



Nepal Heart
Foundation



EDWARDS
LIFESCIENCES
FOUNDATION

Nepal Heart Foundation Caring for Underserved Children

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

November 2017

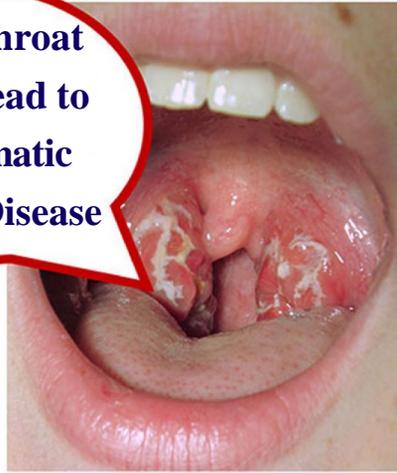


Nepal Heart Foundation, Central Office

Pulchowk, Lalitpur, Tel: 01-5009263, 9851051170, 9840070100

Email: nepalheartfoundation@yahoo.com, neh1988@gmail.com, Web: www.nepalheart.wix.com/nehf

**Sore Throat
May Lead to
Rheumatic
Heart Disease**



Nepal and Rheumatic Heart Disease

Nepal has a population of some 28 million people, of whom 35% are under the age of 15. Over 80% of the population lives in rural areas. Nepal ranks 144th on the UNDP Human Development Index. More than a third of all Nepali children are chronically undernourished and 47% of Nepali women are illiterate. Three distinct geographical bands traverse 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, and surgical facilities still do surgery on many cases of adolescents. A study of over 5,000 students in Eastern Nepal published in 2016 showed that for 15 year olds, the Echocardiography prevalence of RHD was 1/1000. The Nepal Heart Foundation registered around 9,000 patients with rheumatic fever and rheumatic heart disease.

Nepal Heart Foundation

The Nepal Heart Foundation (NHF) aims to ensure a better life, free of heart disease, in Nepal. Founded

in 1988, it helped the government establish Nepal's first center for advanced cardiac care. With a focus on prevention and public awareness, NHF works to: strengthen health services for the prevention, diagnosis and treatment of heart disease; 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 63 (of 75) districts across the country, NHF's current activities include: prevention and control 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 have 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 and Rheumatic Heart Disease

The NHF was originally founded by a patient with rheumatic heart disease 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 46 RHD units in 25 districts located in all 6 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 third 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 50,000 children in 75 schools in 15 districts of Nepal. In each district, a team of 6-8 (health professionals and staff of the Nepal Heart Foundation) made 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 (RHD educator)
- 90-minute education session on RHD with students in 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 CHD) and how to obtain it. The family is given a referral slip 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: Screening visits in Kailali, Dadeldhura, Rasuwa and Sarlahi

Kailali and Dadeldhura District are situated in far western region of Nepal which is remote and under developed challenged. Some 44% of people in the far west hills and 49% in the Himalayan districts live below the poverty line. The region has limited basic services and complex Socio-economic structures along with widespread gender and caste-based discrimination.

Rasuwa District is on the northern border of Nepal, in the Himalayan region; it has a population of some 43,000. It has a women's literacy rate of 46.5%. The team visited Dunche, which is about 3 hours' travel from the nearest RHD control unit and 6 hours' travel from Kathmandu.

Sarlahi District is on the Southern border of Nepal in the Terai (plains) region; it has a population of 7,70,000 and a women's literacy rate of 36.6%. There the NHF visited Lalbandi, Sarlahi which is about 2 hours' travel from the nearest RHD control unit and 7 hours' travel from Kathmandu.



Defining 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



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, Nepal had disastrous flooding this year that killed over 100 people and caused damages estimated in the billions. 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 of 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 decline 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 Federation Global 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 50,000 children in 15 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 the World Heart Federation and the government of New Zealand are working to pass at the 2018 World Health Assembly with the support of many other countries, 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.

- 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.

- Ensure integration of primary prevention of RHD into government health services and expand promotion of sore throat treatment.
- Expand systematic access of INR monitoring.

Expenses Statement

S.N.	Topic	Budget in US \$	Budget in NRs	Total Expenses in US \$	Total Expenses in NRs	Remaining in US \$	Remaining in NRs
1	Heart Screening of 10,000 School Children	2,000.00	205,500	2,002.80	205,788	(2.80)	(288)
2	Echocardiography of 1,000 children	6,000.00	616,500	6,042.00	620,815	(42.00)	(4,315)
3	Registering of RHD cases, providing secondary prophylaxis, and follow up of children	500.00	51,375	508.52	52,250	(8.52)	(875)
3	Advanced Medical and Surgical Support	1,500.00	154,125	1,494.48	153,558	5.52	567
4	Training of Trainers (TOT) training for 16 Medical Officers for 5 days	4,000.00	411,000	3,992.27	410,206	7.73	794
5	Awareness activities	2,000.00	205,500	2,067.51	212,437	(67.51)	(6,937)
6	Transportation for field visit	1,500.00	154,125	1,500.10	154,135	(0.10)	(10)
7	Administrative support	2,000.00	205,500	1,944.43	199,790	55.57	5,710
8	Miscellaneous (salary, audit charge)	475.00	48,806	417.67	42,916	57.32	5,890
	TOTAL	19,975.00	2,052,431	19,969.78	2,051,895	5.22	536

टन्सिलको उपचार नगरे बाथ मुटु रोग लाग्न सक्छ ।

बालबालिकाको मुटु बचाउँ ।

बालबालिकाहरुको घाँटी दुख्दा, टन्सिल बढ्दा, पाक्दा, हात खुट्टाका जोर्नीहरु दुख्दा, औषधि नगरे बाथ मुटुरोग लाग्न सक्छ । सावधान !

Nepal Rheumatic Heart Disease Prevention Program



Nepal Heart Foundation



EDWARDS LIFESCIENCES FOUNDATION

Photo Features

