

# Newsletter

May 2011



pacific leprosy  
FOUNDATION

[www.leprosy.org.nz](http://www.leprosy.org.nz)

## Stories from the Solomons

*The following two stories are reports from a WHO representative who recently visited Honiara*

In the Solomon Islands leprosy lurks in the shadows of settlements and villages.

Two beautiful young teenage girls cover their eyes and weep when asked how they feel about contracting the illness, even though they have been cured and have no ill effects.

Two strapping young men, with sores on their bodies, stare at you with eyes haunted by shame and, perhaps, anger. Joshua, 25, has arresting good looks, piercing black eyes and leprosy blemishes on his body. He speaks Pidgin English, pausing constantly to think about his responses to questions before directing his answers through Oliver, a male nurse from the Ministry of Health.

He has had "the sickness", a euphemism for leprosy, since he was 16. Like many fellow sufferers, the disease has lingered because shame and denial cause patients to stop taking their drugs before treatment has been completed.

Joshua now takes his pills daily, and the ulcers are going. "The people at school didn't know I had leprosy," he says through the interpreter. "Only members of my extended family knew. "I didn't want to tell people. If they knew, they wouldn't want to come for a chat. They would isolate themselves". And yes, it has affected his life profoundly; he stopped going to school and socialising. His unsmiling face speaks volumes.

In the same village on the outskirts of Honiara, 19-year-old Tenatake, a vibrant teenager with a sparkling smile and an ambition to become a nurse, crumples into tears when asked to describe her life over the seven years since she had leprosy, until recently. Her

symptoms started as numbness and small red patches on her back and legs; a mild case which left her with no disabilities and no disfigurements.

But the stigma of the disease is such that, like Joshua, her friends don't know she has had "the sickness" because she fears they will shun her. "I feel sorry for myself sometimes," she says haltingly. She brightens when asked about her future plans. "I study science, mathematics, English and social science," she says, beaming. "I want to be a nurse, to help people like myself".

There are many such tales from people who live in their communities in Honiara, playing out lives of quiet suffering. The stigma of being a leprosy sufferer is still so strong that 21-year-old Samuel and his infected mother and siblings were nearly run out of his small community on the outskirts of Honiara when his condition became known. The leprosy specialist from the World Health Organization, Dr Giampaolo Mezzabotta, asks Samuel about a weeping, open sore on his hand. It has clearly not been treated for some time, and a visit to a doctor is organised.

Lack of consistency of care, a dearth of well trained health care professionals, fear and lack of community education combine to represent a serious stumbling block to the final eradication of leprosy.



# The Solomon Islands

Noelyn, 26, covers her face with her hands and weeps as she talks about her experience with leprosy. And then she recovers as quickly as she fell apart, though tears still quietly roll down her cheeks.

Now healthy, with a fresh face and open attitude, Noelyn speaks quietly when she recounts first noticing little spots on her body in 2005. "At first I didn't know I had it [leprosy], until I realised it was a lot more than just a few spots," she says.

"My aunty took me to hospital, where I was diagnosed. I was treated, and the spots went. Now they've all gone".

As one of hundreds of leprosy patients in the Solomon Islands, Noelyn is unique in that she told a few of her friends she had the disease. Most try to hide it, even those with mild cases such as hers. Living with the stigma is more difficult than recovering from the disease, which is as easy as following a daily three-pill regime.

But even her openness to her close friends about her condition did not stop an inner anguish and shame about contracting a disease seen as unclean and, in some communities, a curse by the gods for bad behaviour.

"I felt different, unusual", she says. "I hated myself. I didn't know how I got it". It is difficult to determine, but it is likely that she contracted it from her brother Michael, 22, who was diagnosed in primary school. His sickness was more severe than his sister's, requiring time off school for hospitalisation and treatment.

To this day he is behind scholastically. "It affects my education up to now," he says, his Pidgin English translated through an interpreter. The disease dragged on because

he was irregular with his medication "for fear of recrimination".

It's a common refrain from leprosy sufferers. They don't want to be seen going to clinics for medication, or having health professionals visit them to check on their progress. People live cheek-by-jowl in Solomon Island villages, in clumps of extended family setups. Secrets are hard to keep.

Like his sister, Michael told his friends he had the disease, and "they were cool with that".

But not everyone was so kind. "People avoided me," he says, eyes cast down. He shuffles off. Even though he is now disease-free, he no longer studies, and has no work. He just "stays in", he says.



