

Community, Hope and Rehabilitation

HART visit to Myanmar and Chiang Mai



SWAN CHW's: Nang Mwe Khao, Nang Shwe Hean, Nang Kharn Wyo, San Pount, Lauo Nguen

HUMANITARIAN AID RELIEF TRUST

APRIL 2019

*“You showed us light in a time of darkness, hope in a time of despair
and most importantly, you gave us the unbreakable bond of
sisterhood.”*

Ying Lao, SWAN advisory member

*“We want to see the use of political means to solve the issues rather
than weapons.”*

Nang Harn Noan, SWAN Co-Founder

*“Many people are dying from disabilities because of a lack of
services. The people who are surviving must be in a very bad
condition, isolated from their community.”*

*Vardan Tadevosyan, HART partner and disability
rehabilitation therapy specialist*

*“There are no government clinics in my area. For emergency
cases, it is a 2-3 hour drive to hospital by car which is almost
impossible in the rainy season with flooding and mud.”*

Lauo Nguen, SWAN Community Health Worker

*“We hope to become an example for the other schools along the
border about how to increase food security and access to water.”*

Larn Tai, Director of Education for Shan State

*“We need more skills training for CHW’s so they can better respond
to needs in their communities.”*

Ying Charm Hom, SWAN Education Director

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List of Abbreviations

HART	Humanitarian Aid Relief Trust
SWAN	Shan Women's Action Network
KWAT	Kachin Women's Association Thailand
UNHCR	United Nations High Commission for Refugees
ICRC	International Committee of the Red Cross
IDP	Internally Displaced People
CHW	Community Health Worker
CBR	Community Based Rehabilitation

Executive Summary

HART exists to provide aid and advocacy for people in conflict and post-conflict situations who do not receive help from major aid organisations. We work with and through local partners who continuously inspire us with their resourcefulness and resilience, making transformational changes for their communities in very challenging contexts.

In Myanmar, we have provided more than 10 years of support for our partners in Shan State with SWAN (Shan Women's Action Network); Chin State with Dr Sasa's Health and Hope Programme; Kachin State with KWAT (Kachin Women's Association Thailand) and, in previous years, we worked alongside the Karen people.

Our research has revealed a significant lack of provisions for people with disabilities in Myanmar. Most notably, in the remote areas where our partners operate, people living with disabilities have zero access to any type of relevant care, causing them to suffer greatly. They become a burden on their families and too often die prematurely.

With this in mind, HART has sought to connect the knowledge and expertise of HART partner Vardan Tadevosyan in Nagorno-Karabakh with that of our Burmese partners. Since 1999, Baroness Cox has supported Vardan in his provision of disability rehabilitation in a once bomb-damaged school building that Vardan has transformed into an internationally recognised Centre of Excellence. He has trained more than 60 staff to provide therapeutic services for more than 1,000 people per year suffering from both physical and psychological disabilities (such as infants with cerebral palsy and Downs Syndrome, to children with autism and elderly people with strokes). Vardan's experience in providing such education in a post-conflict zone means that he is distinctively equipped to provide care for the disabled in Myanmar.

Building on existing relationships with our colleagues in Chin, Shan, Kachin and Karen States, HART hopes initially to bring 20 CHW's together for training in disability care. These will then return to their remote communities to provide help for people with disabilities and share knowledge with colleagues to initiate a multiplier effect.

Having travelled to Myanmar with the HART team, Vardan was able to assess the potential for training CHW's. Hoping to improve the understanding of the concept of rehabilitation, he highlighted his priority to "improve disabled mobility, independence,

walking skills, wheelchair use and self-care”. These improvements will give disabled people more confidence and opportunity to integrate into their community, increasing their self-esteem and reducing stigma surrounding disability.



