

inTOUCH

MAGAZINE OF THE LEPROSY MISSION NEW ZEALAND

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Articles Include

- No, You Can't Go Home – Grassroots Leprosy Organisations
- Eyesight Saving Project – China
- Jesus, Advocate and Activist for Human Rights
- Bougainville's Unsung Heroes – Ruby's Story

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COVER PHOTO



TLMNZ is helping to give today's children a leprosy-free tomorrow by supporting the work of ENAPAL in Ethiopia. These children's parents are members of ENAPAL in Awassa, Ethiopia. Without the solidarity of belonging to ENAPAL, and the subsequent benefits the membership has brought into their families, the rights of these children would continue to be denied them. Instead they now have access to suitable housing, education, and adequate health facilities. Most importantly of all, there is integration into mainstream civil society with the stigma of leprosy reducing, so it is clear that their membership of ENAPAL is enabling them to secure their rights.



Chair of the Board of ENAPAL Mr Leugesed Berhane, Vice Chair of the Board of ENAPAL Mrs Birke Ngatu and David Hall

Director's Notebook

"The Right to a Life of Dignity" is the name of our new four-year Strategic Plan, adopted by the Board of TLMNZ in November 2008. This plan is a further step in the journey of The Leprosy Mission which began in 1874 in India. Wellesley Bailey, the founder of The Leprosy Mission, first saw a group of people sitting in isolation under a tree. Why? Because they were no longer welcome in their village – they had leprosy. Sadly, today this is so often still the same. Therefore, our journey will only end when the causes and consequences of leprosy are finally eradicated.

One of the major barriers to eradicating leprosy is the reluctance of people who may have the disease to seek medical advice. Instead they prefer to buy time rather than face the prospect of discrimination and stigma. By advocating for the right to a life of dignity for people experiencing leprosy we are helping to break down these barriers as well as being activists in response to Jesus' commandment to "love your neighbour as yourself."

Some time ago I advised the Board of TLMNZ that I wish to retire in mid 2009. As this is the last edition of InTouch before my retirement, I would like to say a heartfelt 'thank you' to everyone who supports this very special work. Your cards and letters over the years have been a real inspiration to me and my staff.

Thank you very much. May God bless you all.

David Hall
Executive Director

VISION A world without leprosy

GOAL To eradicate the causes and consequences of leprosy.

MANDATE The Leprosy Mission New Zealand, relying on the grace of God and motivated by Jesus Christ, exists to join in mutual partnership with individuals, families, communities and organisations to share resources, experience and learning in order to eradicate the causes and consequences of leprosy, and actively supports the right to a life of dignity for all people.

The Right to a Life of Dignity



PHOTO: JASON OXENHAM

BY HARRIET SEWELL



Pride of Bougainville

Ruby Mirinka an Unsung Hero

**To see the beauty of a gem it takes a lot of hard work and someone with an “eye”.
To display the beauty of a Ruby is no exception.**

Ruby Mirinka, Programme Manager of Bougainville Healthy Communities Programme, is one such gem. As described by Dame Carol Kidu, Minister for Community Development Papua New Guinea, “Ruby is an ordinary woman doing extraordinary things”.

At the Pride of Papua New Guinea Awards for Women 2008, Ruby Mirinka received the medal for Bravery and Courage for her contribution to Bougainville during the 10 year civil war. When hostilities started in 1988, Ruby, with the support of her family, believed that as a nurse educator she had an important role to play. Instead of seeking the safety of living in the PNG government controlled area, she remained behind the government military blockade and walked through the mountainous terrain from village to village, training community members in basic health care and prevention of disease - when there was no other health care available. The blockade meant that medical supplies could not get in to where the people needed them most and this included the most vulnerable of people, pregnant women and children. Later, Ruby as an independent humanitarian aid worker, established clinics in the mountains and trained volunteer staff. Putting her life on the line Ruby made

over one hundred trips between the Solomon Islands and Bougainville to smuggle critical medicines in to treat the sick – life saving medicines, such as insulin.

Ruby was shot at, and endured being lost at sea for five days without water in a boat full of sick people whom she was ferrying out of Bougainville; people that urgently needed medical treatment in the Solomon Islands. She helped establish the Bougainville Community Based Integrated Humanitarian Programme (BOCBIHP) and Ruby championed internationally the cause of women and children’s health needs while they were trapped behind the blockade. Ruby lobbied both the New Zealand and Australian governments to respond and take action and took her cause to Geneva and the United Nations.

Today Ruby is Programme Manager of The Leprosy Mission International’s Bougainville Healthy Communities Programme. We are honoured and proud to work with Ruby in partnership with the Autonomous Bougainville Government Division of Health to establish grassroots primary health care for all of Bougainville and at the same time work towards eradicating the causes and consequences of leprosy and other diseases.

