



Leprosy-Info

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Throughout the millennia, victims of leprosy have been subject to a process of stigmatization far in excess that that brought about by any other type of illness. Initially the disease was viewed as a sign of spiritual impurity reflecting a punishment for heinous sins committed. Thus, contact with the healthy supposedly pure souls was supposed to 'infect' the latter with the conceived sins of the leper. Fortunately following the writings of the Cappadocian fathers of the Church in the 4th century, lepers started to be viewed as individuals placed in our midst to provide us with the opportunity to succour and care for the needy and thus gain heavenly rewards. This concept was the *raison d'être* for the establishment of the leprosaria set up by the brethren of St Lazarus. In spite of this alternate image of the leper, those afflicted by this infection were still look upon with dread and stigmatized in excess of what was their due relative to the infectivity of the infection. This became even worse after the discovery of the microorganism by Hansen. The confirmed infectivity of leprosy, albeit requiring long term contact, led to the adoption of legally enforced segregation - lepers were forcefully torn from their households, 'arrested', and locked up in segregated leprosaria to be forgotten by the rest of society. While the infection is now curable with multiple drug therapy, the ravages of past infection on the neural system results in stigmata that characterise and stigmatise the [now treated past] leper. Society should concentrate on identify victims of Hansen's Disease early to institute timely treatment and prevent the secondary complications that actually stigmatize the victims.

Numismatic reminders of enforced legal segregation

After Gerhard Hansen (1841-1912) identified the bacillus *M. leprae* in 1873 and thus the infective nature of the disease, legislation was introduced in Norway in 1877-85 requiring that leprosy-affected people be segregated to stop them from communicating the disease to others. This led to an apparent diminution of the disease by the end of the nineteenth century, an observation that convinced the rest of the world to emulate the Norwegian model. This led to the sprouting of several leprosaria and leprosy colonies aiming primarily to segregate rather than treat the unfortunate victims. In some regions the segregation was taken to the full extent including the minting of dedicated coinage having legal tender only in the colony. This was believed to be effective to restrict the possible spread of the infection to non-infected individuals living outside the colony through transfer by coins. This degree of segregation was eventually shown to be useless. Reminders of this segregation still occasionally present in numismatic sales. A catalogue of such leprosy-related numismatic items entitled *The Numismatic Aspects of Leprosy: Money, Medals, and Miscellanea* was compiled by Roger R. McFadden, John Grost and Dennis F. Marr in 1993 [Publishers: D.C. McDonald Associates, +167pp.] listing and illustrating the coins and paper money that circulated in the leper colonies in fourteen countries: Brazil, China, Colombia, Costa Rica, Danish West Indies, Hawaii, Japan, Korea, Malaysia, Nigeria, Panama Canal Zone, Philippines, Thailand, and Venezuela. Some examples of such coins are given below.



Lazaretto – Republic of Colombia
1921 - 2 Centavos coin



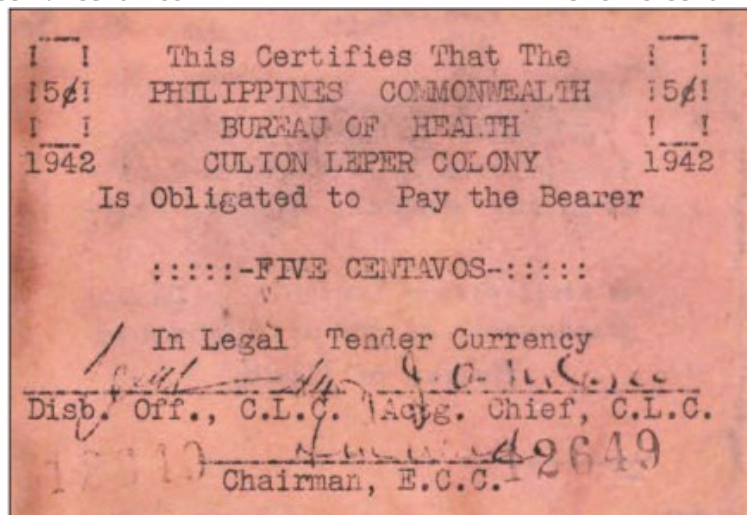
Lazaretto – Republic of Colombia
1921 - 50 Centavos coin



Leprosarias Nacionales – Island of Providencia
1939 - ½ Centimos



Maracaibo Leper Colony – Venezuela
1916 – 5 Centimos coin



Culion Leper Colony – Philippines : 1942 [following Japanese invasion] – 5 Centavos note