Uniting HART's partners

Ying Charm Hom (SWAN Education Director) with Dr.Sasa (Health & Hope, Chin State, right) and Vardan Tadevosyan (Founder of the Lady Cox Rehabilitation Centre in Nagorno-Karabakh, left)

Celebrating 20 Years of SWAN

The HART team's first stop was in Taunggyi, the capital of Shan State, to celebrate with the SWAN team on their 20th Anniversary. Attended by SWAN staff, founders, advisory team members, partner organisations and supporters, the event consisted of several exhibitions which exemplified SWAN's commitment and success over the last 20 years. The programme offered a photo exhibition and traditional dancing, as well as a variety of inspirational speeches by those present when the organisation was founded in 1999, which provided an array of avenues to explore SWAN's rich 20 year journey of activism.

SWAN was established to provide education, healthcare and wellbeing support to Shan women and children. Initially the organisation was set up to provide quality care for those arriving as refugees at the Thai border following on-going persecution by the Burmese military, most notably since the displacement of more than 300,000 Shan people in 1996.

“Shan people were not recognised as refugees in Thailand and they had to work in fields as migrant workers. Women and children had no support - that was a motivator to start up SWAN.” – **Nang Lao Liang Won, SWAN Co-founder**



A celebration of HART's partners: (from left) David Thomas, Ying Charm Hom, Nang Hearn Noan, Dr.Sasa, Baroness Cox and Vardan Tadevosyan arrive at SWAN's celebrations

At the celebration, the key speakers addressed the ongoing problems that SWAN faces. Concern was expressed for the newly displaced women and children caught up in the current conflict in northern Shan State and the widespread intolerance of diversity they face. Stressing the importance of collaborating with other national women's organisations,

SWAN's Education Director Ying Charm Hom explained that “we used collective sisterhood and determination to drive us forward in our mission”.

As a progressive organisation, SWAN operates under collective leadership in order to bring an end to gender discrimination. With a commitment to support not just Shan people but also women from other ethnic minorities in Myanmar, SWAN advisory member Ying Lao claimed “any criticism we get drives us and makes us work harder [because] any backlash shows us that we are making change”.



The SWAN team at its 20th Anniversary celebrations

“We would like to renew our commitment to bring social justice and gender equality to our community” – **Nang Harn Noan, SWAN Co-Founder**

Success stories from SWAN CHW's

For the last 3 years, HART has funded SWAN's Women's Wellbeing Programme (WWP). The programme facilitates two training workshops for CHW's, as well as 30 reproductive health sessions for women and adolescents, 30 health education sessions in primary schools (including toothbrush and toothpaste provision), reproductive health services for women and the development and dissemination of health education material. Annually, the programme remains one of HART's key funding priorities as it is crucial to SWAN in maintaining its long history of increasing the contraceptive prevalence rate in Shan State, reducing maternal, child and infant mortalities.

Whilst in Taunggyi, the HART team took the opportunity to visit one of SWAN's training centres to hear from some of those CHW's who are crucial to the WWP.

San Pount (34 years old) told us of the main challenges in community health that CHW's face in the field:

"Lack of medicine and vitamins is a threat to mothers and children because there is no milk, no protein and an unbalanced diet."

"Poverty is the biggest challenge. Many rural women cannot afford food or clothes."

"In the nearest hospital, there are only three members of staff – one doctor, one nurse and one administrator."

The CHW's whom we met in Taunggyi are highly motivated volunteers who work in a notably self-sacrificing way. Where poor families cannot afford treatment, the CHW's often pay for medicine and medical supplies out of their own pockets.

“We feel great compassion for all the needs of the especially poor families but feel powerless to help more. Money is a great challenge in the villages I serve. Even at hospital, you won’t be seen at all unless you pay upfront, even in emergencies.”



Lauo Nguen, SWAN CHW



“Right now, we have no salary. SWAN can only support our transport and a small stipend. If I had a salary, I would be a CHW full-time because there are more people to help.”