Jesus, Advocate and Activist for Human Rights¹

BY DAVID HALL

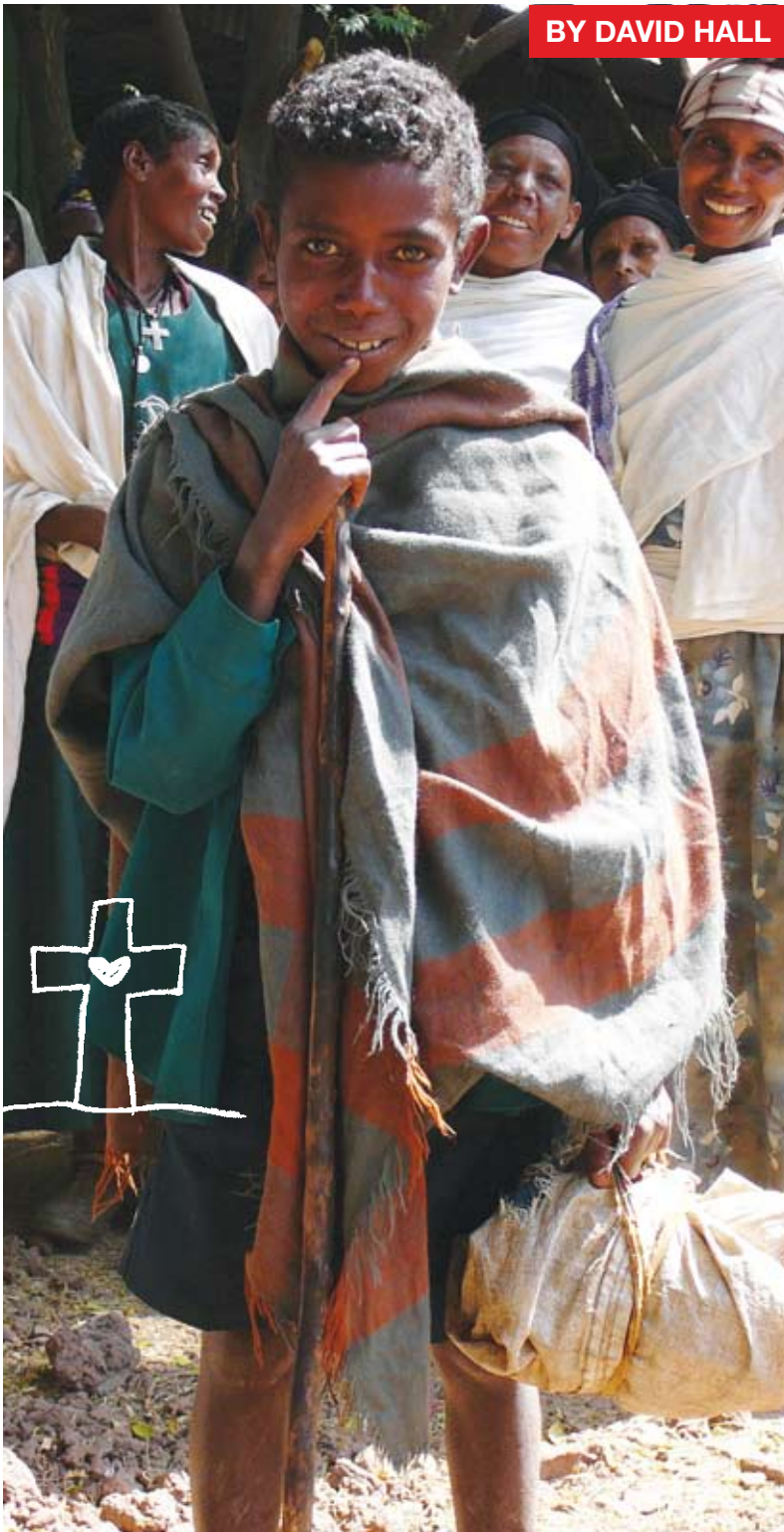
One thing that fascinates me about the Gospels is the way Jesus was interrogated by the Jewish religious leaders. Always in public, they tried to trip up Jesus and make him seem foolish. In Matthew's gospel, Jesus was asked by a lawyer, 'Which is the greatest commandment in the Law?' and the response from Jesus was, 'Love the Lord your God with all your heart, with all your soul and all your mind.'

And then, probably to the surprise of his listeners, he added, 'This is the first and greatest commandment. And the second is like it: "Love your neighbour as yourself"² .

Luke's Gospel told us that a lawyer asked Jesus what he must do to inherit eternal life. Jesus then asked the lawyer, 'What is written in the Law?' I suspect this lawyer had heard Jesus' response which is recorded in Matthew's Gospel, because he quotes Jesus almost verbatim, and then goes on to ask Jesus, 'Who is my neighbour?' This seems to me a bit like a set up; the Jewish leaders had been surprised by Jesus' earlier response and were again out to trick him³.

But in Jesus' response, known as the Parable of the Good Samaritan, they got much more than they bargained for. The Jewish leadership had a very clear definition of 'neighbour'. Over many generations the doctrine of Jews being the 'Chosen People' had become stronger and was used by religious leaders to tighten their control over the people. As far as the Jewish leadership was concerned, loving your neighbour did not extend beyond the 'Chosen People'. In this parable Jesus was saying that a Samaritan was one of their neighbours, and that they should love each Samaritan as they loved themselves. This was radical indeed because the Samaritans were despised by the Jews, and they did not accept that God could be worshipped only in Jerusalem. They were heretics, and, even worse, they were competitors.

Before continuing we briefly need to look at how society was organised in Jesus' day. Since the beginnings of civilisation in Babylon, Egypt or China, the basic model for society's organisation was hierarchal and authoritarian, based on the ownership and control of land – the source of sustenance and wealth. Whoever controlled access to water and food controlled 'you' and 'you' were a 'subject'. However, for one short spell in history the Jewish people followed



a radically different model. Land was shared equally amongst families, and to guard against land aggregation the 'year of jubilee'⁴ was introduced. There was no need for 'Kings' or 'Pharaohs', God was the leader and God's laws prevailed. All the people were treated with fairness and dignity. It did not last long but the memories of that time of freedom and dignity were part of the culture of Israel, their special relationship with God and the remembrance at the time of Passover of the saving grace of God and the promise that Israel would again be free.

Jesus not only reminded the people of the time when Israel was free, but also when the poor were not poor but blessed, the prisoners free and the blind could see. Jesus went a step further and taught that no longer should we take an eye for an eye, but that we should go the second mile. And perhaps the most radical of all Jesus' teaching is 'we should love our neighbour as ourselves.'

Jesus articulated two very radical concepts in the Parable of the Good Samaritan:

- Our neighbour includes everyone, without exception
- Everyone has a right to be treated with dignity

As I think about this parable, it brings to my mind the concepts underlying the Universal Declaration of Human Rights signed 60 years ago in 1948. I see the same two radical concepts coming through in both. The drafting and signing of the Universal Declaration of Human Rights was in response to the way people had been abused and mistreated during the Second World War, and the way their dignity had been stripped from them. Read any book about the holocaust and you will see what I mean. But it was more than that. It is also a recognition that everyone is 'our neighbour' and if Jews and Gypsies can be abused, mistreated and murdered, then we have a duty as good neighbours to come to their assistance and even more, to strive to stop such treatment ever happening again. The Universal Declaration codifies the teachings of Jesus and the Bible. It recognises the right of all people to live lives of dignity.

The Universal Declaration of Human Rights is not a long document, and no time is wasted on long and convoluted preambles. It opens with:

Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world...

There are 30 'articles' in the declaration. Thanks to the untiring work of organisations like Amnesty International, we are familiar with the articles about freedom of speech, freedom of movement, freedom from arbitrary arrest. The declaration also covers such rights as access to education, health, and a reasonable standard of living. For many who have experienced leprosy, the right of access to education and health services has been only a

dream. Too often we hear of instances where these basic rights are being denied simply because the individual suffers from a specific disease, even after being cured! It is this discrimination and stigma that moved The Leprosy Mission New Zealand to focus on the rights of people affected by leprosy, and their *right* to live a life of dignity.

