

## The Pacific Leprosy Foundation Archive and Oral Histories of Leprosy in the South Pacific

In November 1998 the Pacific Leprosy Foundation, an organisation dedicated to the eradication of leprosy and the assistance of those affected in the Pacific region, deposited their archival material in the Macmillan Brown Library, University of Canterbury, Christchurch, New Zealand. The materials include minutes, correspondence, photographs, a few interviews with members of the organisation and official proceedings of the Pacific Leprosy Foundation.<sup>1</sup> The materials can be consulted with written permission from the Pacific Leprosy Foundation, New Zealand.<sup>2</sup>

The Pacific Leprosy Foundation Archive is an essential source for the study of leprosy and, more broadly, the development of 20th-century public health strategies in the West and South Pacific regions.<sup>3</sup> Most academic historical research into leprosy in the Pacific has focused on the Hawaiian experience and the iconic figure of father Damien, who lived in exile with leprosy sufferers of Molokai Island.<sup>4</sup> Apart from technical papers by the South Pacific Commission, memoirs and biographies of prominent figures in leprosy care, and a few institutional and personal histories, such as Sister Mary Stella's *Makogai: image of hope*, little has been published on leprosy in the South Pacific.<sup>5</sup> There is still much research to be done on the experience of the disease, community attitudes and understandings, the role of dedicated volunteers from New Zealand, and the cooperative engagement of New Zealand charitable organisations with the New Zealand and Fijian governments in caring for those afflicted and in controlling the disease.

This paper first offers a brief history of leprosy in the South Pacific, in particular the beginnings of the Pacific Leprosy Foundation's role in leprosy treatment and care in the 1920s, then describes the recent development of a new oral history archive to add to the existing Pacific Leprosy Foundation materials.

The Pacific Leprosy Foundation remains a key player in the history of leprosy management and treatment in the Pacific. The Foundation began with the initiative of New Zealanders Benjamin Pratt and Pat Twomey, later known in New Zealand as 'the leper man', who worked together during the 1920s to bring material comforts, entertainment and friendship to leprosy sufferers held in isolation on Quail Island in Lyttleton Harbour in New Zealand's South Island. From as early as 1851 Quail Island

<sup>1</sup> Details on the holdings of the Pacific Leprosy Foundation Archive are available online from the Macmillan Brown Library website (<http://library.canterbury.ac.nz/mb/>).

<sup>2</sup> Pacific Leprosy Foundation, 115 Sherborne St, Christchurch, New Zealand. Further information is available online (<http://www.pacificleprosyfoundation.co.nz/>).

<sup>3</sup> The term 'leprosy' is used throughout this paper to refer to the disease caused by infection with *Mycobacterium leprae*. Leprosy is also known as Hansen's Disease, named after the Norwegian physician who discovered the leprosy bacillus in 1873. Although in some contexts the term 'leprosy' is now avoided because of associations with stigma, it is used here in preference to 'Hansen's Disease' as the more familiar name for the affliction caused by *M. leprae* and the more current term in both international public health discourse and the historiography of the disease. It also best matches the historical understanding of the disease in the South Pacific and the way it is understood in both the written archive and by the sufferers whose oral history testimonies are discussed here.

<sup>4</sup> Perhaps the best-known study in this Hawaiian corpus is Gavan Daws, *Holy Man: Father Damien of Molokai* (2nd edn, Hawaii 1984).

<sup>5</sup> Sister Mary Stella, *Makogai: image of hope: leprosy patients in Fiji* (Christchurch 1978).

had been used to quarantine sick passengers and seamen entering the port and, in 1892, it became the official quarantine station for New Zealand, providing quarters for both sick immigrants and imported livestock. Its role as a leprosy isolation area began informally when the New Zealand Minister of Health ordered the removal to Quail Island of the first person in Christchurch discovered to have leprosy. A hut was built for the man, Will Vallance, separate from the quarantine quarters but within the quarantine boundary. In 1908, a second leprosy sufferer was banished to Quail Island and, after being released as cured in 1909, returned to care for Will Vallance who was nearly blind and made helpless by his disease. By 1924, there were nine leprosy sufferers on the island under the medical care of the doctor at Lyttleton. Cooked food was left for them by the island's caretakers, while individuals and church groups from Lyttleton provided friendship, books and other items to ease their loneliness. It was in this context that Benjamin Pratt and Pat Twomey began fundraising and developing broader community interest in Christchurch to help support leprosy sufferers on Quail Island.<sup>6</sup>