San Pount, SWAN CHW

The HART team was deeply moved listening to some of the stories that the CHW’s told us that afternoon:

“In a remote village, one lady did not inform us that she was pregnant and due to give birth. After she gave birth at midnight, a fellow CHW received an urgent call at 5am because the placenta was not coming out. The mother was in distress, had lost a lot of blood and was very pale. The CHW urgently needed to get the mother to a hospital but it was rainy season and they needed a good car. After finding a car but no driver, the CHW (with only a learner’s licence) took matters in to her own hands and drove the mother for several hours, reaching the hospital at 11am, having borrowed money at her own risk to ensure the mother was seen upon arrival.”

Lauo Nguen, SWAN CHW

We learnt that the doctor was able to remove the placenta without surgery and the mother survived and recovered.



Swan health workers: Nang Mwe Khao, Nang Shwe Hean, Nang Kharn Wyo, San Pount and Lauo Nguen with her 2 year old child

Nang Mwe Khao, also shared some of her extraordinary experiences as a CHW:

“A man arrived on a motorbike and told me that his wife has been in labour for two days. I was reluctant to go with him because I did not want to get on a motorbike with an unknown man. He kept begging, so I agreed to go. It was a five-hour ride back to his village. His wife was only 4 feet tall and the baby was large. I was able to deliver the baby, but it was not breathing. I resuscitated it by mouth-to-mouth but then realised that the mother was in trouble. Her blood pressure had dropped very low. I put her on a drip, but that was not enough. So she put a drip in the other arm also, and the woman finally began to recover. The family was very poor and only had a tiny hut, but I stayed for two days to feed the lady soup, before I travelled for 5 hours back home.”

Nang Mwe Khao continued:

“Once I was doing an antenatal check on a pregnant woman. When I listened with a stethoscope, I heard two heartbeats. The woman was very small and I told her to go to hospital, but she refused. I became very nervous because I had never delivered twins before. When the time for birth came, the woman began bleeding profusely. Her heartbeat was getting faster and her blood pressure was dropping. I put a drip into each arm and put one hand inside the woman against her uterus, pressing my other hand on her uterus from the outside. The pressure was enough to stop the bleeding and the woman lived.”



Nang Shwe Hean, Dr Sasa, Vardan Tadevosyan, Nang Kharn Qyo, Baroness Cox and Nang Mwe Khao share stories about working in remote communities

An update from Loi Tai Leng School

During the visit, HART Fundraising & Communications Executive, Lola Yusuf and HART Trustee, Jo Russell separated from their colleagues to visit Loi Tai Leng School along the Thai/Myanmar border, which HART supports via SWAN.

In October 2017, cross-border aid was cut in order to be redirected to the Rohingya suffering persecution in Western Myanmar. This resulted in a severe food shortage and the closure of two dormitories at schools along the border. Mwe (responsible for all 6 schools for displaced children along the border) explained that the soil around Loi Tai Leng School is infertile and therefore unable to provide adequate farming opportunities and food.

With funding from HART in January 2019, a new dam has been built in the valley below Loi Tai Leng School. Water from the dam has facilitated agricultural development to improve school food security and nutrition awareness for children, as well as to facilitate a fish farm.



The dam made out of bamboo, located in a jungle clearing below Loi Tai Leng School

Larn Tai (Director of Education for Shan State) showed Lola and Jo the newly established farm and he was keen to outline his main intentions for the future of the dam.



The farm will produce food for Loi Tai Leng school and most crucially, for its 400 students who board. As food aid was cut, the need for a balanced and nutritious diet for the 700 students at the School has soared since they mostly now live on rice, provided by the Shan State Army.

Larn Tai hopes that the farm will become an agricultural child-learning centre where people from all over Shan State can go to learn techniques in sustainable agriculture and self-sufficiency.

Due to the farm's proximity to Thailand, Larn Tai plans to invite agricultural specialists as guest speakers to train the local people.

"Every time I come here it makes me happy because we have been waiting for a dam for 10 years. Thank you to HART for making it happen."

Larn Tai, Director of Education in Shan State

Whilst the cut to food aid was immediate and devastating at the end of 2017, Larn Tai has been extraordinary in his resilience and drive to help combat local food insecurity. Through improving water and food accessibility, Larn Tai's dam project is now an inspirational example to the other 5 IDP schools along the border about what can be achieved. Through this initiative, Larn Tai is striving for Loi Tai Leng School to grow less dependent on foreign assistance and more innovative in its approach to food security.

