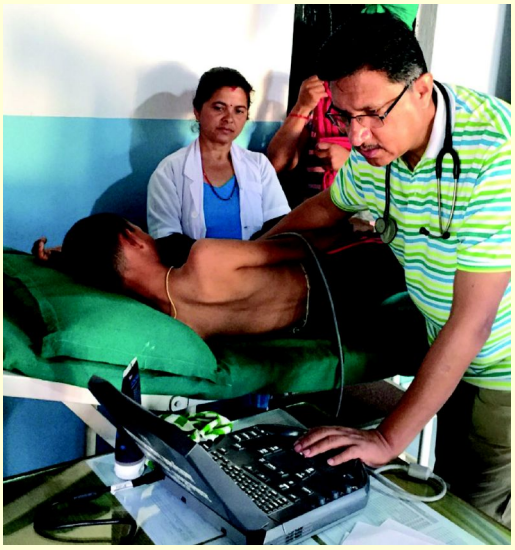
Screening: Total 23521


श्री महेन्द्र आदर्श उच्च माध्यमिक विद्यालय
SHREE MAHENDRA ADARSHA HIGHER SECONDARY SCHOOL


Children

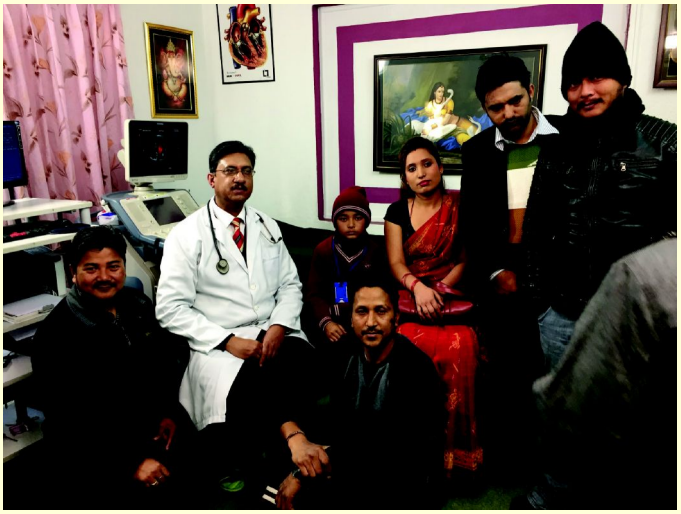

Heart Screening of School Children
Dadeldhura, Nepal

Echocardiography Testing: Total 2225 Positive Cases RHD 82, CHD 74

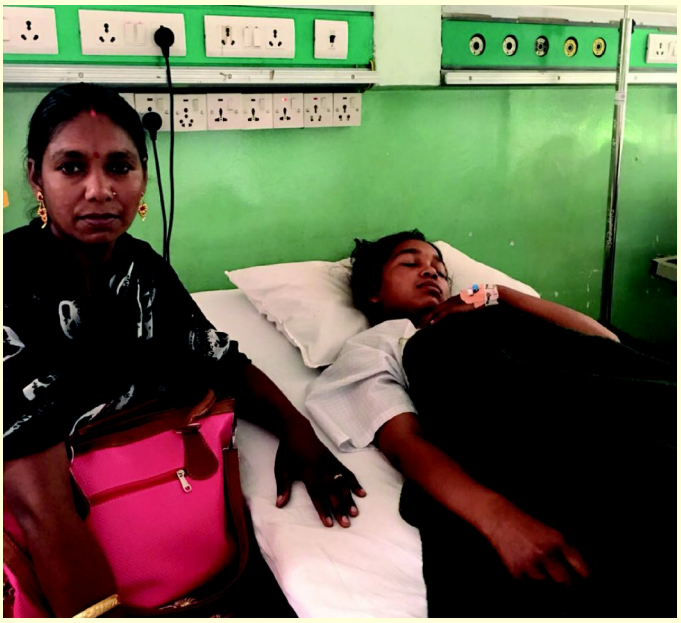


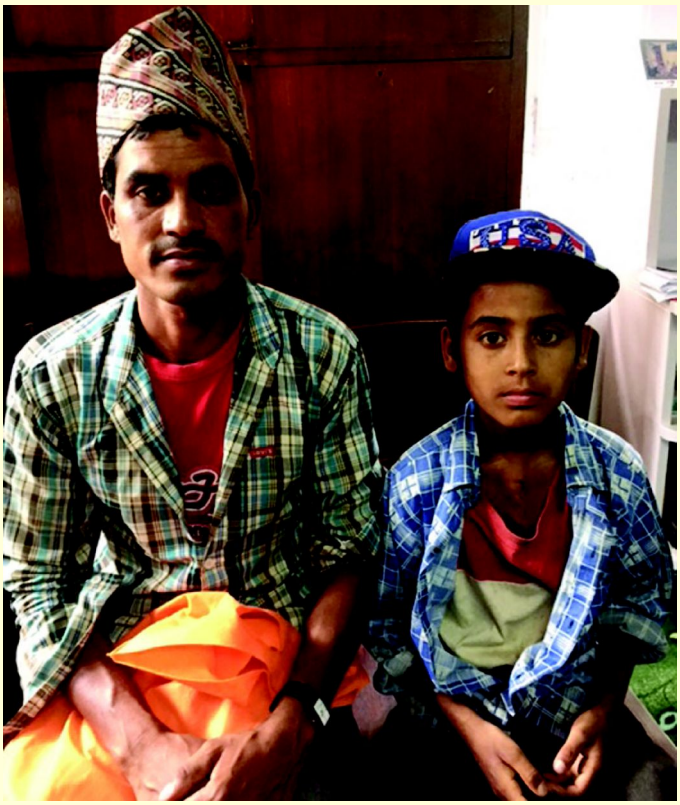
Heart Health Camp: Total 2 Jajarkot-600 Patients, Chitwan-200

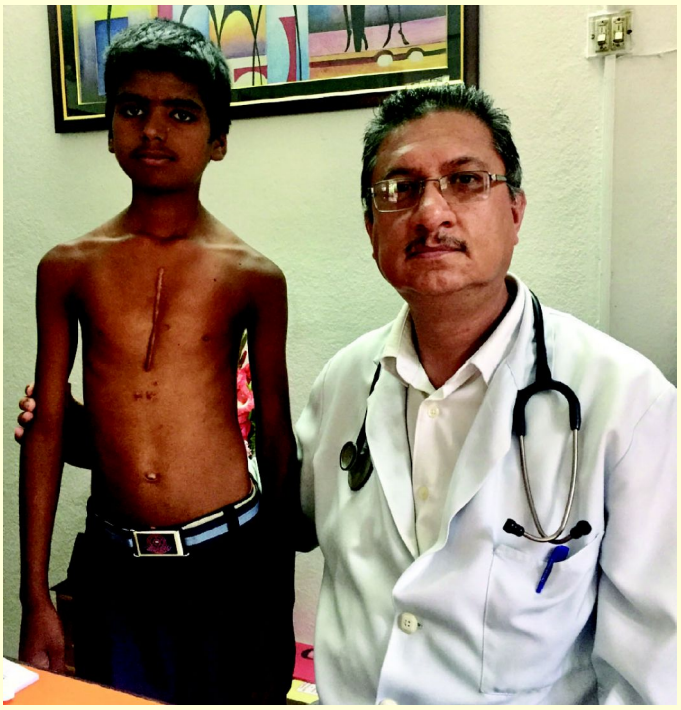
Public Awareness: Lectures, Radio, TV, Billboards, Pamphlets, Stickers, Calenders



Advanced Medical and Surgical Support: Medical-40, Surgical-9







Training on RHD: Clinicians-47, CHW-207, Teachers-59

Sustainability and Challenges

General Context.

While the NHF RHD program is run with the government of Nepal and through its staff, the Ministry of Health has many other higher-priority health problems that it struggles with. Even for its priorities, it often has difficulty systematically implementing the plans it makes, especially in the country's many remote districts. On top of these challenges there are the emergencies: far from still recovery other from the destruction and loss of life of the 2015 earthquake. This leaves RHD low on the government's agenda.

Through a decade of transition from monarchy to democracy, Nepal's political system has continued to evolve; the government is now being restructured under a new constitution. This offers new promise for increasing reach to isolated areas but often leaves action suspended while people figure out what new structures are, how to make them work and who is responsible for what. In this context, frequent changes in leadership make advocacy frustrating and reinforce the challenges of delivery or health services.

In spite of all these challenges there has been considerable progress improving the health and living standards of the population: over the past 20 years, infant and maternal mortality and stunting have declined dramatically, and there has been an impressive rise in literacy rates (especially for women) and school attendance. A decade has passed since the end of the civil war that toppled the monarchy: crime rates are low and violence is no longer a common problem. Remittances from labor abroad have transformed many parts of the countryside with an infusion of cash, improving the standard of living and access to health care. However, there are still many remote regions and vulnerable populations that have been left out of this progress.