NEWS

The Maltese Parliament: On 14 May 2024, the Minister for Home affairs, Security and Employment introduced a bill on behalf of the Minister for Inclusion and the Voluntary Sector. This Bill No. 98 is a landmark bill in regards to the general legal viewpoint of victims of leprosy or Hansen's Disease putting aside once and for all the legal stigma these individuals were subjected to. The bill proposed the past Lepers Ordinance and Regulations, originally promulgated in 1893, be repealed thus elevating these individuals from a stigmatised status of victims of a specific disease to simply sick individuals like any other without distinction. While the concept of enforced segregation was removed during the mid-20th century, Maltese legislation still viewed the victims of Hansen's Disease as different that those individuals suffering from other illnesses. This amendment does away with the past legal discrimination closing an important chapter in the community's outlook towards those with Hansen Disease.

A BILL entitled

AN ACT to repeal the Lepers Ordinance, Cap. 45, and the Lepers Regulations, S.L. 45.01.

BE IT ENACTED by the President, by and with the advice and consent of the House of Representatives, in this present Parliament assembled, and by the authority of the same, as follows:-

- | | |
|---|---|
| Short title. | 1. The short title of this Act is the Lepers Ordinance and the Lepers Regulations (Repeal) Act, 2024. |
| Repeal of Lepers Ordinance, Cap. 45. | 2. The Lepers Ordinance is hereby repealed. |
| Repeal of Lepers Regulations, S.L. 45.01. | 3. The Lepers Regulations are hereby repealed. |

Objects and Reasons

The objects and reasons of this Bill are to repeal the Lepers Ordinance (Cap. 45) and the Lepers Regulations (S.L. 45.01).

L-PRF Feedback Report for The St Lazarus Charitable Trust: Thanks to the efforts of The St Lazarus Charitable Trust, the medical team in Ethiopia was able to purchase two L-PRF (Leukocyte and-Platelet Rich Fibrin) centrifuge machines, train 18 medical professionals in their use and buy important supplies. Since then, these professionals have treated the ulcers of 109 people affected by leprosy using these two centrifuges. This has restored their mobility, removed the risk of amputation and enabled them to work once more. It has also enabled them to be reunited with their families much more quickly than would otherwise have been possible. This modality of ulcer treatment involves the separation of the red from the white blood cells and platelets, the latter being applied to the ulcer.



ABSTRACTS

Miranda-Galarza B. Elimination of discrimination against persons affected by leprosy (Hansen's disease) and their family members. Human Rights Council, United Nations. 2024.

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Abstract

In the present report, the first since her appointment, the Special Rapporteur on the elimination of discrimination against persons affected by leprosy (Hansen's disease) and their family members, Beatriz Miranda-Galarza, provides an overview of the impact of the mandate since its establishment in 2017, with a strong focus on the views of persons affected; outlines her vision for her work over the coming years; and details the working methods, as well as the areas of concern and priority issues, for her work.

White C, Franco-Paredes C 2015. Leprosy in the 21st Century. Clin Microbiol Rev 28: <https://doi.org/10.1128/cmr.00079-13>.

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Abstract

Despite significant improvements in leprosy (Hansen's disease) treatment and outlook for patients since the introduction of multidrug therapy (MDT) 3 decades ago, the global incidence remains high, and patients often have long-term complications associated with the disease. In this article, we discuss recent findings related to genetics, susceptibility, and disease reservoirs and the implications of these findings for Hansen's disease control and health outcomes for patients. We describe the continued difficulties associated with treatment of inflammatory episodes known as "leprosy reactions," which cause much of the disability associated with the disease and can affect people for many years after MDT is complete. We also discuss some of the contemporary challenges for physicians and patients, including international and internal migration of people affected by the disease. We suggest some important areas of focus for future Hansen's disease research.

Ossai EN, Ekeke N, Esmail-Onyima A, et al. Understanding the burden of poor mental health and wellbeing among persons affected by leprosy or Buruli ulcer in Nigeria: A community based cross-sectional study. PLOS ONE. Public Library of Science (PLoS). 2024; 19 (6) : 1-15.

