

# Special Session : History of Leprosy

**SPL-18**

## The Acworth Leprosy Museum, Mumbai

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In anticipation of "A World Without Leprosy", this paper focuses on a project to set up a Museum on the History of Leprosy in India. The idea was mooted by the late Sharad Naik in 1999, and is bearing fruit as a joint project of the Acworth Leprosy Hospital and the Research Society with major financial support from the Sasakawa Memorial Health Foundation. Its two main objectives are: education/information of the public and provision for research into the multifarious histories of the disease. The Museum is fittingly housed in an old ward, and surrounded by a medicinal garden of leprosy remedies mentioned in Ayurveda. The "Homeless [later Acworth] Leper Asylum" established in 1890 is integral to Mumbai's history, embodying affluent urban society's interactions with a category of marginalized people. Special displays highlight its establishment, early years and subsequent history from the social, legal and medical angles. Other major displays centre on (1) The Disease; (2) Treatments; (3) Documentary material; (4) Public perceptions; (5) Philanthropic Efforts for and by Leprosy Sufferers; (6) Legal Aspects; (7) Public Policy. In order to promote historical research the Museum houses a substantial collection of copies of leprosy documents, reports etc., dating from the nineteenth century colonial period to modern times, obtained from the Maharashtra, Rajasthan, Andhra Pradesh and Tamil Nadu State archives. A warm welcome awaits interested persons.

**SPL-19**

## The Emergence of the International Leprosy Association

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**Objectives :** 1. Emergence of the International Leprosy Association **Methodology :** Archival research, League of Nations Archives, Geneva **Results :** 3. This paper describes the international collaboration that grew out of the Berlin (1897), Bergen (1909), Strasbourg (1923) and Cairo (1938), culminating in the formation of the International Leprosy Association. It will focus particularly on the request from the Third International Leprosy Conference in Strasbourg (1923) that the League of Nations constitute an international bureau of information and inquiry regarding leprosy and renew the publication of « Lepra », the International Archives of Leprosy. It will then discuss the subsequent League of Nations Inquiry into Leprosy, the Bangkok meeting, in December 1930, and the Manila Conference, in January 1931, from which emerged the International Leprosy Association and the Cairo Congress, in 1938. Using reports, photographs, and leprosanaria plans gathered by the League of Nations Inquiry, it will describe the leprosy work throughout the world, at this time. 4. This study will provide an historical perspective on the aspirations of the 2008 Hyderabad Congress: "A World without Leprosy". **Keywords :** League of Nations, International Congresses, International Leprosy Association.

**SPL-20**

## Metamorphosis of Hand Reconstruction in HD

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Reconstructive surgery on deformed hands in Leprosy disabled originated in the Christian Medical College Hospital Vellore, India in 1948 and was pioneered by Dr Paul Wilson Brand. It stands as one of the greatest contributions in the Annals of Surgery of the 20th Century to alleviate disability and restore dignity through social integration. Its ongoing metamorphosis, still largely indigenous, is serving the purpose of the changing demands of function and the socio-economic situation. Would rehabilitation preceding reconstruction, which has fast gained acceptance, see the need for : 1. abandoning or greatly minimising complex surgical corrections altogether 2. compelling the practice of preventing deformities 3. the intermittent use of light weight and user friendly hand orthosis ? The author presents the historical directions that were once taken indigenously and what changes that can be taken to preserve the deformed hand.

