

From Wendy at the top of the world – Thalassaemia in the Himalayas



Wendy with Harimaya

As I walked down a busy street in Thailand and saw a tiny sign in a travel agent's window saying... "2 week return ticket to Nepal – 170\$" I had no idea how my life was about to change! I had been a traveler for 15 years already and was once again happily on one of my many 4 -5 month trips of a lifetime in Asia. Though Nepal was not on the agenda this trip I could not resist such an opportunity so... I bought the ticket!

Having already traveled in over 27 countries, Nepal stole my heart from the moment I arrived, so much so that I decided to return and help rebuild a small school in the village (Pokhara) of the owner of the guest house I was staying in. A year later I was back fulfilling my dream. It was then that I met little Harimaya Upreti... She was barely alive and at the age of 5 she was the size of a 2 year old. I immediately asked permission to take her to the local health post for treatment but sadly they could not help us so it was decided that we would go to the capital, Kathmandu (Ktm) for further investigations. I'm pretty sure it was Harimaya's father's first trip to Nepal's biggest city.

It soon emerged that Harimaya was suffering from thalassaemia, and that her two older sisters who had already passed away had probably been suffering from the same condition. My world fell apart. How would we ever save this beautiful little girl? it would be near on impossible for Harimaya to have regular blood transfusions - her father is a very poor farmer in a remote village; and the idea of taking the long bus journey to Kathmandu every two weeks and staying overnight for treatment was just a distant pipe dream. There is no National Health Service in Nepal. Basic health care is a privilege that very few people have the means to afford.

It was then that I came in contact (purely by fluke) with Durga Patak, the founder of the Nepal Thalassaemia Society (NTS); whose niece is also a thalassaemic. Things were about to change! My husband and I managed to convince Harimaya's father that if he could commit to maintaining regular trips to Ktm, it would be very good for his reputation in the village (reputation is of the utmost importance in Nepal). We also promised that we would be committed to helping him physically and financially with her health for the rest of her life. With the help of Durga giving practical help on a 2 weekly basis and my Uncle Patrick giving financial help from his pension in the UK, 4 years on Harimaya is leading a full and healthy life and her father has not missed a single appointment!

It was through all this I decided to support and help Durga and NTS as much as I possibly could. On my last trip to the UK I decided to run a half marathon to raise funds for the Society. Enough money was raised to provide free blood for one year for almost all the registered patients; and a blood project is due to be launched on August 1st this year.

The Nepal Thalassaemia Society was established in 2004 with the goal of creating a thalassaemia free society. It was established by the parents of thalassaemic

children and associate professionals. NTS is a registered independent, non-profit social organization solely committed to the welfare and dignified living of thalassaemic children. It receives no government funding and is totally funded by donation. This is the only organization that is available to help people with thalassaemia in Nepal.

Thalassaemics are scattered in Nepal, they are not in one particular area and ethnic community. Most parents of the patients have no knowledge of this condition. The patients in the rural villages are taken to local health posts where there are no required facilities for check-ups. Local health workers prescribe iron tonic and iron containing food items. Very often this treatment proves only to be more



Harimaya with her parents

detrimental to the patients since increased amounts of iron only further aggravates their condition. In most of the rural parts of the country people have access only to either their local health post or to the village faith healers or shamans. A very small number of people from rural areas can afford a bus ticket into Kathmandu, let alone the costs for a regular check-up in a big hospital in the capital.

Some of the families have been reported to have waited until the child's Hb level had dropped all the way down to 2.8gm/L before obtaining a blood transfusion for their child and still others simply cannot



Upreti family with Durga Pathak, Founder of the Nepal Thalassaemia Society

afford the costs of treatment and are compelled to make the most horrible decision a parent ever has to make; to let their sick child die in order to sustain the rest of the family. In short, these parents can not afford to keep their thalassaemic child.

We have 52 recorded thalassaemics and we are sure that there are many more yet to contact us. Out of 52, 16 are from Kathmandu and 36 are outside of the Kathmandu valley. Patients from Kathmandu are regularly getting packed cell blood transfusion but the 36 patients from outside Kathmandu are not

regularly transfused. As for iron chelation - in Kathmandu 40% of patients are on oral chelation and only 1 patient is on Desferrioxamine. Sadly, none of the children living outside Kathmandu have been able to have any iron chelation as yet.

Thalassaemia is a very heavy burden to the parents - especially in a poor country like Nepal. There is no proper diagnosis or treatment facility even in the country's capital. It is assumed that many thalassaemic children have already lost their lives in absence of general treatment for thalassaemia. Most of the parents of thalassaemic children coming from outside of Kathmandu for treatment are either returned back because of their inability to continue treatment or are struggling in Kathmandu doing labouring work for very often less than 1\$ a day (50p) with the aim of providing the best possible treatment for their loved ones. The whole night or day journey to Kathmandu with a baby, just for a blood transfusion - not once or twice a year but every two to four weeks - is not easy work; and in many cases impossible for these poor and ultra poor families. In such cases an occasional blood transfusion

is the only treatment that they can provide for their sick child. Regular treatment and transfusions are simply beyond their capacity. It is a fact here that all the thalassaemic patients who are receiving treatment are receiving just enough to enable them to survive. Our project aims to provide all the medication that would enable them to live a complete life.

In most parts of Nepal there are no blood transfusion facilities and it is practically impossible to set up health posts with such facilities due to the country's mountainous terrain and lack of skilled medics in rural regions. Our project aims to set up a complete care centre in Kathmandu which will provide housing, healthcare, food, clothing and education for thalassaemic children and their families.

I am now settled here in Pokhara, Nepal and consider it a privilege to call it my home. My husband and I have 2 beautiful orphaned children that we love and care for in our family home. Life is good... we are blessed.

"You can't change the world but you can make a difference in your own space"..... **Wendy Pinker (Pinky) UK**



**Swedish Orphan International:
Focusing on Alternative Therapy**