Although conveniently located as a place for isolating leprosy sufferers, Quail Island offered little shelter from the wind and, during the winter months, was in shadow from two o'clock in the afternoon, adding to the physical affliction of those quarantined there long-term. The presence of leprosy patients also caused anxiety among those living in temporary quarantine close to the leprosy patients or visiting the island to care for livestock. Further, the New Zealand Health Department was not prepared to invest for so few patients the resources needed to improve medical care, nursing and housing. These disadvantages led in 1925 to the transfer of leprosy patients from Quail Island to the Fijian island of Makogai, off the coast of Suva.<sup>7</sup> Quail Island remained active as a general quarantine station from 1931, but Makogai subsumed Quail Island's role as an isolation centre for leprosy sufferers.

The Central Lepers' Hospital had been built on Makogai in 1911 to provide medical and nursing care to leprosy sufferers from the Pacific region.<sup>8</sup> The establishment of Makogai as a place of isolation for leprosy sufferers in the South Pacific had its origins in the first International Leprosy Congress held in Berlin in 1897. One of the resolutions of that congress was that isolation of leprosy sufferers must be practised as far as possible to prevent transmission of the disease.<sup>9</sup> Fiji, which had been a British Colony since 1874, responded to international pressure from congress delegates to establish an isolation area for leprosy sufferers from the Pacific. At first, Walu Bay was chosen, but the local people objected to the proximity of leprosy sufferers. The Soliaga Peninsula in Beqa provided the next site but, as the number of people being sent increased, the area became too small and Makogai was selected as the base for Fijian and South Pacific leprosy care.<sup>10</sup>

During its time as a leprosy isolation centre, over 4,500 patients were treated on Makogai and, of these, more than 1,500 died and were buried on the island. Fear of the disease was so great that the British colonial Government in Fiji was unable to persuade government medical and nursing staff to work there and ultimately sought the help of the Roman Catholic Church to run the hospital. The Missionary Sisters of Mary took on the role and, supported by individuals and other Christian religious communities, provided

<sup>6</sup> 'The Lepers of Quail Island', *Lazarite*, 12 Aug. 2002; New Zealand Department of Conservation, *Te Papa Atawhai*, 'Otamahua/Quail Island', (<http://www.doc.govt.nz/Community/001~For-Schools/003~Field-Trips/010~Canterbury/Otamahua-Quail-Island/012~Cultural-Heritage.asp>, accessed 23 Jan. 2006).

<sup>7</sup> *Leprosy Trust Board: a brief outline of the development and operations of the Leprosy Trust Board (The Leper Man Appeal)* based on a series of talks by Derek Douglas, Secretary of the Board (Christchurch [1985]), 2-3.

<sup>8</sup> Esaroma Daulako and Kumar Jesudasan, *Leprosy Control in Fiji: a report prepared for the World Health Organisation/Pacific Leprosy Foundation/South Pacific Commission Workshop on the management of tuberculosis programmes and leprosy elimination in the Pacific, Suva, Fiji, 21-30 November 1994* (Suva 1994), 3.1.

<sup>9</sup> Jane Buckingham, *Leprosy in Colonial South India: medicine and confinement* (Basingstoke 2002), 184.