Hearing from students and teachers at Loi Tai Leng School

We learned of the difficulty in keeping teachers within displacement schools due to a monthly salary equivalent to only £62.50. Meeting with students and staff from Loi Tai Leng School, we were informed of the school's array of needs. Most notably, both students and teachers wish for a volunteer English teacher.



"We need more English teachers because we don't have enough. To study at University, we need to know how to speak English. It is necessary for all higher education."

Nang Ying, 18-year-old high school student

"We really need an English teacher to teach the staff so that they can communicate with foreigners who come to help."

School headmaster, Su Meh Na aka 'Super'



"We need more qualified teachers. The whole world uses English and I want to be able to communicate with other people."

Lurn Kham, 18-year-old high school student

We were told of an overwhelming need for electricity, particularly during the rainy season when the existing solar panels are inadequate to power the 8 dormitories, dining hall and computer room. For this, Larn Tai discussed his ambition to use the dam to produce hydroelectric power.

Santi, a Grade 10 teacher at the school, told us that “food aid is desperately needed”. He asked us to continue sharing their story and always remember their community of displaced people trying to sustain a livelihood in difficult and uncertain times.



Sunset over the boys' dormitories at Loi Tai Leng School

Partnership with Dr Sasa and Health & Hope

Health and Hope was founded 10 years ago by Dr Sasa, who originates from Chin State and completed his medical studies in Armenia. His passion was to train CHW's to provide life-saving health care in remote villages where there was no healthcare at all. His training enables these CHW's to save the lives of 8 out of 10 people who would previously have died from preventable or treatable illnesses.

Dr Sasa has since fundraised to enable 10 doctors and 11 nurses to study overseas in countries such as India and the Philippines. With this close-knit, young team he has now been able to train 1000 CHW's, who provide life-saving primary health care in Chin State and Rakhine State.

Health and Hope began in Lailenpi, a remote village in Chin State. It has since established an office in Yangon, through which it provided hospitality and logistical support for the HART team's visit. Recently, Dr Sasa advocated with the UNHCR to prevent the forced return of refugees from Chin State back from India and Malaysia. He convinced UNHCR that continuing conflict made it unsafe for them to return. As HART had already been advocating for these refugees, we were very happy to hear of Dr Sasa's achievement.



The HART and Health & Hope teams, with Dr. Sasa in the centre

A series of providential meetings enabled Dr Sasa to enhance the value of HART's visit. Through the British Ambassador, Dr Sasa was able to meet the head of the ICRC in Myanmar, who in turn introduced him to the head of the World Bank in South-East Asia. Subsequent meetings arranged for the HART team provided useful contacts for HART as a basis for developing relevant relationships.

Project launch: CHARM (Community, Hope and Rehabilitation in Myanmar)

The project

A key objective of HART's 2019 visit to Myanmar was to explore the possibility of launching a project that will provide education and training for CHW's to help people with disabilities in Myanmar. The project's title is CHARM – Community, Hope and Rehabilitation in Myanmar.

To enable a cross-fertilisation of ideas, HART introduced Vardan to a series of in-country partners and facilitated a meeting with Gevorg Sargysyan, head of the World Bank for Myanmar, Cambodia, Laos and Vietnam. Additionally, Vardan and the team met with Stephan Sakalian, head of the ICRC in Myanmar.

People in Myanmar living with disabilities have a generally poor and sometimes tragically low quality of life. Understanding of their needs is poorly developed, and there are few facilities to help them to integrate into the community.

Due to a lack of training, teachers frequently exclude disabled children from school. Adults with disabilities often suffer stigma and discrimination, and remain out of sight at home, where they lack social inclusion and meaningful opportunities to contribute economically.