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This case is based on my first-hand experience and participation in the closure of a leprosy home in Madhya Pradesh. None of us who participated in the act were aware that our participation would lead to what I consider such a momentous event – the first one perhaps in the country. When I last visited Sihor, little did I think that the events of that visit would take a permanent place in my vivid memory. Sihor is a village about 35 km away from Bhopal, the capital of Madhya Pradesh. Through my association with Danlep, a group dedicated towards the rehabilitation of leprosy patients in Madhya Pradesh, I was very closely working on the issue of leprosy. It was a pleasant summer evening when I arrived at the Home and Hospital in Sihor. I found out from some men sitting under a tree that there were women patients as well, who were placed in a different ward. I wanted to meet the women as well. The men and women, I found, always maintained a distance from each other. Although they stayed in the same institution, their spaces were clearly demarcated. Seeing me approach the female ward, one woman sitting at the door suddenly rose and started to go inside muttering about her ill health. The sudden presence of a stranger might have intimidated her. I saw another woman sitting a little away. She was about 35, rather too lean, with hunched shoulders and downcast eyes. She was absent minded drawing patterns on the floor. Without so much of an upward glance she explained that Kamala's mental condition was not very good and that is why she sometimes doesn't realise what she does. I asked her what her name was. "Murti. Murti Bai", she replied, eyes still following the patterns she made on the floor. And then silence. That was when I first met Murti Bai – withdrawn, emotionless and an epitome of dejection. I could not help but think about this woman. She seemed to be sick, yet strangely willing to live on. She refused to make eye contact. I asked her what she was doing. This time she looked up exasperatedly. "If I do not keep myself occupied some how, any how, I'll lose my sanity like Kamala!" she cried out. The sudden outburst opened up a window into her life. The eerie silence in this place was eating her away. She would get a chance to talk only when the doctor came to dress her wounds. Otherwise everything was dead silent. I returned to the hospital after three days. On enquiring about her family, Murti broke into a deep sob and cried for a long time uncontrollably. Between sobs she answered that she had a big happy family. When she was asked to leave the village and go away, she had to leave behind her youngest child who was only eight months old then. When she calmed down a bit, I asked her how she came to be in this hospital. "It's all a matter of fate," she said, more to herself than to me. These were touchy questions, but I went on. I asked her since when she was suffering from the 'disease'. She had observed some discoloration on her skin but did not think much of it. Since it was not interfering with her work, her family did not bother about it, either. After a while the villagers began to talk about it openly. Suddenly everybody started to keep away from her. The entire village feared that she might spread the disease to the others. The Patel was an influential man in the village and nobody dare disagreed with anything he said. Three days later, Murti Bai's father in law was called at the village gathering. Everybody vehemently declared that she be sent out of the village. Didn't she say anything at all? To this, "the damn incurable disease!" came out with all the pent up frustration. I was taken aback at the amount of suppressed stigma. When I recovered after a moment, I explained that leprosy was no different from any other physical ailment. People are unaware, and that is why they understand leprosy as a contagious, horrifying disease. After these first few interactions, I was convinced that she is a survivor and has enough motivation to fight back. With a little support, she can get back to her normal life. My mind started racing. If Murti's family and the other villagers can be convinced that leprosy is not an evil and that there are other victims who stay with their families, there might be a ray of hope after all. I got the support of several local self help groups that contributed actively towards concretizing the need to generate awareness among people about leprosy. The next task ahead of us was to educate the villagers and make them aware that leprosy is curable and not a disease bigger than life itself! It was the villagers' ignorance that proved to be the biggest evil for Murti Bai. Something that had started off as a small effort that I initiated, now turned into a campaign. The objective of this campaign was to take Murti Bai back to her family and spread awareness among the people in the village. It was not me who was driving the campaign any more. My role was that of a connecting link that brought several people together for a common cause. On arriving at Surajpura, we gathered some preliminary information about the village head and some other prominent figures. We were told that the Patel of the village, Daulat Ram was the most affluent and influential power head. We could no longer contain our curiosity and asked them where the Harijan community lived in the village. We found the place and reached Murti Bai's husband, Failiram's house. We found several mats and other household cane things outside the house. The other women in the group began interacting with him, enquiring the prices of the cane things and slowly shifted to asking about the family and how many people stayed in the house. I think this is where our tact faltered. The seemingly unknowing villagers figured out that this had to do something with Murti Bai. After a little while a small clump of people had gathered in front of Failiram's house - Murti Bai's parents in law, all her children, veil clad women from the neighboring houses, the preachy elders, the contemplating educated youth, the giggling young girls, the curious children and the randomly gathered people waiting for some theatrics. When asked why Murti was sent away, nobody dare mentioned the word 'leprosy'. They brushed the question away saying it was a big dangerous disease that Murti was suffering from. I wondered if avoiding naming the disease was a mark of respect for the victim or an