<sup>10</sup> Daulako and Jesudasan, *Leprosy Control in Fiji*, 3.1.

the core of both medical treatment and material and spiritual support for those sent to Makogai, many of them children.<sup>11</sup> After Benjamin Pratt's death in 1930, Pat Twomey established the Makogai Lepers (N.Z.) Trust Board, formalising the work that they had begun while Quail Island was a leprosy isolation area. The Makogai Lepers (N.Z.) Trust Board was set up as a non-government, interdenominational charitable trust funded by donations from New Zealand citizens and developed principally to bring care, comfort and entertainment from New Zealanders to all the leprosy sufferers on Makogai.<sup>12</sup>

International advances in the treatment of leprosy were to have an impact on the role of Makogai and the Makogai Lepers (N.Z.) Trust Board. During the 1940s, Diamino-Diphenyl-Sulphone (DDS), a sulphone drug, was trialled at Careville Hospital USA and proved to be the first agent effective against the bacterial cause of leprosy. As late as the 1938 Cairo International Leprosy Congress, the South Asian remedy Hydnocarpus oil (Chaulmoogra Oil) injected hot, 'intramuscularly, subcutaneously and intradermally' and so requiring medical supervision had been recognised as the best treatment available.<sup>13</sup> But besides being extremely painful for the patient, it was at best a remedial measure, easing symptoms but not attacking the bacterial cause of the illness. The sulphone drugs, which could be taken orally in tablet form, released many leprosy sufferers worldwide from the need for hospital management and long-term care. Many patients on Makogai were effectively treated and repatriated to their homes throughout the Pacific. Others, however, remained on Makogai, too sick and physically damaged to be cared for outside a hospital, some without homes to return to, and others whose family and community either refused or were unable to care for them. The Makogai Lepers (N.Z.) Trust Board adapted to fit the diverse rehabilitative and therapeutic needs of both hospital-based and relocated leprosy patients and altered its name in November 1942 to the Lepers' Trust Board, reflecting its assumption of a wider commitment to the care of leprosy sufferers who had returned to their homes throughout the South Pacific.<sup>14</sup>

With the reduction of leprosy in the Pacific and the opportunity for early out-patient treatment which DDS provided, the number of people requiring residential leprosy care declined, and fear of contagion lessened, enabling the closure of the leprosy treatment facility on Makogai. To serve the needs of the remaining leprosy patients and to coordinate and train people to continue leprosy eradication work, P.J. Twomey Hospital was opened in November 1969 on Tamavua Heights near Suva. Named after the founder of the Leprosy Trust Board and in recognition of the Board's substantial funding of the building, Twomey Hospital continued to embody the interest and involvement of New Zealanders in Pacific leprosy care.<sup>15</sup>

While DDS had brought massive change in treatment methods and had significantly reduced the severity and incidence of leprosy in the Pacific, it was not to prove the 'miracle cure' which it had seemed. The tragedy of DDS was revealed in the 1970s, when the first relapses among those treated with mono-drug therapy in the 1940s and 1950s became evident. In addition, drug-resistant leprosy strains had developed during the 1960s, rendering the treatment ineffective for many. In 1978, an agreement was signed by the World Health Organisation, the Leprosy Trust Board and the Government of Fiji that the facilities built at Twomey Hospital would be used as a Leprosy Training Centre for the South Pacific, preparing specialised leprosy workers for all aspects of treating and managing the effects of the disease in the region.<sup>16</sup> Twomey Hospital continues to

<sup>11</sup> Ibid.

<sup>12</sup> *Leprosy Trust Board*, 2-3.

<sup>13</sup> Leonard Rogers and Ernest Muir, *Leprosy* (2nd edn, London 1940), 232.

<sup>14</sup> *Leprosy Trust Board*, 3-4.

<sup>15</sup> Daulako and Jesudasan, *Leprosy Control in Fiji*, 3.2; *Leprosy Trust Board*, 7.

<sup>16</sup> Ibid., 3.2-3.3.

combine this role with treating in- and out-patients, providing long-term residential care for those unable to return home and managing leprosy control activities in Fiji.

Throughout the changes in treatment modalities and the shift in the focus of leprosy treatment away from Makogai, the Lepers' Trust Board continued to build within New Zealand a sustained community interest in the plight of leprosy sufferers in the South Pacific. In 1978, the Board became the Leprosy Trust Board in accordance with international agreement among leprosy workers to avoid the term 'leper' as demeaning to leprosy sufferers.<sup>17</sup> In 1991, reflecting its contemporary charitable status, the Leprosy Trust Board was renamed the Pacific Leprosy Foundation.