Meanwhile the number of people in Myanmar who are trained in the field of physiotherapy and occupational therapy is very low compared to neighbouring countries. Without the input of foreign professionals, it is consequently difficult, if not impossible, to initiate programmes which could rectify these serious problems.

The aim of the CHARM project is to provide training for CHW's from remote areas in basic treatment and rehabilitation for people with disabilities. Through enhancing mobility, preventing and healing pressure sores and changing attitudes and behaviours in the wider community, the project will create greater independence and a better quality

of life for people with disabilities. As stigma is reduced, those with disabilities will gain increased self-esteem and CHW's can begin to integrate disabled children into schools.

HART has worked for more than a decade in Myanmar with partners who are firmly community-based and have extensive outreach programmes. This enables collaboration with colleagues in whom HART has confidence and makes it possible to reach the people in need who live in the most remote communities.

Yangon Findings

In Yangon the HART team met Dr Mike Griffiths, a physician who has been in Myanmar since 2003. From 2003-2012 he was Director of the Leprosy Mission in Myanmar. Since 2011 he has been conducting research around social welfare and has written a national strategic plan of action for people with a disability.

Dr Griffiths reminded HART of the context in which they will be working and that Myanmar is suffering from the world's longest running civil war, which has been going for 70 years. He explained that under the current government, there is a National Strategic Plan for Social Protection, which has been designed by UNICEF and is based around cash grants. This initiative is currently driving the country's disability policy.

Surveys in Myanmar, meanwhile, have shown that people with a disability are most interested in being able to earn a livelihood of their own, having appropriate housing and access to education or pensions.

With this in mind, Dr Griffith's opinion of the most likely effective approach is Community Based Rehabilitation (CBR), which assesses how people with disabilities are supported by, and contribute to, their local community. This takes a social welfare approach to disability rather than merely medical or financial.

A further step would be Community-Based Inclusive Development (CBID), which seeks to benefit the whole community, while focusing on those within it who have a disability.

This 'bottom up' approach is based around 3 simple questions:

1. *What do people with a disability want to do?*
2. *What's stopping them?*
3. *What are we going to do about it?*

Discussions with Dr Griffiths have helped to create a longer-term strategy to complement the medical and educational work of Vardan, which will include treatment, healing, mobility, social inclusion, employment opportunities and eradication of stigma.

The Ayemyitta Rehabilitation Centre

The HART team visited the Ayemyitta Centre in Yangon, which was founded to care for children with a range of disabilities. It is situated in a poor township with a population of 800,000 from which it draws the majority of the children for whom it cares. The Centre has 108 children, of whom 22 are boarders. Their disabilities include blindness, deafness, Down's syndrome, cerebral palsy and autism.



Dr Sasa with a young boy at the Ayemyitta Rehabilitation Centre

The team was deeply impressed by the loving care which the centre provides, and the consequent peaceful atmosphere. The centre has won a grant to build a 3-storey extension behind the current building which is now under construction. It will be equipped with a lift and ramps, and have room for an indoor playground, classrooms and dormitories.

The Centre is recognised by the Myanmar government, from which it receives a small annual grant to help with running costs. Its facilities provide a possible venue for the rehabilitation training which HART intends to initiate.

The McKean Hospital

Whilst in Chiang Mai, the HART team took the opportunity to visit Dr Heather Smith at the McKean Hospital, which was originally established to treat leprosy. Heather and her husband Trevor have served in Chiang Mai for several years, and as the number of leprosy cases declined, they gradually transformed the hospital into a centre for people with disabilities. It now primarily focuses on care for the elderly.

When Heather started working with people with a disability, she realised that families were often unable to bring disabled members to the hospital. So she pioneered CBR, where the community was the primary provider of care and the hospital was available for additional support.

Heather and her team asked villagers what they would like to achieve and then calculated which practical aids and equipment –such as wheelchairs and catheters - would be needed to achieve these goals. Financial cost to the hospital was relatively low as villagers offered their assistance in making their own equipment. The hospital provided ideas for income generation and set up local disability centres, using existing buildings such as Church halls. It also established a child disability rehabilitation project through sending out mobile teams of physiotherapists, nurses and occupational therapists.