unbearable embarrassment. Probably it was ignorance as well. They kept referring to it as the numbing disease. We shifted tack and began asking questions about why Murti was not kept in the village. The Patel replied to this firmly saying that that nobody else was afflicted with the 'deadly' disease. Coming to more questions, we asked if anybody else in Murti's family was suffering from leprosy. No, there was nobody. Then how come Murti was infected with a contagious disease? We moved on to find out from Failiram about when he last met his wife. Failiram looked embarrassed and it seemed like he met her clandestinely. He admitted that he visited her once in a while and that they were still sexually involved. Then where was the question of the disease being contagious? Everybody looked at each other with surprise written clearly on their faces. After the first wave of astonishment had passed, they began talking among themselves. Surprise gave way to inquisitiveness. Now they wanted to know more about leprosy and its treatment. They looked to us for more information to add to their limited knowledge. The leprosy worker from our group Shukla ji patiently explained all about the causes, symptoms and cure of leprosy. The Patel announced that Failiram should go and bring back Murti. Our efforts seemed to bear fruit sooner than I had imagined. A sudden paradigm shift with the Patel was the last thing we had expected. Further, it was agreed that nobody would discriminate against Murti ever again. The villagers were so deeply occupied in their discussions that we now became mere spectators. It was no longer required for us to facilitate the talks. The Patel finally spoke over everyone else and agreed to give Murti's father in law a joint consent in writing. It was really an atmosphere of emotional repenting. After a few days, Failiram along with the Patel and a few other village elders went to Sihor to get Murti back to Surajpura. I'm sure to remember that day as the second home coming of Murti. Her rightful place amongst her family was finally restored. That day, Surajpura wore a real festive look, since the daughter in law of the village was once again brought in like the bride as she had come from her parents' house twenty one years ago.

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**SPL-22**

### **Centenary Year of Dr Stanley Browne, (Mr Leprosy)**

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**Introduction :** Dr Stanley Browne would have been 100 years old today. He was born 8 December 1908 and died 29 January 1986, His wife Mali died on 29 January 2006. Both died on World Leprosy Day. The date overlaps this ILA conference. Stanley Browne from the age of 5 wanted to be a medical missionary. After a difficult childhood he entered medical school at Kings London gaining most of the medial prizes. In 1934 soon after qualifying he was appointed to Yakusu, a Baptist Missionary Society Hospital in the former Belgian Congo. His epidemiological research identified an area around Yakusu with the highest incidence of Leprosy in the world. Chaulmoogra oil was the standard treatment at that time until the arrival of Dapsone in 1946. His main interest now was the control and treatment of Leprosy. He and his colleagues set up the Yalisombo leprosarium and kept detailed notes of patients now treated successfully for leprosy. In 1958 he was appointed Senior Leprosy Research Specialist at Uzuakoli in Nigeria and succeeded Dr Frank Davey. He researched several new drugs. In 1955 his research on B663 known as Clofazamine is still used in Multidose Leprosy treatment. In 1966 he succeeded Dr Robert Cochrane as director of the Leprosy Study in London. Dr Browne advised over 60 countries on their Leprosy Control programmes and in 1982 initiated the integration of Leprosy into General Medical Services. He was keen on countries reducing the social stigma of Leprosy. He was on the ILA board as secretary and later secretary/treasurer, and organised 5 International Leprosy Congress meetings.

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**SPL-23**

### **Leprosy in the Time of Dyarchy : Ernest Muir's 'Propaganda, Treatment, Survey' Scheme, India 1925-1935**

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The 'Propaganda-Treatment-Survey' (PTS) scheme which dominated public policy in leprosy in late colonial India was the brainchild of Ernest Muir(1880-1974); it functioned through the Indian Council of the British Empire Leprosy Relief Association (ICBELRA). The period of Muir's leadership of PTS (1925-1935) coincided with "dyarchy", a political landmark in India's freedom struggle, when administrative authority in some subjects (such as health) devolved to elected provincial governments. It was the backdrop to the interactions between the new administrative set up and the quasi-governmental ICBELRA. The paper locates the PTS strategy which was based on out-patient clinics, early detection through contact examination and 'propaganda', in the anti-tuberculosis work of Robert Philip of Edinburgh in the early twentieth century. But unlike tuberculosis which was then incurable, PTS also drew on the claimed efficacy of derivatives of chaulmoogra-hydnocarpus oil. ICBELRA Health Education posters show that Muir's indebtedness to tuberculosis extended beyond strategy to biases about leprosy predilection, transmission and prevention. Although apparently well thought out, Muir's scheme failed to make an impact. The reasons proposed are: failure of the therapy, poor cooperation from provincial governments, and studied aloofness of the imperial government. Nevertheless PTS was the (unacknowledged) precedent for independent India's strategy in its National Leprosy Control Programme.