The Pacific Leprosy Foundation remains active throughout the Pacific and New Zealand, supporting leprosy research and medical students, educating the public, raising funds for leprosy treatment and rehabilitation, and managing and monitoring Multi-Drug Therapy (MDT). Introduced in the mid-1980s, MDT replaced DDS, offering the second hope of effective cure for leprosy in the 20th century. Rather than a mono-drug therapy like DDS, MDT combines a variety of antibiotic and anti-inflammatory drugs and requires shorter treatment times, factors which reduce the likelihood of resistant strains of leprosy bacteria developing and enable earlier eradication of leprosy in people identified with the disease. Continuing in the spirit of its founders, the work of the Pacific Leprosy Foundation remains intent on providing the most advanced available medical, economic and social care to those with active leprosy and rehabilitative and occupational support for those socially and physically disabled by the disease.<sup>18</sup>

A new dimension to the understanding of leprosy in the Pacific has been added to the Pacific Leprosy Foundation Archive by the inclusion of oral history interviews, conducted by Dorothy McMenamin in August 2004 with leprosy sufferers, all of whom, except one, had been sent to Makogai and at the time of interview were either patients currently resident in Twomey Hospital or in the suburbs and outskirts of Suva. Two of the patients had been part of the 1999 documentary video on the Makogai experience, *Compassionate Exile*, conceptualised by the Fiji playwright Larry Thomas, and some had been interviewed for radio and other media at various times.<sup>19</sup> This was, however, the first opportunity for most leprosy patients in Suva to have their memories of illness and life, both on the island and after leaving Makogai, preserved for posterity.

The interviews took place over one week against the background of constant rain. The patients were interviewed in English or, where English was not a common language, with a nurse or friend acting as interpreter and providing simultaneous translation. Those interviewed were willing to have their stories recorded and offered many unexpected insights into the experience of confinement and the return, for some at least, to a relatively normal life once their illness was arrested. The cohort interviewed consisted of 15 people from various parts of the Pacific region, nine men and six women. Of those interviewed, 13 were Fijian in origin, one from Tonga and one identified herself as from the Gilbert Islands. The majority had been taken to Makogai as children on the government boat that travelled the Pacific picking up leprosy sufferers from the islands to take them into isolation. One of the most powerful insights from the interview process was the sense among some patients that, on Makogai, they left isolation behind and found a community in which they could again fully participate. Separation from home, family and friends had for many already begun in their home villages. On Makogai, they were to find friendship, education, work and companionship, together with medical treatment

<sup>17</sup> *Leprosy Trust Board*, 14.

<sup>18</sup> Daulako and Jesudasan, *Leprosy Control in Fiji*, 3.2.

<sup>19</sup> Bob Madey and Larry Thomas (filmmakers), *Compassionate Exile*, 60 mins, VHS, colour, X-Isle Productions, Suva, 1999. Copies of the video are available from Larry Thomas, Secretariat for the Pacific Community, Suva. See also Teresia K. Teaiwa, review of *Compassionate Exile*, *The Contemporary Pacific*, 13 (2001), 302–6.

and nursing care. Initially, though, the dominant emotion was of fear, abandonment and the expectation that they would never return home but would die on the island as so many did.

Archival materials additional to the existing Pacific Leprosy Foundation material held in Christchurch can be found in Suva. The original volumes of the Makogai Patient Register recording the name and brief biographical information for each patient and the dates of their admission and discharge were recently deposited in the National Archives of Fiji. In addition, Twomey Hospital holds seven volumes of photographs related to both Makogai and the foundation and continuing work of the Hospital. The photographs are a rich pictorial record of a life barely glimpsed through the medical records. The visit to the patients of Makogai by the 'Queen of Suva', as she was described in the photo caption, is recorded along with photographs of more ordinary daily activities. Village life and the routine of cooking and working interspersed with entertainment for the adults and school and scouts club activities for the children are all recorded. Most photos were preserved and carefully labelled by the Catholic nuns who lived on Makogai with their patients.