HART will draw on such models of low-budget, community-based and integrated development as it develops CHARM, its own project for people with disabilities.

Stories from Kachin Women's Association Thailand

Kachin State is currently experiencing some of the worst conflict in Myanmar. Although a 4-month ceasefire has brought a cessation of aerial bombardment, fighting on the ground has continued.

KWAT supports vulnerable women and children either living as refugees in Thailand or living in IDP camps in Kachin State, along the China/Myanmar border. We were told that China has recently blocked the movement of refugees into its country but women continue to be trafficked across the border for work.

KWAT provides assistance to people who have been disabled from the conflict. Eager to build on this work, Vardan shared his vision of training CHW's in the rehabilitation of disabled people.

'Uncle Stan's' advice for CHARM

The HART team visited SWAN's headquarters in Chiang Mai to meet with some of their team, including Stanley Zankel also known as Uncle Stan. Uncle Stan is a Public Health specialist with over forty years of experience in the region.

The team was eager to hear Uncle Stan's thoughts on the CHARM project and he was clear in his explanation of project requirements. He told us that "you have to have outreach - if you don't go to your patients, it won't work". Uncle Stan confirmed Vardan's belief that "even if you train CHW's, there won't be much impact if the CHW's don't go into the home and train the families".

Most crucially, Uncle Stan shed light on the need for a professional co-trainer/translator. "Not just a normal translator, but someone that also knows what they are talking about so that they can translate the correct medical terminology."



The HART team
with Uncle Stan
and Nang Hearn
(former Director
of SWAN)

Vardan's concluding thoughts

Discussing the basic rehabilitation skills he would introduce, Vardan stressed the importance of "improving disabled mobility including walking strength and skills, using a wheelchair, and practicing self-care such as bathing and dressing, as well as preventing pressure sores".

Repeatedly, Vardan stressed the importance of training CHW's in how to train the families of disabled people - "CHW's won't be with the patients all of the time, so it is crucial that families are properly trained in the simple methods to improve their disabled family member's lives."

Vardan's next steps are to draft a 6-day curriculum for an initial training week for 5 CHW's from each of four regions in Myanmar and identify which of his staff from Nagorno-Karabakh to bring to assist training.

HART is now seeking funding to support the training week, the first step in this exciting project.

We will subsequently need financial resources to fund the next stage of the programme. This would involve visits by Vardan and colleagues from his rehabilitation centre to the locations in Myanmar where the CHW's are working. The purpose of these visits would be to monitor, assess and affirm the work of the CHW's and to provide further training for more local CHW's. This would expand professional knowledge and treatment capabilities for a further 20-25 CHW's in each region, which would serve as a basis for a 'multiplier effect'. We hope this will promote expansion of knowledge and care for people with disabilities throughout increasing numbers of locations and regions in Myanmar.



Vardan showing SWAN CHW's a basic example of mobility therapy

Acknowledgments

At the core of HART's ethos is a commitment to working in partnership with local people. All of our projects are locally-led from vision through to implementation by partners who possess the requisite knowledge, skills and commitment to find and deliver appropriate solutions.

HART wishes to thank everyone who made us welcome and who provided the help we needed to accomplish our visit, including Larn Tai (Director of Education for Shan State), Ying Charm Hom (SWAN Education Director), Dr Sasa (Founder of Health & Hope) and Vardan Tadevosyan (Founder of the Lady Cox Rehabilitation Centre).

We also thank all who spoke to us, sharing information and advice. We are particularly grateful for the grace and dignity with which we were received by people living in extremely difficult conditions. We will try to be a voice for them and make known their needs. In doing so, we hope to obtain the necessary funding for the CHARM project in order to bring help, hope and transformational change for disabled people in Myanmar.



Baroness Cox and the HART team celebrate SWAN's achievements and partner collaboration with Ying Charm Hom, Dr Sasa, Vardan and SWAN CHW's