Jesus said we must 'love our neighbour as ourselves'. He puts this as second only to loving God. This goes to the heart of his teaching and actions. Everywhere we look in the New Testament we see this coming through. In the time of Jesus this was very, very radical; today this may still be considered radical, because we are continually faced with neighbours who are not loving neighbours. I do not have to give you examples; you see them every day in the newspapers and on TV.

In his day, Jesus reached out to people affected by leprosy who were outcasts of society. He reached out and touched them physically, emotionally and spiritually. His message was one of inclusion and love. He believed in...

The inherent dignity and of the equal and inalienable rights of all members of the human family.

And it was not just people affected by leprosy that Jesus reached out to and included, but to us all. Jesus spoke out and acted against the dominant powers of his day – the leaders of the Jews and the Roman occupiers. Just as Jesus was arguably the first Human Rights advocate and activist he invites us to join him and follow his example. In the same manner we need to be prepared to speak out and act against dominant powers to help our neighbours wherever they are.

TOO OFTEN WE HEAR OF INSTANCES WHERE THESE RIGHTS ARE BEING DENIED SIMPLY BECAUSE THE INDIVIDUAL SUFFERS FROM A SPECIFIC DISEASE, EVEN AFTER BEING CURED!



- 1 Based on a Sermon given by David Hall at St John's Church, Buckland's Beach, Auckland on Sunday 11 January 2009.
- 2 Matthew 22:34-39
- 3 Luke 10:25-37
- 4 Leviticus 25



Dr Daniel Chen examining a patient at a leprosy village

BY CATHY MCINTOSH

Eyesight Saving Project - CHINA



Dr Daniel Chen talked about the pressures he faced after turning his back on a potentially lucrative career as an eye surgeon in China. He did this so he could work with people whose eyes had been affected by leprosy.

Daniel visited New Zealand on his way to an Ophthalmology Conference in Melbourne, Australia. He had developed a close working and personal relationship with Dr Keith Maslin, a Kiwi eye surgeon who has twice visited Daniel in China to assist with his work and provide training. This was Daniel's first visit out of mainland China. Daniel visited The Leprosy Mission New Zealand Offices in Auckland, as well as Keith's home and office in Wellington. He even found the time to attend lectures and make a well-received presentation to staff at Wellington Hospital.

Despite increased awareness and knowledge about leprosy in China, there are thousands of people who still

live in the remote villages to which they were banished many years ago. Under the old Chinese Leprosy Control Policy, those diagnosed with leprosy were sent to live the remainder of their lives in separate purpose-built villages, where life was not easy and care was all but nonexistent. Misunderstanding of leprosy was such that those diagnosed were often refused basic rights, like the opportunity to marry, seek education or receive medical care. Today the Chinese Government has set up a special department (Dermatology Institute) which focuses on new methods of leprosy detection, diagnosis and treatment. HANDA works on a more holistic approach, working *with* people who are already cured

but who remain stigmatised or disabled and fall through the government sphere of assistance; mostly this means those still residing in the leprosy villages.

The Eyesight Saving Project team consists of an Optical Surgeon (Dr Daniel Chen), a Surgical Assistant, an Operation Nurse and a Driver. Together this small group travels in a converted Toyota van and visits the isolated leprosy villages around the Yunnan, Guangxi, Guangdong and Sichuan Provinces, where they perform eye surgery on people whose sight has been affected by leprosy. Daniel's team performs four kinds of surgery:

1. **Cataract surgery** is the most common eye surgery performed by this team. Before the introduction of MDT in 1984, residents of the leprosy villages in China did not receive treatment for the disease. Those who received treatment did so at such an advanced stage that their eyesight was usually already affected. The majority of people affected with such cataracts are over 60. In addition the leprosy bacteria can attach to the iris, which can lead to secondary complications.

2. **Lagophthalmos**, otherwise known as 'eye droop', describes the inability of the eyelid to close completely. This causes the eye to dry, which makes the surface of the eye susceptible to damage from dust or scraping when asleep and can easily lead to blindness. The corrective surgery involves sewing the upper and lower lids closer together so that the open gap is not so large and thus manageable with eye drops and glasses.

3. **Trichiasis** is a disease with which people with advanced cases of leprosy often suffer. Trichiasis is

when eyelashes scrape the cornea of the eye. It is not only uncomfortable, but also results in damage to the cornea. Surgery is used to turn the eyelashes outwards. The natural protection the eyelashes give is lost, but coverage is helped through wearing glasses and care by the patient.

4. **Pterygium** is a 'hyperplastic tissue growing from the conjunctiva'. If it develops to the point where it covers the corneas then blindness can result. The hyperplastic tissue is removed with surgery.

HANDA's Eyesight Saving Project, is a new addition to The Leprosy Mission New Zealand's SEED Partner Programme. SEED Partners are big-hearted New Zealanders who contribute regularly (usually through automatic payment) to a chosen SEED project. Because this project partnership is new to The Leprosy Mission New Zealand, new supporters are needed to help ensure that this project can plan for a secure future, and the care of people can continue while needed.

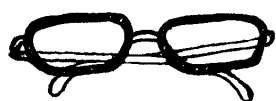
In 2008 Daniel's Eyesight Saving Project team carried out basic eye examinations and provided eye care education to more than 1,200 people affected by leprosy. They successfully conducted 110 eyelid repair operations for people suffering from problems such as lagophthalmos and trichiasis. They also conducted 198 special leprosy cataract operations. The number of pairs of protective sunglasses given out to those in need is extensive, - and unknown.

* Non Government Organisation

* Sexually Transmitted Disease

* HANDA Rehabilitation and Welfare Association is a Chinese non-profit organisation that works with and for people affected by leprosy.

DANIELS STORY



After my first year working with HANDA, the surgeon I was learning under took me to a leprosy village, where we performed cataract and eye-droop surgery on some people there. In this village I met an old man living alone. He was completely blind. This was in the Guizhou Province of China, where people predominantly use coal for heating and cooking. Because of the coal smoke and dust, this man's room was completely black, even his face was black, his hands, clothes, walls and even his blankets were black. I remember seeing a bowl of rice on the table in his room which was full of grey lumpy stuff... obviously when cooking he would grab coal with his hands, then grab rice with the same hands, mixing the two, but because he was blind he was unable to see. The sight of this grey black lumpy rice made me feel sick.

On the first of our three-day visit with this village, I examined this blind man and performed surgery on one of his eyes. On the second day, when we took the dressing off, the man was able to see. He was so excited, but really just too shy and overwhelmed to be able to thank us, though he did show us a glimpse of his humour when he stopped to ask me, "Doctor, why do you wear glasses?"