**SPL-24**

## The Renaissance of Leprosy in the Baltics in the 19th Century

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The present historical study concentrates on the discussions about leprosy emerging in the Russian Baltic Provinces (historic Kurland, Livland and Estland, modern Latvia and Estonia) at the end of the 19th century. In 1896 from these territories the disease had entered Germany, triggering a series of events that culminated in the First International Congress on Leprosy (1897) in Berlin. By this time the social, economic, medical, political conditions in which the disease flourished had already been operating for more than a decade. In these conditions, medical matters were entangled with the local social and political conflict which had three participants: Estonian and Latvian indigenous populations, German-speaking upper levels and the Russian central authorities. The arguments on the origin of the disease, fate of the sick, and the question whether the disease symbolised the degeneration of the local population created an atmosphere of leprophobia, (remembered even nowadays.). **Key words :** history of leprosy, Baltic states, Russian Empire, political reception of leprosy

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**SPL-25**

## Leprosy and Estatal Imposition

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The present study aims to examine the relationship between the Brazilian state and public health in the first half of the twentieth century, having as joint question the politics of obligatory isolation of the carrying patients of leprosy and the reactions to the same one. The theoretical instrumental chosen can be summarized through the definitions of State and *bureaucratic field* developed by Bourdieu, P. coercion and consensus from the indications of Antonio Gramsci A and developments of Godelier M. The documentary *corpus* of this work consists of oral sources, interviews from the research project “Memories and history of Hansen’s disease in Brazil. From these theoretical assumptions, we found in the documentation rather than mere acceptance of state policies that are violent (the compulsory isolation), but the operation of mechanisms that by the naturalization of such practices, creates and maintains a popular demand for these types of domination and imposition. The construction of the state is only possible through their naturalization undertaken by physical and symbolic coercion. However, the acceptance (or even demand) required for the establishment and reproduction of state power can only be built and distributed by consensus. Leprosy; Health Public Policy; Patient Isolation; State.

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**SPL-26**

## Oral Histories : The World of Leprosy Seen Through Words

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For over 3.000 years, the thoughts of persons affected by leprosy have remained a “secret” just like their lives have become a secret once a diagnosis of HD has been confirmed. Through this process of secrecy, many persons with HD have been abandoned by their loved ones, their existence erased from the community registry, their dreams become nightmares, and their footprints blown away by the wind of ignorance as their bodies or ashes have not been returned to families. In the 21st century, many of us have an opportunity to record the words, thoughts, and feelings of persons affected by leprosy. This presentation will show how oral histories conducted at the Ukraine National Leporsarium in Kutschergan Village, Ukraine, the Sanatorio San Fransisco de Borja-Fontilles in Alicante Spain, and what was previously known as the United States Public Health Services Hospital in Carville, Louisiana have assisted with the restoration of dignity to those interviewed, and will help to dispel HD related myths among those who will listen to or read their stories. The stories shared by brothers and sisters from three countries and separated by thousands of miles are bonded in similarities....physical and emotional pain, lost dreams, love, hope, creativity.

**SPL-27**

## The Museum Experience : Documenting and Retelling the Social History of Leprosy in Norway

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This paper discusses the importance of historical documentation and leprosy site preservation today, seen through the experience of the Leprosy Museum in Bergen, Norway. In a time when the world is looking forward to a total eradication of leprosy, social history issues are important, but the sources are fragile. The Leprosy Museum and the Bergen Leprosy Archives have been working successfully to document and display the social history and personal narratives of Norwegians who have suffered from the disease. Seen through the experiences and exhibitions at the Leprosy Museum, the paper discusses the importance of public access to the history of leprosy, many decades after the disease itself disappeared from the Norwegian society. The study is based on the experience from developing the museum and its exhibitions, and from participating in larger museum-archival co-operations. The paper concludes that leprosy continues to be a social issue for several generations after the disease has ceased to be a problem in its actual society. Leprosy museums and archives may play an important part when people trace the lives of their relatives, often silenced by earlier generations. This requires, however, well-reflected methods of museum display and archival work. **Key words** : Museum, history, social aspects, stigma.

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**SPL-28**

## Tracing the Stigma in Historical Texts : Norwegian Examples 1850-1920

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Through selected readings of texts on leprosy from 19th and early 20th century Norway, this paper discusses how modern cultural historians can contribute to the understanding of leprosy and stigma. Within the modern field of cultural history, several studies have argued that stigma and leprophobia should not only be understood as a result of religious or social traditions, but also as a result of political conditions, such as imperialism, colonialism, missionary activities, and racism. Based on methodology from critical cultural theory, this work also studies the relationship between the scientific leprosy research and public health work in Norway in the late 19th century, and highly profiled Norwegian leprosy missions in Madagascar during the same period. The study is based on Norwegian texts on leprosy, written for both medical and religious audiences, from 1850-1920. The paper argues that critical cultural theory provides valuable insight into the history of the stigma, also in a country like Norway, and that medical and religious leprosy discourse more often should be investigated as a whole. The study reveals an interplay in which medical as well as missionary men, often caught in ambiguous positions, developed metaphors which loaded the disease with subtext contributing to the stigma. **Key words** : Stigma, social aspects.