## 2011 ANZAC of the Year

It gives us the greatest pleasure to announce that Brigadier (Retired) Dr Brian McMahon, CBE, KStJ – former Chairman of Board of Trustees of the Pacific Leprosy Foundation and current Deputy Chairman – has been named 2011 Anzac of the Year. His services to this organization have been invaluable for many decades and he continues to travel to the Pacific on our behalf on a number of occasions.

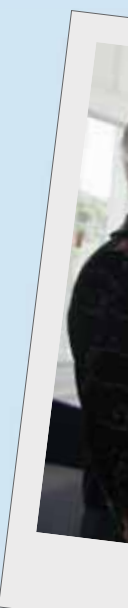
Dr McMahon was described by the President of the RNZRSA as "a soldier, a citizen, a doctor and a humanitarian." He went on to say "Brian McMahon has exhibited the qualities of comradeship, compassion, courage and commitment throughout his 60 years of service to his fellow citizens, his comrades in arms and

those he has served through his activities in overseas aid projects. He is a dedicated professional whose commitment and compassion for his fellow servicemen and women and their dependants, for those he has touched in his profession as a doctor, and for those he has touched in aid activities in Vietnam and the Pacific Islands are a matter of public record".

The award was presented to Dr McMahon by the Governor General, Sir Anand Satyanand.

► **RIGHT:** Brian is presented with his award by The Right Honorable Sir Anand Satyanand, GNZM, QSO and Lady Susan Satyanand.

PHOTOGRAPH COURTESY OF RNZRSA



Below is the media release following the visit to our office by the Regional Director of the World Health Organisation, Dr Shin Young-soo.

# “World Health Organisation Recognises Kiwis’ Fight Against Leprosy in the Pacific



The work of a small Christchurch-based NGO has so impressed the World Health Organisation (WHO) that a very senior overseas official popped in for a visit this week.

The Christchurch-based Pacific Leprosy Foundation is the only NGO in the world to focus solely on eliminating leprosy in the Pacific—something the WHO Regional Director for the Western Pacific Region Dr Shin Young-soo from Korea is also committed to achieving.

He knew about the Foundation’s work and saw it in action when visiting Kiribati. So when he found himself in Christchurch to see the earthquake emergency response, he squeezed time into his packed schedule to visit the Foundation in St Albans.

Dr Shin Young-soo told Foundation General Manager Jill Tomlinson and Foundation board member Dr Graham Watson that WHO is making a big push towards

reaching their “elimination” target of less than one case per 10,000 population by 2015.

Three Pacific countries—Kiribati, Marshall Islands and the Federated States of Micronesia—are still over that level. Leprosy is also still a problem in other Pacific countries including New Zealand.

“The Regional Director is giving the lead in this and it is the first time in many years that WHO has committed considerable resources to leprosy elimination. It is pleasing to get recognition from WHO for the work we do,” says Ms Tomlinson.”



Jill Tomlinson, General Manager, Pacific Leprosy Foundation with Dr Shin Young-soo, Regional

## Lala's office ...

I was at my motel in Invercargill, preparing for a donor meeting, when the news broke that Christchurch had suffered a second, far more serious earthquake. Transfixed by the images and stories, I was unable to tear myself away from the television news, and rushed into the donor meeting with only minutes to spare. Thank you so much to all of our supporters there who helped me to set up the meeting and afternoon tea and who didn't mind me leaving my mobile phone switched on to get the latest news from family and friends. I must have delivered my talk on autopilot as I can't remember a thing about it! I am glad to be able to report that the staff of the

Foundation have not suffered any personal losses or property damage, and the offices themselves are fine. Our thoughts and prayers are with any of our supporters who have suffered loss or damage caused by the earthquake.

This month I am staying near to home and talking to the Lions Club in Oxford; next month I am heading for Whangarei – and speaking to Warkworth Probus Club on the way past.



## Information . . .

### WHERE IN THE WORLD?

We currently manage projects to assist those affected by leprosy in the following countries:

- Fiji
- Tonga
- Samoa
- Vanuatu
- Solomon Islands
- Kiribati
- Indonesia
- Viet-Nam
- New Zealand

Thank you so much to all of you who make this work possible through your interest and generosity.

### DIRECT CREDIT

We are happy to receive donations by direct credit. If you wish to use this option, please use your surname and donor number (six figures to the right of your name and address on our appeal coupon) as a reference, so that we know where to send the receipt. The bank account number is: 02-0800-0037987-000

### OUR PRINCIPAL ACTIVITIES

The principal activities of the Pacific Leprosy Foundation in the South Pacific are: the funding of programmes the purpose of which is the elimination of leprosy; the continuing care of patients (and their families) with disability or social or economic disadvantage due to present or past active leprosy.



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