On the third and final day we met him again and something had changed; he was clean! His hands, face, clothing everything had been properly washed and kept clean! This was the very best way of thanking us. By returning his sight we had allowed him to return to living his life with dignity.

I saw that the work I was doing with HANDA helped people, and it moved me.



Soni Shrestha, outside her home

CAP Project Creates Hope

We celebrated the successes of candle-maker, Bidhya Maharjan, from the Community Active Participation (CAP) project in Nepal for World Leprosy Day earlier this year. Soni Shrestha, also from the CAP project in Nepal, reminds us there are many more people whose lives have been transformed and their achievements worthy of recognition and celebration as a result of this project.



SONI'S POEM



Excellent work of CAP
A light came like of moon
Representing itself as CAP by the name
Let us develop ourselves was its slogan

Arouses the feelings of active
participation to everyone
Educated student poor
and laborious one
Provided new life to poor,
leprosy and disabled

Arranged non formal class for elder
Selecting illiterate and poor
Focusing on saving and credit
With the great instigation

Providing skillful training
Door to door to the people
Representing itself among all
With CAP Bara Nepal

Thanks to CAP Nepal and
All its members and will
Remain as its members forever



Translated by: Basu Karki (CAP staff)

People like Bidhya and Soni are now living fulfilled, dignified lives, because of their membership in the CAP project self-help groups.

Soni lives with her mother Bulsiba, and despite her struggles because of poverty, she is an aspiring poet with high hopes and dreams. As well as her keen interest in poetry, Soni is studying commerce and hopes to become an accountant when she graduates. Soni and her family are affected by leprosy and have been marginalised from mainstream society. Soni's mother Bulsiba struggled to survive in their poor community and to provide for her family without a husband. This stark reality meant that Soni and her younger brother's education were at risk. The financial struggle was tough enough without the added stigma of being a single woman in a male dominated environment. The news that Soni had won a scholarship from the CAP project to help with education changed their lives, and turned Soni's dreams to reality.

Overjoyed to receive the scholarship and marvelling at the opportunities that lay before her, Soni was inspired to write a poem about the CAP project:

"I am very impressed with the CAP

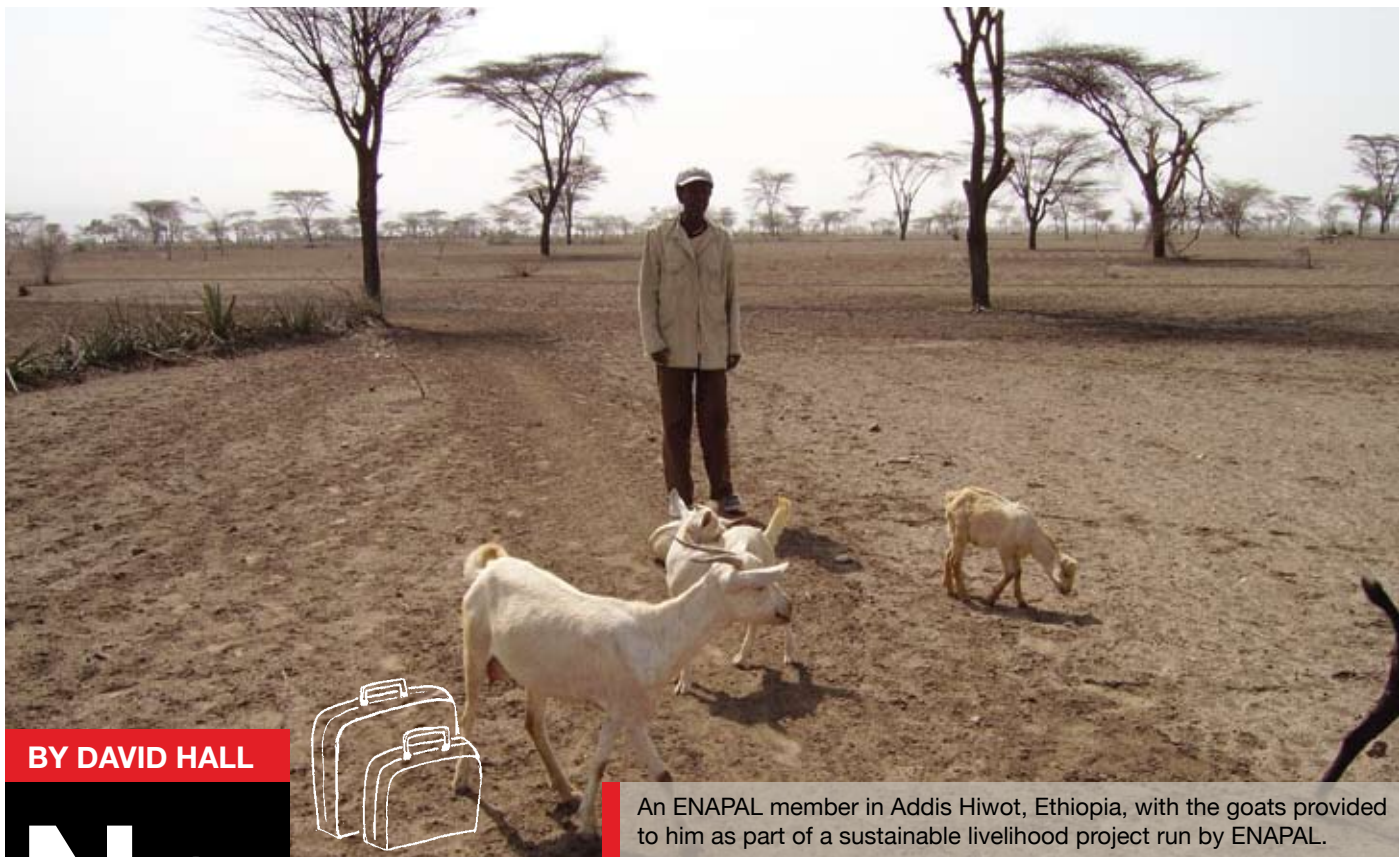
project, it is helping many people in Bara and everyone knows of the work – it is famous!"

Soni's mother Bulsiba is a member of a self-help group and now has a loan to start a business. Advocacy through the CAP project is enabling Bulsiba, and others, to finally break free from the stigma. She is now comfortable working with others in the community, and is accepted. There is no class discrimination and little leprosy stigma. There is no other organisation working in the same way that the CAP project does. It is a huge achievement that such a historical barrier has been overcome.