Patient records remain one of the most important elements of the archival materials held at Twomey. Longstanding patients have records that date back to their time on Makogai. The files from the Makogai period are very brief, distilling patient identity and medical history into two charts. The first, the Progress Record includes a head and shoulders photograph of each patient, basic details of name, age, address, race, sex, date of birth, admission and type of leprosy observed on admission, but no comment on social or other aspects of the patient's life. Greater detail is provided in the description of symptoms on admission, including a map of the illness pattern on the patient's body, and in the medical analysis of leprosy 'activity'. The second, Chart 2, provides additional biographical data adding the names of relatives and contacts, and the patient's race and religion to a summary of his or her medical history and the examinations, including tests and X-rays performed. On the whole, however, the Makogai records are intensely focused on the medical aspects of the patient's condition and give little indication of the complex experience of life on the island evident in the photographic record, both at Twomey and in the Pacific Leprosy Foundation Archive, and the oral testimonies of the patients themselves. Later records dating from the early 1970s, when Twomey Hospital was opened to the care of leprosy patients, include a case report on each patient that summarises their medical history at Makogai but offers more qualitative material than the Makogai records. Details such as the patient's and medical staff's feelings about difficulties with treatment, the personal circumstances of the patient, and the personal and social life of the patient outside the hospital can be found in these later hospital records, but are absent from the Makogai period.

The oral history interviews now added to the Pacific Leprosy Foundation Archive held in Christchurch invite a deeper appreciation of the personal impact of leprosy hinted at in the detail of the medical records and the photographs of life on the island. One of the most striking aspects of both the interviews conducted and the general conversation with patients at Twomey Hospital during the interview week was the emphasis by many patients on the positive aspects of their experience of Makogai. While leprosy itself was a source of fear, physical weakness, and often pain and disability, the island offered far more than the security of the best available medical care consistently administered. For many, once the initial fear had passed, Makogai was like a 'paradise', beautiful and with abundant food easily cultivated. The loneliness of stigmatisation in home and village was eased by inclusion in a community of people connected by their illness. For many children separated from siblings, friends and parents, Makogai meant a return to normal schooling, the fun of joining scout troops, team sports and simply being able to play with other children and be looked after by adults again. For men and women, the opportunity to learn a skill, craft or trade was not only a source of encouragement when all hope of a

productive life had been lost. The skills learned on Makogai and often some additional resettlement support from the Leprosy Trust Board enabled many who returned home to earn a living and begin a normal life, even to the extent of raising children and financially supporting a family.<sup>20</sup>

The gathering of the oral history interviews was conducted in cooperation with the Pacific Leprosy Foundation. Financial support was provided by the International Leprosy Association, Global Project on the History of Leprosy (funded by the Nippon Foundation), Wellcome Unit for the History of Medicine, University of Oxford, and institutional support by the University of Canterbury.<sup>21</sup> The interviews, transferred from tape to compact disc, have been lodged with the Pacific Leprosy Foundation Archive in the Macmillan Brown Library, together with photographs of those interviewed, basic autobiographical information provided by each person and the consent forms for the interviews. These oral testimonies, their supporting documentation and the records of the Pacific Leprosy Foundation form the basis of the Pacific Leprosy Project based in the School of History at the University of Canterbury and offer an invaluable archive for those interested in the history of health, medical identity, community and isolation.

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<sup>20</sup> Dorothy McMenamin, 'Recording the Experiences of Leprosy Sufferers in Suva, Fiji', *Oral History in New Zealand*, 17 (forthcoming); also published in *The Fiji Social Workers Journal*, 1:1 (Nov 2005), 27–32; Wati Maria, Interview, 25 Aug. 2004; Fakatava Polutele, Interview, 24 Aug. 2004; Metuisela Volau, Interview, 23 Aug. 2004 (tape damaged by humidity); Viliame Wainiqolo, Interview, 23 Aug. 2004, Pacific Leprosy Foundation Oral Histories, Macmillan Brown Library, University of Canterbury.

<sup>21</sup> International Leprosy Association, Global Project on the History of Leprosy (<http://www.leprosyhistory.org/>).