



Media Release

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Leprosy Still a Problem in NZ and the Pacific

Social attitudes, rather than a lack of medicine, are the major reason leprosy continues to be a problem in the Pacific Islands and to a lesser extent in New Zealand according to Jill Tomlinson, General Manager of the Pacific Leprosy Foundation in Christchurch.

World Leprosy Day is being held on 31 January 2010 to raise awareness of the disease. Past policies of segregation and isolation designed to prevent the spread of the disease made leprosy a disease out-of-sight and out-of-mind. As a consequence many people believe leprosy no longer exists. Unfortunately it certainly does— every week new cases are diagnosed in New Zealand and the Pacific.

People with leprosy tend to keep a low profile because of the stigma associated with the disease. They are often reluctant to seek medical treatment and instead hide the first tell tale signs of leprosy--strange pale patches on their skin.

“Because of this stigma associated with leprosy, patients are reluctant to seek medical help. Even when they have the disease diagnosed they hide the fact. Reimbursing medical costs using cheques is difficult for the Foundation as some patients won’t even bank our cheques because they have the word leprosy on them,” says Jill.

Leprosy can be cured with Multiple Drug Therapy but treatment needs to start as soon as the symptoms appear. If treatment is delayed, leprosy can cause nerve damage and permanent disability and disfigurement.

“There is still a lot of public confusion and mystery about leprosy which is why sufferers are often in denial. Even if they realise they can be cured

they don't want to admit they have the disease because they know they may be shunned by their families, friends and community. The stigma is so acute sufferers never speak the word leprosy aloud. Instead it is referred to as 'the sickness'." (see Katalina's story below)

With the help of public donations and bequests, the Pacific Leprosy Foundation works to eradicate leprosy and care for patients and their families. It also educates the community about leprosy so the stigma is diminished through understanding.

"With many health workers being removed from leprosy programmes to work with TB and other communicable diseases, there is a real danger leprosy will increase in the same way that TB has. We work to support and train health workers and provide them with the necessary resources to diagnose and treat leprosy," says Jill.

Rehabilitation and welfare is also a strong focus.

"People suffering from and disabled by leprosy and their families are a low priority for governments with limited resources. We fund rehabilitation and welfare work throughout the Pacific and provide money for medical treatment and clothing to protect hands and feet which have no feeling due to nerve damage."

Patients are encouraged to provide for themselves and their families. Funds are provided for income generating projects such as livestock improvement, growing crops and making crafts to be sold in the markets. The Foundation also provides funds for housing, housing improvements and the education of the children of leprosy sufferers.

ENDS

Photos available on request

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Background Information

Katalina's Experience of Leprosy

Katalina arrived at Auckland A & E with severe burns to one hand. She claimed not to be in pain, but was reluctant to answer the doctors' questions. Her whole demeanour showed fear and shame; her head was lowered and her eyes turned away.

Gradually the kindness of the doctors and nurses broke through her reserve and she began to tell her story. She had been lucky, she said, to be able to move from her Pacific Island home to live in New Zealand a few years ago. She and her family had settled down and she was able to get a good job to help her parents out with the bills. She had been very proud of what they had achieved.

Not long after this she noticed some strange patches on her skin – they were lighter than the rest of her skin, and when she touched them they had no sensation. She knew it was 'the sickness' – the disease so terrible that its name, leprosy, is never spoken aloud. She had seen other people from her village back home who had suffered from the sickness and been shunned by their friends, even though they had been given medicine which had cured the disease. She could see all the wonderful things in her new life in New Zealand disappearing before her eyes – she was afraid that she would lose her job, her new friends and bring shame to her family.

Her leprosy gradually became more noticeable on her arms and legs and she was careful to always wear long sleeves and pants. Gradually she developed a tingling in her hands and feet, which soon became totally numb. It was as a result of this numbness that she had burned her hand on the stove – she hadn't realised that it was hot.

The doctors treated her burns, and she was prescribed Multiple Drug Therapy for her leprosy. She had to take the pills for a year and over that time her skin gradually returned to normal. But it was too late to do anything about the damage to the nerves in her hands and feet. That was permanent and could never be reversed. The doctors weren't able to save all her burnt fingers and she was no longer able to do her work. In the future she might suffer from clawing of her hands, dropped foot or difficulty in closing her eyes. Luckily, all of those problems can be helped with simple surgical procedures.

