

Dear Friends of NLT...

World Leprosy Day

This Sunday 30th January 2022 is World Leprosy Day (WLD): a day when organizations working in the field of leprosy seek to raise awareness of this disease that continues to trouble many people around the world. It coincides this year with 'World Neglected Tropical Diseases Day', which brings focus to 20 diseases in this category, including leprosy. Nearly all these diseases are endemic in poor countries, which is why they are 'neglected'—because those who have the most power to research and develop cures, and conduct effective programmes, have little financial incentive to do so. That leaves most of the work to small organizations with a particular interest in them. However, the World Health Organization has been calling on everyone to address the inequalities that characterize Neglected Tropical Diseases, and hopes the day will be an opportunity to re-energize momentum to end the suffering from them, and to focus on the millions of people who have limited or no access to prevention, treatment and care services.

WLD itself was initiated in 1954 by the French writer, poet, journalist, lawyer, orator and Christian philanthropist, Raoul Follereau, who travelled the world extensively, seeking solutions to many problems and raising awareness of the plight of the sick, poor and marginalized. He was a remarkable man, and in 1965 he founded a federation of associations involved with fighting leprosy, which is now called ILEP, and which continues to coordinate leprosy work around the world today.

In recent years, we encouraged our supporters in the UK to organize coffee mornings for WLD, or for churches to have a 'leprosy awareness slot' at one of their meetings. Last year we enjoyed promoting the excellent film 'I am Belmaya', and many of you joined us in watching and appreciating it. This year, with things still difficult to plan, we felt we should simply write to you to share some stories that are special to us.

NLT's Journey

NLT's journey began 50 years ago in 1972, when a small UK charity was established to support Eileen Lodge's work in Kathmandu amongst people affected by leprosy. This same work in Kathmandu continues today through NLT's fair-trade workshops, social support schemes for vulnerable people, and the child-sponsorship scheme which many of you support. Alongside that, our Kathmandu office (pictured right) provides a vital interface with the Government of Nepal that enables the work to continue. NLT was set up formally as an NGO in Nepal in 1991, and became the platform for establishing NLT's main project, Lalgadh Leprosy Hospital and Services Centre, in south-east Nepal (pictured below). Lalgadh Hospital was officially opened 25 years ago, in November 1996, and has rapidly grown to become one of the busiest leprosy centres in the world, with many thousands of people coming for help each year.



Our widespread work in the Terai (plains) villages of southern Nepal, in the districts close to Lalgadh, has given us a window into the lives of many people who are extremely poor and vulnerable. A network of relationships and self-help groups has developed, helping many families in a variety of ways, including life-saving support. Part of that work—the Village Alive programme—has so far enabled 14 Dalit communities to be greatly transformed: with real improvements in terms of health, education, and hygiene, and reductions in depression and alcoholism. Five more villages have recently joined this exciting programme.



We are so grateful for our God-given opportunity to be involved at the 'sharp end' of the leprosy problem, and the poverty problem, taking 'Kingdom values' into situations that seemed to be without hope, and assisting broken people to discover that their lives can be rebuilt. We are so grateful for all of you who have shared this journey with us and helped to make it possible—in some cases over many years—and have been part of the ups and downs, tragedies and triumphs that have characterized it. We are hugely grateful for our colleagues in Nepal who have been at the more uncomfortable and exacting side of this work, using the resources that you have provided, and supported by the prayers that you have made. Between us all, we have shown that attitudes towards leprosy can be changed, and lives stripped of dignity, by stigma and fear, and relegated to the very edges of community, can be brought back into the centre of things—with dignity and hope restored.

Underlying all of this has been God's faithfulness and His commitment to minister to the poor, to set the prisoners free, to heal the broken-hearted, and to change lives. And He has indeed changed many lives!

What is Leprosy?

Leprosy (or 'Hansen's Disease') is a mildly contagious, but complex, bacterial disease. It affects the upper respiratory tract and peripheral nerves supplying the hands, feet and eyes. It is strongly linked to poverty and malnutrition, but can affect anyone who may be susceptible; although about 95% of people are naturally immune. It is thought to be mainly transmitted through infection by droplets from the nose and mouth. The resulting damage to affected nerves can lead to loss of nerve function, commonly evidenced by a mix of numb patches of skin, loss of feeling and function in the hands and feet, loss of the ability to blink, and 'clawing' of fingers. Early diagnosis is vital—as soon as patches are detected—as further damage can be irreparable, disfiguring and disabling.

Treatment is by a multi-drug therapy (MDT), is free, and takes 6 months or a year depending on severity. Once treatment is completed, a patient is no longer infectious, but may be left with permanent damage from leprosy. The fear of leprosy in Nepal's culture means that many people affected by it can no longer live normal lives; so they are often isolated and denied participation in their communities.

NLT is dedicated to early case detection and stigma reduction; so nearly all of our community work has these themes. NLT has diagnosed more than 40,000 new cases of leprosy at Lalgadh Hospital, and has provided on-going care and treatment to hundreds of thousands of people affected by leprosy, as well as other conditions.