The CAP project works in selected areas in the Bara District of Nepal. The primary goal of the project is to enable people affected by leprosy, people with disabilities and marginalised groups of people to be empowered so their socio-economic situation is improved, helping to bring them into the mainstream of society. The project is successfully running into its fourth year with plans to expand this into other neighbouring areas.

Madan Ghimire, the project manager says: "I'm happy because these people really feel what CAP does for them."

For more information about supporting the Community Active Participation (CAP) project in Nepal please contact our office: 0800 862 873 or enquiries@leprosymission.org.nz



BY DAVID HALL

An ENAPAL member in Addis Hiwot, Ethiopia, with the goats provided to him as part of a sustainable livelihood project run by ENAPAL.

No, You Can't Come Home

“No, you can't come home. You've got leprosy.” Thousands, probably millions, of people have heard these words after discovering they had leprosy. Many have then been forced to live out their lives in isolation, often in isolated leprosy settlements.

For centuries isolation has been the world's only response to leprosy, from Kalaupapa in Hawaii to Shashamane in Ethiopia; from Champa in India to Quail Island in Lyttelton Harbour. Everywhere, people experiencing leprosy found themselves forced together into groups, isolated and rejected. Thankfully many of these places of rejection have now been officially closed, but some of the settlements still have many residents and their descendants remaining – around 6,000 in Shashamane, some 3,000 in Champa, fewer than a dozen in Kalaupapa, but none on Quail Island. Although the descendants of these people may have never had leprosy, they are nonetheless still affected by the stigma of the disease, simply because they were born into a leprosy settlement.

People experiencing leprosy generally support each other by coming together in groups. Wellesley Bailey, the founder of The Leprosy Mission in 1874, experienced this. Cyril Davey wrote, in 'Caring Comes First, The Leprosy Mission Story':

“...Outside were gathered a group of people waiting for worship to begin. Staring at them Wellesley realised that

he had seen people exactly like them without realising what or who they were, thrusting out begging bowls at him in the bazaars with misshapen hands. These then were sufferers from leprosy, quite unlike his Sunday School picture of them. Some had hands with fingers permanently clawed inwards; some seemed half blind; others had disfigured faces. The children, on the other hand, seemed perfectly normal...”¹

The groups of people that Bailey saw that day in Ambala, India, nearly 140 years ago, had been banished from their communities because they had leprosy. Leprosy, then, could not be cured. The people were forced to live in small rough huts; begging their only form of income. In many respects little has changed, however, there is one big, positive difference. Increasingly over the last ten years or so people experiencing leprosy are organising themselves and joining together in groups to make their collective voice heard, to achieve strength through solidarity and to advocate for the right to a life of dignity.

The Leprosy Mission New Zealand (TLMNZ) has been privileged to share in the journey with two such groups, HANDA² in China and ENAPAL³ in Ethiopia. The road



Executive Director David Hall,
Executive Director of ENAPAL Menberu Adane,
Chair Board of ENAPAL Leugesed Berhane, Chair Board
of TLMNZ Ross Dillon.

is not easy for these groups and they have had to work hard to achieve progress. Last December ENAPAL hosted a Consultation attended by both local and international partners. Three from TLMNZ were able to be present, Isabelle Duff (Programmes Director); Ross Dillon (Board Chair) and myself. As part of the occasion we attended the opening of a new grain milling facility which is to be operated by the Addis Ababa branch of ENAPAL to serve the local community and to provide a steady income stream for the association. This project has been funded by TLMNZ with co-funding from NZAID's KOHA programme.

After the formal opening by Ross Dillon and Leusedged Berhane (ENAPAL Chair) a number of ENAPAL members shared the story of their journeys over the last 10 years, since they had become members of ENAPAL. The common theme from all the speakers was not that they had more income... not that they could put more food on the table for their family... *but that they now have self-confidence, confidence to speak out. Previously voiceless people now have a voice!*

Over the last 10-15 years, these leprosy membership organisations have achieved significant results. In Japan, after much lobbying, the Government apologised and compensated people affected by leprosy who had been banished and isolated from society under the strict Leprosy Prevention Law, not repealed until 1996. In South Korea, a leprosy membership organisation lobbied for many years for discriminatory legislation to be repealed, and was finally successful in 2007. However, although many discriminatory laws regarding leprosy in India, passed in the days of the British Raj have been repealed, many still remain. According to its new Strategic Plan, The Leprosy Mission New Zealand prioritises its work with leprosy membership organisations. Both ENAPAL and HANDA have thousands of members who have been isolated and stigmatised. Many of their members had leprosy before a cure was available

and have been severely disabled as a result. In addition, each organisation also has younger members, some of whom did not receive treatment in time and as a direct result now have to suffer lifelong disability, while others who did receive treatment early enough are still the victims of stigma. Then there are others who simply because of their lineage are stigmatised, ie, their parents had leprosy, even though they themselves have never had the disease. By walking alongside leprosy membership organisations and journeying with them we are moving towards our long-term goal of eradicating the causes and consequences of leprosy. We are also responding to the second commandment of Jesus – to love our neighbours as ourselves.

The discovery of a cure for leprosy, Multi Drug Therapy (MDT), and its introduction in 1982, is seen as possibly the most significant milestone in the long history of leprosy. Arguably we believe the next most significant milestone in the history of leprosy is the emergence of membership organisations made up of people who have experienced leprosy - such as ENAPAL. These people who have experienced leprosy and the subsequent human rights abuses have found collective strength as they have organised themselves into groups. These groups have gradually formalised themselves and registered within their own countries as non government organisations. This is a hugely remarkable achievement for each of these organisations and we honour them for having the courage and fortitude to reach this goal despite the obstacles which we know they encountered along the way.

We have clearly seen and I acknowledge with great humbleness what Paulo Freire wrote about, "The finest struggles with the best results are those fought by oppressed people themselves."⁴



Self Care Group in Ethiopia, learning about care for damaged limbs.

- 1 Caring Comes First. Cyril Davey, Marshall Pickering: England. 1987. page 22.
- 2 HANDA Rehabilitation and Welfare Association is a Chinese non-profit organisation that works with and for people affected by leprosy.
- 3 Ethiopian National Association of People Affected by Leprosy
- 4 Paulo Freire. (1989) *Pedagogy of the Oppressed*. New York, Continuum.

MEETING THE MEMBERS OF ENAPAL

Ross Dillon, TLM NZ Board Chair, visited ENAPAL in Addis Ababa, in December 2008. His experience moved him to write these words.