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**SPL-29**

## The Islam View About Primary Prevention of Leprosy

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**Introduction** : Medical sciences have a specific situation in human sciences because it is related to body and mind. Islam is one of the divine religions and as a complete religion has many useful guidelines about different domains of medical sciences that can help us to health promotion. This research aims to obtain Infallibles sayings about primary prevention of leprosy. **Material and Methods** : Data gathering was done from more than 4000 religious books such as Jameo'ol Ahadith Shia, Osool'e Kafi, Behar'ol Anvar, Vasayel'oshia and Mostadrak'ol Vasayel. **Results** : Data analysis showed numerous quotations about primary prevention of leprosy. Some of cases consist of using leek, beetroot, turnip, wild rue, ocimum album, oleaster (sorb), to begin & end meal with salt and not consume garden cress, the glands of meat and vessels. Personal health for example tooth brushing were recommended too. Also there were sayings about isolating patients suffering from leprosy. **Conclusion** : The results express the view of Islam with respect to medicine. It is a hope that humans greatly benefit from this valuable and virtuous treasure. More researches are needed for more results & prescription. **Keywords** : Leprosy, Primary prevention, Islam.

Osamu Usami

The Imperial Bequest Hall, built for the purpose of training the leaders for the planned leprosy sanatorium where, during the WWII, one million patients from all over Asia were to be isolated in the Hainan Island in southern China. But this purpose was lost and in 1949 it was renamed 'Imperial Bequest Memorial Museum'. The museum which had lost its original purpose was turned into an exhibition hall for the photographs of people who had contributed toward the establishment of Nagashima Aisenen Sanatorium and other objects such as a big jar, a gift from the Empress dowager, and the patient children's artworks. On the other hand, important material that would testify the inexplicable hardships experience by the people in sanatorium those days were lost to repeated fire and rebuilding of the sanatorium facilities. Patients those days had to endure extreme poverty in addition to their physical problems with their hands, feet and eyes. In order to manage their lives they have created various tools and devises but these had all been lost. Under these circumstances I have decided to record the history of misery not just by writing but by "artifacts" and began preserving them. No one understood my thoughts. The residents and sanatoria officers alike, they all looked at me with disdain as if I were a beggar. I consider it is my mission to testify what had taken place under the notorious Leprosy Prevention Law. I consider this a negative legacy that has to be recorded in history so that the history will not repeat this misery and violation of human rights in future.

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Leprosy in Spain is dated to the Phoenicians ages and lately to the colonization of Roma during six centuries from the east to the west of Spain by troops from the Medium Orient and then by the Arabic invasion during eight centuries in Valencia, Murcia, Andalucia and Extremadura, where there were scientific publications by Arabic Doctors who wrote about Leprosy. Another way of penetration were the religious peregrinations to Santiago de Compostela located in the north of Spain getting founded "lazaretos" (leproseries), being less important the Jews exodus and the crusades. After the reconquest to the Arabs, a lot of Leproseries were founded in Sevilla, Valencia, Granada, Mallorca and Islas Canarias, being important the help and interest by the Catholic Kings and Doctors such like Arnau de Vilanova. From the year 1492 a lot of Spanish spread out the Leprosy in America because most of the soldiers came from endemic areas. In the 19th century increases the Leprosy in Spain publishing the first statistic in 1851 with 284 cases and Benito Hernando published in 1881 "Lepra en Granada" being visited by Virchow and Neisser. The enemy still increased and in 1909 and Fontilles sanatorium was inaugurated in the province of Alicante for the big amount of patients in that region. In 1944 sulphones were applied being the total number of patients 1518 being begun a Sanitary campaign by the Dermatologist and mobile teams by the initial detection being discovered 300 new cases every several year which got in 1970 6000 patients. From 1948 were started in Fontilles International courses of Leprosy for Doctors, Missionaries and to paramedical workers being organized over 100 editions. In 1970 there was a decrease of the prevalence and incidence, multidrug therapy was applied and in the 2006 the total number of cases were 60 in control and 14 new cases with 10 of them were in immigrants. The Leprosy has been eliminated in Spain because of the important work of Fontilles in this aspect by his assistential labour, research and formation.