

Nepal Update 2017

Nepal Thalassaemia Society



Clinic visit 2017

It was with much excitement that Taal and I finally arrived back at our beloved clinic after a whole year of forward planning and fund raising.

We entered the gates to a sea of beautiful smiling faces, most of whom we already knew but to lots of new faces too. Over the past year our clinic members have grown by over 30% to 220 registered patients, a clear indication that our efforts to raise the awareness of thalassaemia in Nepal is working.

The most striking part was just how old and grown up our children have become. All of our original children have suddenly become young adults, something that historically is very rare for a thalassaemic child in Nepal to achieve. Likewise our new children are much younger than our original children proving once again that children from all over Nepal are being diagnosed at a much earlier stage and thereafter being directed to our clinic, the only medical establishment in Nepal specifically set up to thalassaemia children at a much sooner time. Oh the joy in my heart is one that I just can't explain, each and every child a blessing to care for and to be so very proud of. Their little lives are so tainted by their illness that it's such an honor to be able to offer them some comfort in their treatment at our clinic. Taal and I were blessed to have my old friends Kate and Jackie and a new friend Dot make the visit with us this year and together we had great fun giving out gifts of T-shirts, hats made by my aunty Doreen and her friends and fun things that people from the UK had sent. Our yearly visit has now become a time to celebrate us all being together



Ayush and Ashish update.
News of kindness and support for a family at their lowest.



Cross matching lab now open at NTS Clinic Nepal
This year see's the opening of our very own blood lab

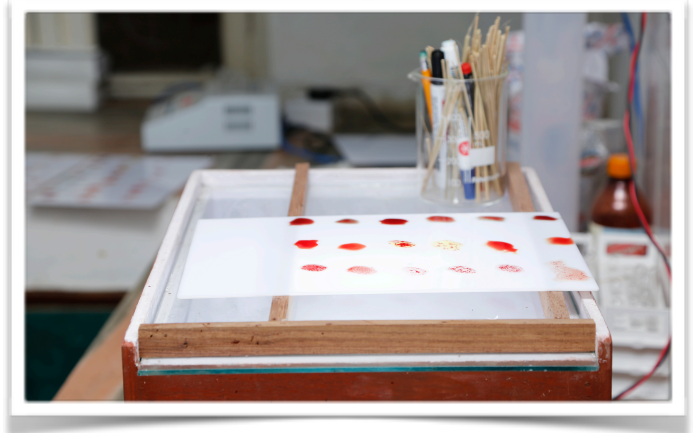


Post earthquake new homes built
Hear the news of 2 of our families who now have a secure roof over their

and its tradition now for us to take picnic box for everyone, children, parents, staff and grandparents! It's a day not to be missed.

Blood cross matching laboratory and other clinic news.

Earlier this year, after much hard work our President Durga Pathak managed to open a small blood testing lab inside our clinic meaning we can carry much of the essential blood testing in-house saving hours and hours of time trying to cross Kathmandu to get to the Red Cross Blood Bank which very sadly was irreparably damaged in the earthquake and relocated much farther from our clinic than before. Durga has also spent much of the past year trying to lobby the government into recognizing thalassaemia in Nepal and to offering some kind of financial support. This is still very much work in progress and although his requests are now being heard and listened to, to-date all of the funds to run the clinic come from donations my friends, family and kind donors who hear of our cause. It never ceases to amaze me how by hook or by crook we just about manage to keep it all going and our children live to enjoy more life and gain more hope. Its clear that until the Nepal government step up to the plate our NTS team will have to work hard to keep our little clinic open and able to provide the daily life saving treatment we give.



THE DOWNS SCHOOL MINI LIBRARY 2017

Many of you will remember that last year my son's school, The Downs School, Bristol raised the funds for a buffalo to be delivered to the remote village of Ayush and Ashish. This year once again the school raised enough funds to purchase a small library for the clinic. Each transfusion takes up to 6 hours and each child has to come once every 2 weeks meaning there are many hours to pass while they are hooked up to their transfusions. Until now we have not had the funds to purchase books and other educational goods but this amazing donation I was able to go out in Kathmandu and buy over 100 brightly coloured and illustrated books and other creative fun items. Its true to say that some of our children will never have had the chance to even hold a book let alone read one, Ayush and Ashish are examples of this. Our little library will provide hours of educational time pass for each and every child that attends our clinic. My sincere thanks to The Downs School for their continued support.



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Post earthquake house rebuilding

During the enormous earthquake of 2015 some of our patients lost pretty much everything apart from their lives. Ayush's and Ashish and Harimayas families are example of this and you can read below how we have managed to rebuild their home for them.