Ethiopia was a real eye opening experience. To spend three days meeting with the leaders of ENAPAL and hear, in their own words, the history of the organisation, and their plans for the future was amazing. But the thing that sticks with me most strongly was their answer to this question. What one thing do you think has been ENAPAL's greatest achievement in the last 12 years? The answer from about three of the Board members was this – *we have been given the confidence to believe in ourselves and our ability to change our circumstances and the circumstances of others like ourselves.*

That was no idle answer – because the second most impressive thing that struck me was their ability to organise themselves, and identify, organise and fund their own projects. They co-operate with each other to improve their mutual circumstances, without outside help or resources. That is an amazing feat for people whose income is otherwise restricted to begging.

When people ask me about this organisation, I point out these factors – ENAPAL started 12 years ago with 30 people who literally had nothing. It is now an organisation with over 15,000 members, every member must pay

a subscription in order to join. How good must that organisation be, in the eyes of its own members, to be of that size, and require that commitment? When everything you have is from begging, you must be very careful what you spend your very meagre resources on.

In that context, when the Board members (all of whom are people affected by leprosy) say that the one thing they are most appreciative of is self-confidence, it literally humbles you, and gives you a new context in which to appreciate all the blessings we so casually enjoy.

I think the ENAPAL story is brilliant, and is a template for development work worldwide: self-initiated, self-planned and self-implemented, with the outside help in the nature of facilitation rather than either simply funding (throwing money at a problem) or the provision/delivery of a 'project' into a community, which is not what the local people themselves actually desire. It is a true example of all the best elements of what 'partnership' involves.



David & Ross watch Menberu become a TLMNZ society member

Inclusion... Mutuality... Sharing

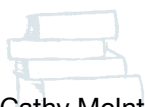
Inclusion... mutuality... sharing. How many of us truly understand the depth of what these words? While my experiences of exclusion have been painful, I have never been excluded from my family, my work or my community. So recently when I was with friends from ENAPAL in Ethiopia who have faced complete exclusion from family, for years because they contracted leprosy, I witnessed a moment in time which profoundly moved me. Let me explain. The Leprosy Mission New Zealand (TLMNZ), as an incorporated society and in accordance with its constitution, invites interested people to become members of the society. As part of our new Strategic Plan, and in a considered and planned move to become a more inclusive organisation which operates on the basis of sharing and mutuality, we want to strategically include people who have experienced leprosy as members of our society. After all, it is for these people we exist. So last December, when David Hall (Executive Director), Ross Dillon (TLMNZ Board Chair) and I were in Addis Ababa, we invited three people from ENAPAL, Menberu Adane (Executive Director), Leulseged Behane (Board Chair) and Birke Ngatu (Deputy Chair), all

of whom have experienced leprosy, to become members of the society of TLMNZ. At the next Board Meeting of TLMNZ this will be formalised.

This process took place in the presence of many members of ENAPAL in a public forum. It was a highly charged, emotional moment as those present realised TLMNZ had invited representatives of their organisation, to be included as equal members to share in, what is essentially a white, western organisation. They said mutually sharing in TLMNZ as equal players in this way is not tokenism; it is real. In all the work we in TLMNZ have ever done as an organisation, in my opinion, the significance and symbolism of this one occasion is by far the most powerful and will have the most profound impact in years to come. Inclusion, for these people, as they said after the documents had been signed, is what gives them confidence, self-worth, and the knowledge they are truly valued as people.

Isabelle Duff, Programmes Director

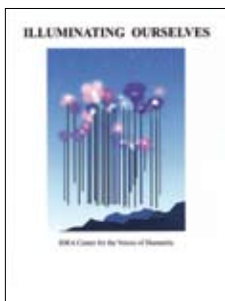
1 Ethiopian National Association of People Affected by Leprosy



I'VE BEEN THINKING, LORD - EDDIE ASKEW

Sadly, Eddie Askew passed away in September 2007, but this didn't stop the flow of writing! Eddie's daughters have put together a book called 'I've Been Thinking, Lord', a collection of previously unpublished prayers that their father had written. Eddie has left a lasting legacy of his love for God, and wise guidance for many of life's situations.

"We are delighted to introduce this compilation of our father's prayers, illustrated as always by his paintings. Dad died last year at eighty, only seven months after our mother. As Dad came to the end of his life, he said that his prayers increasingly consisted of holding the person or problem wordlessly before God. Yet he retained a wonderful ability to put into writing the conversations he had with his God. His prayers have it all – the doubts and anxieties, the frustrations and anger, the longing and love and the quirky ability to come at things from an unexpected angle in a way that deepens our understanding."



ILLUMINATING OURSELVES

'Illuminating Ourselves' is one of the most beautiful collections of stories, poems, photos, art and music that I have seen in a long while. Every page tells a story of survival and suffering, of self-growth and self-actualisation. I feel honoured to own this collection and I pick it up regularly, always finding something more in the words within... or sometimes I will be just as fulfilled by one of the drawings or photos. This is a collection of art in many of its forms, by

people of many abilities from all over the world. Leprosy is a common theme, the lessons within are common throughout the ages and throughout life.

Published by IDEA Center for the Voices of Humanity
IDEA International Association for Integration Dignity and Economic Advancement

Both publications are available from the Auckland office; feel free to contact us on freephone 0800 862 873 or enquiries@leprosymission.org.nz

Stop Press!

Please Pray for Leulseged

Please pray for **Leulseged Berhane**, Board Chair of ENAPAL in Ethiopia, and Society member of The Leprosy Mission New Zealand.

Leulseged, already an amputee due to leprosy, although agile with a prosthetic leg, sadly had a second leg amputated in late February. The condition of his leg was aggravated by his mobility doing work for ENAPAL, but he has been determined to be a voice for 'his people' who as yet have no voice. With Menberu Adane, Executive Director of ENAPAL, Leulseged was in Geneva from 13-17 February 2008 for a meeting of the United Nations Human Rights Council (UNHRC). The UNHRC also organised a meeting on the elimination of discrimination of persons affected by leprosy and their family members and Leulseged and Menberu spoke about the situation in Ethiopia and ENAPAL members' experiences.

Pray for healing and restoration for Leulseged and that in good time he will be able to continue the work for ENAPAL, for which he is so passionate. God bless you, Leulseged.

YOUR "GIFTS OF GOLD"



We know the time and effort our Moneybox collectors and supporters put in to the Moneybox Programme. So to ensure your efforts continue to make maximum impact we are launching a revamped Moneybox Programme called 'Gifts of Gold'. The new name focuses on the greater worth of \$1 and \$2 coins, and links donations to our projects in Bangladesh. But of course all coins, and all notes, will be very gratefully accepted.