RHD program

Globally, the NHF program is one of the few systematic programs of RHD control that exists in a low-income country; the World Heart FederationGlobal Status Report on RHD (p.41) has featured it as a model. In the decade since the program began, RHD incidence has decreased in many areas, as has the severity of new cases; the number of children and adolescents needing hospitalization and valve surgery has dropped. This improvement can be attributed to a combination of the program's success increasing awareness and health system capacity in RHD control, and the overall improvement in living standards and health status in the country. However, still one half of the districts of Nepal do not have RHD prevention units; many of these districts in the most isolated and underserved areas of the country and NHF has not yet had sufficient resources to reach them. While it has committed to extending the program to the whole country, the Government of Nepal has not yet delivered on this promise and has in some cases even decreased its support for RHD control. It has required constant advocacy just to sustain the government's commitment to the program, and expansion has occurred only in fits and starts.

Since the earthquake in 2015, an increase in external funding has permitted the NHF to extend its screening activities to many sites around the country, enabling it to screen over 75,000 children in 25 districts. In this screening it has found new cases of RHD in all areas, but with considerable variation in rates between districts. Increased screening has been complemented by NHF's work in awareness raising, including production and nationwide broadcasting of TV spots on RHD prevention and control and many other press activities, the integration of RHD messaging into school textbooks, the integration messaging into broader campaigns on CVD (like World Heart Day, or campaigns on women and heart disease), as well as a pilot in strengthening primary prevention.

There has been a growing global momentum to end RHD, and it is hoped that the new Resolution on RHD, which has passed at the 2018 World Health Assembly, will mobilize more political will in governments and technical assistance available from World Health Organization and other organizations like RhEACH. Since its beginning, NHF has consistently involved people affected by RHD in its activities, and this has strengthened the sustainability of its programs.

Lessons Learned

1. Screening can save lives only if it is backed up by comprehensive health services: systematic provision of BPG supply and capacity in health centers to administer it properly increased public awareness, systematic followup of RHD patients through a registry and for advanced cases, access to valve surgery. Even when these services are available, ensuring good referral and connection between them is constant work. Sustaining these systems is a prerequisite for responsible screening and should be the priority for all RHD action.

2. As the incidence of RHD decreases with rises in standards of living, efforts in casefinding and health system strengthening need to target more geographical "hot spots" or population groups that are excluded. If not, the experience and results generated may reinforce the misconception that RHD is no longer a problem and weaken efforts to address it where needed.
3. While civil society and private or charity can play an important role, RHD will not be eliminated without the sustained commitment of the government health services: all efforts to address RHD should be conducted in collaboration with Ministries of Health and through government services: this is not easy and requires constant advocacy to sustain political will and monitoring, training and coordination to increase health system capacity.
4. Provision of affordable valve surgery depends, on its outcomes, for systematic access to INR monitoring, which remains weak in most low-income settings like Nepal.
5. Even when it is provided for free, access to heart surgery is severely limited by logistics and extra costs to poor families or those in remote areas.

Priorities for the future

1. Ensure government supply of BPG to current RHD control units: the government has agreed to add BPG to the list of essential medicines provided to its hospitals free of charge, but there is more advocacy and monitoring needed to be sure it happens everywhere; NHF is still filling gaps.
2. Expand RHD control units nationwide, in collaboration with the MoH, and ensure integration of RHD into MoH services as they are restructured. The MoH has committed to do that but since then its leadership has changed and it will require ongoing advocacy.
3. Expand screening to reach new, isolated districts (but not before they have RHD units) and strengthen and expand coordination and analysis of data from register and other sources to have a clear idea of where the hot-spots are.
4. Ensure integration of primary prevention of RHD into government health services and expand promotion of sore throat treatment.
5. Expand systematic access of INR monitoring.
6. Focus RHD prevention activities on high endemic zones of Nepal.

Annual Budget and Expenditure of Edwards Lifesciences Foundation's Fund (2017-18)

Budget Heads	Budget Amount in US$	Expenditure Amount in NRP	Exceed Amount in NRP	TOTAL Amount
Expenditure Details		**(A)**	**(B)**	**(A + B)**
Heart Screening of 20,000 School Children	4,000	488,295	(73,095)	415,200
Echocardiography of 2,000 children	12,000	1,386,351	(140,751)	1,245,600
Registering of VHD cases, providing secondary prophylaxis, and follow up of children	1,000	103,800	-	103,800
Advanced Medical and Surgical Support 40cases	4,000	213,132	202,068	415,200
Ond Day Training to 200 health professionals for 4 times	4,000	355,893	59,307	415,200
Awareness activities	3,000	345,540	(34,140)	311,400
Transportation for field visit	3,000	327,617	(16,217)	311,400
Lodging and fooding for medical team outside Kathmandu	3,000	311,357	43	311,400
Administrative support	4,000	415,200	-	415,200
Medication	1,000	103,800	-	103,800
Miscellaneous (salary etc)	1,000	87,870	15,930	103,800
Total US$/NPR	**US$ 40,000 (NPR 4,152,000)**	**4,138,855**	**13,145**	**4,152,000**

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