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Abstract

Background: Skin neglected tropical diseases including leprosy and Buruli ulcer (BU) are a group of stigmatizing and disability-inducing conditions and these aspects of the diseases could lead to poor mental health. The study was designed to assess the burden of poor mental health and wellbeing among persons affected by leprosy or BU in Nigeria. *Methods:* A community based cross-sectional study design was employed. The study involved persons affected by leprosy or BU. Ten local government areas with the highest number of notified leprosy or BU cases between 2014 and 2018 in southern Nigeria were purposively selected. Information was obtained using Patient Health Questionnaire-9, Generalized Anxiety Disorders-7, Warwick-Edinburgh Mental Well-being Scale and OSLO Social Support Scale. Outcome measure was poor mental health/wellbeing and was determined by proportion of respondents who had depressive symptoms, anxiety disorder and poor mental wellbeing. *Results:* A total of 635 persons affected by leprosy or BU participated in the study. The mean age of respondents was 43.8±17.0 years and highest proportion were in the age group 40–49 years. Majority of respondents were males. A higher proportion of respondents had depressive symptoms, anxiety disorders and poor mental wellbeing. The majority had poor mental health/wellbeing. Among the respondents, there was a strong positive correlation between depression and anxiety scores. There was a weak negative correlation between depression score and WEMWBS score; anxiety score and WEMWBS score. Predictors of poor mental health/wellbeing included having no formal education, being unemployed, being affected by leprosy and having poor social support. *Conclusions:* The burden of poor mental health/wellbeing among persons affected by leprosy or BU is very high. There is need to include mental health interventions in the management of persons affected with leprosy or BU. Equally important is finding a feasible, cost-effective and sustainable approach to delivering mental health care for persons affected with leprosy or BU at the community level. Improving educational status and social support of persons affected by leprosy or BU are essential. Engaging them in productive activities will be of essence.

The Kalaupapa colony on Molokai, Hawaii

In the middle of the Pacific Ocean, you will find the Hawaiian Islands. The Polynesian people lived and worked among themselves, fishing the ocean, and growing their staple foods of taro and sweet potatoes. In 1778 Captain Cook discovered the islands and named them the Sandwich Islands. The arrival of the Europeans made a significant impact on exports and since the Hawaiians had no immunities to disease, they were vulnerable to infections and diseases. King Kamehameha V in 1864, noted that leprosy was rapidly spreading in the islands. By 1865, the Legislative Assembly of the Hawaiians Island passed “An Act to Prevent the Spread of Leprosy” approved by the king. Segregation was the only option, in a place where they could not escape. That place was Kalawao, 12 sq miles, on the isolated Kalaupapa’s baron peninsula protruding from Molokai Island’s north shore. The site surrounded by water on three sides with the highest sea cliffs in the world on the fourth side is a natural “prison”. In 1873, Fr. Damien de Veuster, SSCC assisted in advocating for more supplies and helped to care for them. The number of leprosy patients grew to around 800 people. Mother Marianne arrived in 1883 to care for those with leprosy. In 1888, due to the political, social change, and fear of leprosy, the Board of Health supported only one place for treatment, the settlement at Kalaupapa. They closed the Kaka’ako Receiving Station in November 1888 and asked Mother Marianne Cope, OSF to manage the girls home in Kalaupapa. The number of patients jumped to 1,200. Over the years, Kalawao and Kalaupapa became home to 8,000 patients with leprosy. In 1873 G. Hansen discovered it was a bacterium. The sulfone drug, finally arrived in Hawaii in the 1940s, however, the State of Hawaii did not abolish the isolation policy until 1969. People could leave if they wished, however, this was their home for years and many chose to live out their lives here.

The National Park Service arrived in Kalaupapa in 1980. They assist in caring for the Aina (the land), many of the historic buildings, the graves, safe keeping of the artifacts and educating the public on the history of the people sent to Kalaupapa and Kalawao. Today, we have the remaining 8 former patients, ages 84 to 100. Their needs are simple, they all want to live life to the fullest here in Kalaupapa. While they live here, the Department of Health assists with caring for their homes, yard, medical/food needs, and whatever else they need. Taking one day at a time, they enjoy being outdoors, visiting or talking with friends and staff, listening to talking books, or watching TV, and trying not to engage in political debates. We are here to assist the patients, whether it is going for a ride with them, escorting them for their ID/Driver’s license, or taking care of personal appointments. They are leaving behind their mana, legacy, memories of their friends, family and the kokua who have cared for them. Over the past ten years, the Hawaii Cadre of the Grand Priory of America has actively supported the Kalaupapa Care Home through grants for medical equipment, furniture and supplies as well as items for patient comfort totalling in excess of US\$60,000. Moreover, Cadre members have provided considerable volunteer support and have organized pilgrimages and related religious services.

Fear Forced People into Isolation

Resources:

- <https://www.nps.gov/kala/index.htm> | <https://www.nps.gov/articles/kalaupapa.htm>
- <https://www.cnn.com/travel/kalaupapa-national-historical-park-hawaii/index.html>
- https://leprosyhistory.org/geographical_region/site/hawaii
- <https://trentonmonitor.com/news/2023/dec/20/molokais-leprosy-settlements-the-ohana-of-two-catholic-saints-faces-historic-transition/>

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