Each year we will announce the "Golden Box Holder" in recognition of a spectacular effort towards helping people affected by leprosy in Bangladesh.

In 2008, Miss Pat Christon of Belmont in Auckland received this accolade. Together, with her Moneybox supporters, she raised an incredible \$3171. Congratulations Pat! Pat is one of our longest-serving Moneybox collectors beginning in 1984 after returning from Papua New Guinea. Pat had seen the effects of leprosy, and gave a talk to the Belmont Baptist Church. The generous response of the people inspired Pat to collect for The Leprosy Mission and, nearly 25 years later, she is as dedicated as ever.

To request a moneybox and start collecting 'Gifts of Gold' to help people affected by leprosy, or for more information on the 'Gifts of Gold' Moneybox Programme, please contact

lisa.mclaren@leprosymission.org.nz
For more information on our projects in Bangladesh, please contact us on free phone 0800 862 873 or email enquiries@leprosymission.org.nz.

Running For Rights



Interested in joining the Running for Rights team?
Please contact:
lisa.mclaren@leprosymission.org.nz
or 08000 862 873



For those of you whose New Year resolution was to get fit – joining The Leprosy Mission's Running for Rights team is a great way to keep focussed throughout the year!

Anyone who wants to have a bit of fun and at the same time help people around the world who are experiencing leprosy, read on... Last November, the Running for Rights team embarked on completing the Auckland Marathon for the first time! It was a great success; everyone achieved their chosen distance, which ranged from 5K, 10K, 21K and the full marathon of 42K. **Together, the Running for Rights team raised over \$3650 through individual sponsorship to help people affected by leprosy.** Thank you to everyone who took part. The funds raised were allocated to projects where the need was greatest, and the increased awareness helped greatly towards education and reducing stigma. This year, the Running for Rights team will run again and we are inviting runners and walkers, whatever their fitness ability, to join in:

IN MAY – WE TAKE ON THE LAKE IN ROTORUA!

This is the 45th Anniversary of the Rotorua Marathon – the Running for Rights team will be running the 5K or 10K fun run or walk in preparation for the Auckland Marathon later in the year. This year, 2009 sees the celebration of 45 years of the Rotorua Marathon, so those who take part,



Leprosy Mission New Zealand DRM
Gillian Whitley and son Ben

and their supporters, can expect special activities that showcase the history and progress of this special event.

IN NOVEMBER – WE HIT THE STREETS IN THE AUCKLAND MARATHON!

Choose your distance, 5K, 10K, 21K or the full marathon of 42K, and join us in the biggest running event in Auckland city – and for The Leprosy Mission New Zealand. We'd love you to join the team and take part, and will support you in training leading up to the day, keeping you motivated and informed along the way. After the run we gather in Victoria Park for a family day out with a BBQ – what a great way to start the summer!

'New Look' Website to Launch

An overhaul of both the structure and the appearance of The Leprosy Mission New Zealand's website is currently in progress. By the end of March this year, the new-look website will be going live! www.leprosymission.org.nz

The Internet is a vital element in any organisation's communication, and we understand how important it is to keep our supporters in New Zealand and people around the world up to date. Every effort is being made to design a site that is more accessible, attractive and informative.

We hope visitors to the website will easily find the site and will return again and again. There will be news and project updates, general information about leprosy and the social, physical and human rights implications of experiencing the disease.

Many of the key features of the old site will remain, including detailed information on ways to support current projects, the online shop, resources for downloading and links to further information. Changes will be evident in areas such as the SEED Partners programme section, where

the information has been updated and will continue to be updated throughout the year. Plus there will be new images, more resources and newflashes relevant to the work that The Leprosy Mission does around the world.



An additional feature of the site will be the opportunity to sign up for regular e-newsletters, which will be small in megabits but big in information of interest to supporters.

This is an exciting project and one that we are very pleased to be sharing with you. Watch out for the launch and visit www.leprosymission.org.nz.

Prayer & Praise

THE VALUE OF PRAYER

"Thank you for your recent prayers when I travelled south to Mindanao. The day I was there two foreign and one national Red Cross worker were kidnapped." Mark Macdonald wrote from the Philippines to remind us about increased security risks and the importance of prayer support.

The value of prayer is intrinsically part of The Leprosy Mission's character, and is a legacy of its founder Wellesley Bailey. When confronted with the needs of people with leprosy in India, Bailey stated: "If ever there was a work of God, this is it." After 30 years of dedication to the cause of leprosy, Bailey was asked to address a congress of doctors and scientists in Berlin in 1904. Following his speech, the president of the Congress proclaimed, "You have done more for the 'lepers' of India, Mr Bailey, than all the doctors and scientists together."

What Bailey and his supporters had done was to offer compassionate care to suffering people where others had shunned them. Bailey made increasing numbers of people in Europe and America (and soon after in Australia and New Zealand) aware of the needs of those affected by leprosy. He called on people to support this cause with their gifts and prayers, alerting their minds to the facts, then touching their hearts with the need.

The Leprosy Mission has grown and changed in many ways, and continues to do so. But two of the original elements remain – the need for financial and prayer support. The financial and material need is obvious. Prayer can sometimes be overlooked. Prayer is not wishful thinking, but a demonstration of our trust in the grace of God, to bring about change in the lives of people around the world.

WILL YOU PLEASE JOIN US IN REGULAR PRAYER SUPPORT?

'Prayer and Praise' is available monthly and sent free to anyone who requests it. We can post it or email to you. Please indicate on the reply coupon or email enquiries@leprosymission.org.nz.