Ayush and Ashish - their house fell completely to the ground trapping young Ayush deep under the rubble. They have been living in a tin shack with a tarpaulin roof ever since. When we visited their very high up remote village we assessed the costs and logistics of rebuilding their house and sent out an appeal to our readers. My dear friends Jodie, Tracey and Dave of **Go Zumba UK** were so touched by the boys story that they immediately started fund



raising to not only rebuild their house but to send out 2 enormous boxes of clothing, bedding and other essential items as well. Within a couple of months the boxes had arrived and the family came to Kathmandu to receive their gifts ... they could not believe their eyes ... there were blow up air beds and sleeping bags for the boys to sleep on, hold-all's and child carriers for when the family make their fortnightly 6 hour journey on foot to our clinic and clothes to last a life time!! This was a family at their very lowest and I know from talking to them the great comfort and encouragement is has been to them to be given such tremendous support when they were at the end of the road with now where to go.

A month later Go Zumba had also raised the funds to rebuild their house and I immediately sent out the money so that Kamal could start work. It was with great joy that he came to the clinic last week with the picture below of their new home enormous thank you and sincere that's to Jodie, Tracey, Dave and all at Go Zumba UK you are AMAZING.

Harimaya Upreti - their family home was also destroyed in the earthquake leaving them with no choice but to move into their tiny buffalo shed. For the past year the whole family including grandparents have squeezed into the tiny converted space with a make shift mini kitchen outside. Both the summer heat and bitterness of the winter cold has been such a challenge for all the family but particularly for Harimaya as she try's to cope with the difficulties of living with thalassaemia. Harimaya was one of our very first patients and her father has brought her to our clinic once every 2 week for the past eight years tackling landslides, torrential weather, border blockades and of course the earthquake. It was with



the greatest of pleasure that 18 months after the earthquake when the tremors had finally stopped we were able to provide the funds to complete their new home. The whole village came together to build a beautiful more modern home with 4 rooms.... one for mum and dad, one for the grandparents, one for her brother and his wife and one for the Harimaya who is fast becoming a young woman and in need of her own space. Harimaya was so proud to give us the "Grand Tour". Being there in the village and watching how life works is a million miles from the luxurious facilities that we have in the UK, water is brought from up the steep hill, the buffalo provides the milk the earth provides the rice and nothing comes in shiny packages, the least a family needs is a safe place to call home, somewhere to cook family food, somewhere to shelter from the sun and the rain and somewhere to rest their heads at the end of a long day in the paddy fields. As we headed on to Kathmandu ready to fly back to our little home in the UK I had a deeply satisfying feeling of great joy knowing that finally the Upreti family were safe under their new roof.



It is with great joy that I am able to bring you the news of NTS UK registered charity status. After much deliberation and an overwhelming realization that the NTS Nepal needs were only going to keep growing and growing we decided to take the leap and register the UK end of the Charity. As many of you will know this was a lengthy process with many



Gift Aid - NTS is now register for Gift Aid meaning most of the donations received now and over the past 4 years will be worth 25% more. Elaine has recently emailed out a Gift Aid form to all donors over the past 4 years and we would be extremely grateful to receive the forms back. We have calculated that we could run our clinic for A WHOLE YEAR if we were able to claim the full amount.... but we need your forms to do it. A form only needs to be completed once and will cover all past and future donations.

More news

NTS UK now a registered UK Charity



boxes to be ticked. I am very proud to introduce you to our committee who can be seen on our new website www.nepalts.org.uk. I am honored to have three very dynamic fund raising trustees who all bring something very valuable to the cause. It's wonderful to finally have some support in the fund raising and running of the ever growing needs of the clinic.



Hopes and dreams for NTS in 2017 - the future of NTS

WANTED !! - monthly donors - As most will know NTS runs on the love and kindness of people who care for its cause. We currently have a small number of monthly donors who donate anything from £2 to £100 per month. These donations are a massive gift to us in our efforts to raise enough to keep the clinic open. A £2 donation provides a life saving blood transfusion. Every single penny counts and not one penny is wasted. It is our dream to have enough monthly donors to at least cover the running costs of the clinic. **If you would like to become a monthly donor please see the donations page on our website www.nepalnts.org.uk**

Monthly donations cover the following costs

Annual clinic running cost	£10,000
Doctor	£1000
Lab technician	£1000

Fund raising dreams

As we move forward with our clinic the needs continue to grow. Sadly at the moment we only raise enough funds to keep the clinic running but we hope and dream that one day we will be able to provide the following :

Medical Officer

Our clinic is now in need of a Medical Officer to oversee the medical needs of our children. It is our hope that this year we will be able to raise the extra **£1500** required to pay a Medical Officers Salary

Cell separation Machine

Our clinic is now in desperate need of a Cell Separation Machine which enables us to perform platelet and Hemoglobin counts. We have made enquiries and know that such a machine will cost an enormous **£5000**.

Auto Clave Machine

This machine would enable us to safely dispose of the blood bags after each transfusion - the cost is **£250.00**

So it is here that I close my update for 2017 and say an enormous thank you to All who have helped us over the years and continue to support us today ... we Cannot do it with out you ... thank you with all my heart With much love and Sincere thanks Wendy Pinker

www.nepalnts.org.uk

Registered Charity Number : 1167957