It was Katalina's fear of the stigma of leprosy which prevented her from seeking medical help. If she had, then the disease would not have progressed to the point where she had nerve damage, and subsequent disability.

There has been an effective cure for leprosy since the introduction of Multiple Drug Therapy (MDT) in the 1980s. Although the disease is

curable, sometimes the effects of the disease cannot be reversed. The sooner the disease is diagnosed and treated the lower the chance of nerve damage occurring.

Many people believe that leprosy no longer exists, yet every three minutes, someone somewhere in the world is diagnosed with leprosy. It is vital that awareness of and knowledge about the disease is retained if we are to win the war against leprosy.

About World Leprosy Day

World Leprosy Day is held on the last Sunday of every January. It is organised by the World Health Organisation to promote awareness of leprosy. The theme for 2010 World Leprosy Day is the stigma associated with leprosy. For further information www.ilep.org.uk

About the Pacific Leprosy Foundation

Based in Christchurch, the Pacific Leprosy Foundation is a not-for-profit, non-governmental non-religious organisation working towards the elimination and mitigation of the effects of leprosy in Fiji, Tonga, Samoa, Vanuatu, Solomon Islands, Kiribati, Indonesia, Viet-Nam and New Zealand. The Foundation does not receive any government funding and relies on public bequests and donations to continue its work.

The Foundation was formed by Patrick Twomey, a Christchurch man who taught in Fiji for a short while in the 1920s. Patrick was disturbed by the plight of people with leprosy as there was no cure for the disease back then. When he returned to New Zealand he took up the cause of the leprosy patients on Quail Island in Lyttelton Harbour. When this was closed in 1925 the patients were transferred to Makogai in Fiji where they joined a much larger group of around 750 leprosy sufferers from around the South Pacific. It was obvious that to achieve anything worthwhile for this group would require expanded appeal efforts in New Zealand.

Patrick dedicated himself to the cause and it wasn't long before he became known as the 'Leper Man'. He wrote appeal letters directly to prospective benefactors in Christchurch, then around Canterbury and finally, with the support of others, all across New Zealand. The time had come to establish a more formal organisation and the Makogai NZ Lepers' Trust Board, the forerunner of the Pacific Leprosy Foundation, was set up in 1939. For further information visit www.leprosy.org.nz

About Leprosy

- Leprosy is one of mankind's most ancient scourges, mentioned in writing from ancient India to the Bible to the Middle Ages.
- Leprosy is caused by a bacteria (*M. leprae*) that attacks and damages the nerves under the skin which can result in paralysis,

the loss of sensations, degeneration of muscles and bone, leading to highly visible progressive debilities.

- Leprosy is contagious. It is spread by droplet infection (coughs and sneezes) but, unlike a cold, is difficult to catch
- The long incubation period of leprosy (a few months up to 20 or even 50 years), together with the varied symptoms associated with different forms of the disease, have historically made diagnosis exceedingly difficult.
- There has been an effective cure for leprosy since the introduction of Multiple Drug Therapy (MDT) in the 1980s.
- As a consequence of nerve damage in the limbs, unfelt injuries especially to the hands and feet lead to severe physical disabilities aggravated by accidental injuries and repetitive actions in everyday life.
- *M. leprae* attack the nerves in cooler areas of the body which are, in the main, the peripheral nerves close to the surface of the skin. This gives rise to visible patches and rashes on the skin, flattening of facial features, visual problems and loss of facial hair.
- Fingers and toes are most easily damaged and the loss of these digits is a notorious sign of leprosy. The simple repetitious action of walking with anaesthetized nerves in the feet lead to the later chronic problem of plantar ulcers on the soles. These are extremely difficult to cure and frequently lead to complications that result in amputations.
- Disabilities can occur long after the disease has been arrested either naturally or by medical treatment, because the nerves cannot recover. For this reason early diagnosis of leprosy and treatment are imperative to prevent nerve damage which may lead to later severe physical disabilities.