Bequests

Peggy Shearer	Masterton	Derek Thompson	Auckland
Theresa Douglas	Christchurch	Evelyn Sargent	Lower Hutt
Connie Matuschka	Marton	Arnold Roe	Takapuna
Beverley Brown	Paraparaumu	Barbara Marshall	Raumati
Madeline Wilson	Wellington	Gwendoline Cox	Nelson
Charles Hassall	Havelock North	Harold Nixon	Auckland
Lucy Ringer	Hamilton	Margaret Caverhill	Lower Hutt
Bernard Islip	Christchurch	Gwendoline Barnaby	Pukekohe
Mabel Orange	Nelson	Mary Stevenson	Kaikohe
Annie Mair	Dunedin	Irene Williams	Christchurch
Avis Stark	Foxton	Norah Muir	Havelock North
Betty Elliott	Foxton	Bernard Forlong	Auckland

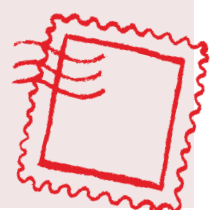
Donations Received In Memory Of

Alison Forbes	Blenheim	Winifred Scott	Hamilton
Veronica Kelly-Reynolds	Wellington	Pearl McAlpine	Hastings
Ethel Mackay	Auckland	Margaret Phillips	Warkworth
Harold Nixon	Auckland	Archie Duff	Waitara

You, Our Supporters

Here at The Leprosy Mission we are blessed to have loyal longstanding supporters such as you. Without you, attempting to meet our goal of eradicating the causes and consequences of leprosy would be impossible. Mrs Lois Cutler has been supporting The Leprosy Mission for more than 77 years, which makes her one of our most longstanding supporters. Thank you Lois, your commitment is valued by everyone, and in particular, the people with leprosy who have benefited from your support. In the 1930s The Leprosy Mission Secretary, Reverend F C Perry, spoke at a combined Church Service in Point Chevalier. He had a meal with Lois' parents after the service and Lois asked for a money box, and so began her life-long commitment to our special work.

One of our youngest supporters, ten-year-old Luke Gordon, was introduced to The Leprosy Mission by his grandmother, who helps with the Stamp Programme. As well as helping his grandmother to collect stamps, Luke also saves his pocket money to give to people with leprosy because they are forgotten and neglected. Luke's act of kindness is special, as it is often children of a similar age who miss out on education and other opportunities. Stigma clings even to those who are cured, and often affects the lives of children.



New Names, Same Faces – BIGGER Smiles!



Two new names appeared among the staff of The Leprosy Mission New Zealand over the New Year. However, the faces were the same – but with much bigger smiles. The reason? They have both recently married. Many supporters in the South Island will be familiar with our Donor Relations

Manager, Gay McNaughton. Gay and family enjoyed balmy Invercargill weather for a beautiful garden-themed wedding in December. Gay has now become Gay Glozier following her marriage to Kerry Glozier.

Our Direct Marketing Manager, Lisa McLaren (nee Carrington), prepares our appeal letters and other fundraising materials. Lisa recently travelled home to Brighton in England to marry Marcus McLaren. We are pleased she returned to our warm summer to settle in New Zealand.

How Your Money Has Helped



We love to thank you and keep you updated on the appeals that you so generously support.

Our August appeal, sharing Mong Tan's incredible journey from a banished existence in the jungle to acceptance back into his remote hilltop village, has raised more than \$174,000. Your gifts enabled us to provide vital health education and training in local clinics for isolated communities in the Chittagong Hill Tracts. You also helped provide training on leprosy prevention and training of trainers, for example, to community and religious leaders, to break down the relentless stigma that is the cause of so much suffering. Despite the isolation of the Chittagong Hill Tracts, TLM project staff are still committed to making long jungle journeys and are able to administer leprosy medication to people cut off from the outside world. With a target of \$245,070, this appeal has taken us forward significantly; even though the target was not reached, your contributions will make an incredible difference in the lives of many.

For more information about supporting the Wellbeing project in the Chittagong Hill Tracts, Bangladesh, please contact our office.

What do you think about our Really Good Gifts?

This year we want to emphasise the benefits and value of our Good Gifts and explain what makes them Really Good Gifts. So we are doing things a little differently from other years. What do you think? We want your feedback; email us at enquiries@leprosymission.org.nz.

So far this year, your Really Good Gifts have provided the adjacent for people experiencing leprosy.

Finally, thank you for joining us in celebrating **World Leprosy Day /Leprosy Awareness Week** in January and helping us shine a light on leprosy. We've had an incredible response to the appeal and are grateful for your willingness to stand up and help to raise awareness that leprosy still exists and that everyone can be a part of the cure.

REALLY GOOD GIFTS GIFTED SO FAR:

Busy Beehives	79
Dairy Cows	36
Crutches for a Child	475
People Cured Forever!	57
Education for a Girl	144
The Gift of Sight	304
Goats	10
Days in Hospital	540
Community Houses	2
Sandals Protect Feet	1726
School Kit	632
Seed Hamper	405
Sewing Machine	54
Small Business Start-up	471
Education Theatre	2
Carpenter's Toolkit	140
Clean Water Pump	35

Thank you sincerely for
your valued support.

Tax Rebate Changes

From 1st April changes to New Zealand tax law mean **individuals** donating to a registered charity (TLMNZ is Registered Charity No CC37638) an amount from \$5 up to their total income, a tax rebate of 33.3% can be claimed.

Companies have had the upper limit of 5% of their income removed as the threshold for donations. From the 2009 tax year, businesses can claim a tax deduction on donations up to their net income. This change has the potential to make more money available for donations to charitable organisations such as The Leprosy Mission.

I WANT TO FIGHT LEPROSY

I would like to become a SEED Partner by making regular monthly donations of:

- \$100
 \$50
 \$30
 \$20
 Other \$ _____

I would like to make a ONE-OFF donation of:

- \$500
 \$100
 \$50
 \$20
 Other \$ _____

For _____
 THANK YOU FOR YOUR SUPPORT

PAYMENT OPTIONS

- Cheque
 Automatic payment (we will send you a form)
 Visa
 Mastercard
 Diners
 AMEX

Card Number

Expiry /

Cardholders' name _____

Signature _____

- Please send me info on leaving a bequest
 I have already included TLM in my Will
 Please send me "Prayer & Praise" [bi-monthly]
 Please send an "Ask" prayer booklet [annual]

MY PERSONAL DETAILS

Mr / Mrs / Miss / Ms _____

Address _____

Phone () _____

Email _____

PLEASE SEND TO

The Leprosy Mission New Zealand
 PO Box 10227
 Dominion Road
 Auckland 1446



Alternately you can donate on-line at
www.leprosymission.org.nz or phone
 0900 900 44 to make an instant \$25 donation

“The association is our voice, our message and our weapon. It is our weapon because we have been segregated and marginalised but now we can stand up for our rights like an angry lion. As citizens we have been defined by our leprosy, but no longer.”

Birke Ngatu, Vice President of the Board, ENAPAL, Ethiopia



A meeting of ENAPAL members at Bahir Dar, Ethiopia, in 2008 where they came together to celebrate their achievements so far. Their strength is in their solidarity and organising themselves, and in this way they are endeavouring to change their circumstances and the way society behaves towards them.