It is wonderful to look back on 50 years of leprosy work in Nepal, from early beginnings helping just a few families per year. But even with the numbers now helped being many thousands per year, it is necessary to consider individual, precious lives to understand the purpose and impact of the work—as we not only look back, but also look forward to continuing the work in the years to come.

Some stories that are special to us...

Man Bahadur, a leprosy self-help group member in a small NLT project supported by the Sasakawa Health Foundation, recently received driver training for a month. As a result, he was able to get a job at a dairy farm as a driver, which has been a very big help to him and his family. He is thankful to NLT and the Sasakawa Health Foundation for this life-changing opportunity.



Many of you will remember **Neelam**, one of two sisters who are both affected by leprosy. She is pictured here between friends at Lalgadh, who are also being treated for some complications of leprosy. Neelam first came to Lalgadh when she was 5; and she is now 18 years old. Her family was very poor, and it was hard for Neelam to avoid housework. This meant that her feet, which were badly affected by leprosy and had no feeling, gradually became more damaged. At age 14, despite much help, she had to have her lower left leg amputated, and was fitted with a prosthesis. Now, the challenge is to keep her right foot intact; but it is not in good shape because of the damage leprosy has done. Despite all these difficulties, Neelam has used her time at Lalgadh to continue her studies, and lives in a girls' hostel in the nearby village with several other girls. This hostel is managed by Hem and Asha, who both worked at Lalgadh for more than 25 years and retired a little while ago. All the girls in the hostel are supported for their education; and Neelam is very bright and studies well. Please pray for this young lady, who has had a very hard start in life.

Sakila, pictured right, is the widow of Mainudin, who tragically died in India in April 2021 during the COVID-19 pandemic while being treated for cancer. They were only married for a short time, but they had a daughter called Upsana; and she and Sakila now live with Mainudin's mother. Our community team has been working with Sakila, who is affected by leprosy, to obtain her citizenship papers. This can be very difficult for people who lack a birth certificate or other proof of identity, born in a poor village and with little or no education; but Lalita and her team finally achieved this for Sakila late last year. This prepares the way for Sakila to be able to own the house and land that NLT supporters helped to buy for Mainudin a few years ago. These should become Sakila's soon—providing some security for her and Upsana's future.



Bikru is 65 years old and is affected by leprosy. He lives in Dhanusha, which is a Maithili district with a conservative Hindu culture. His leprosy marginalized him, until he got involved in one of NLT's leprosy self-help groups and eventually became a group facilitator. This made a big difference; but it was still a struggle. A recent socio-economic rehabilitation project that NLT ran in the community enabled Bikru to acquire a cow to produce milk; and now people are coming to him to buy the milk. This has given him more independence and dignity, and he feels this very much. Before, people stayed away and no one cared about him, because of his leprosy. Now he earns 250 rupees a day and he no longer experiences discrimination.



Anita, a lady in a leprosy self-care group, received three months of tailoring training during the COVID-19 pandemic. Today, she is successfully earning a living for her and her family, which has made a big difference to their lives. She is very thankful to NLT and to the Sasakawa Health Foundation, which supported the training project where she learnt her new skills.

Anu is the daughter of one of our staff who makes special shoes for leprosy patients. She is one of several siblings, and she really wanted to study in the medical field; but her father could not have afforded this. NLT UK found a sponsor to help Anu with her studies, and she is now studying to be a Medical Health Assistant and passed her first year with high marks. Anu may end up working at Lalgadh Hospital!



Phul Kumari is from a village in Dhanusha district, and has eight daughters and a son. Her son was born last, and before he arrived she was struggling with a lot of family disapproval because she was not producing a boy—very important in the culture there. Then she got leprosy, which made things much harder, including financially, until NLT's socio-economic rehabilitation project helped her to start a duck farm. Phul Kumari has been working very hard at this, and it has boosted her confidence. She expects a good profit from this business; and now that she has a son too, her life has improved very much. She is very grateful to NLT for helping to make her situation better.

Saraswati is a bright girl, now 10 years old, who contracted leprosy three years ago. She lives with her mother and two younger brothers in a two-room house; and her father works away from home at a flour mill. Her leprosy started with tingling in her right hand, rather than numb patches. She began to lose feeling in her 4th and little finger, and then to lose movement in them as they began to claw. Other children at school noticed, and began to keep their distance—as leprosy still carries stigma in many places. Saraswati's uncle brought her to Lalgadh Hospital two years ago, and leprosy was diagnosed. Her treatment is now completed. Saraswati recently had surgery done by our doctor, Krishna Tamang. He straightened her clawed fingers, and then split tendons from working muscles and attached them to these fingers which weren't working. Saraswati slowly learned how to move her fingers using the different muscles, and her hands now look fine and work properly. She has no disfigurement, and so her chances of marrying and living a normal life have been restored. She is pictured here with her mother, showing off her new hand to two of our nurses.

