Split Plenary

**R-1: M. leprae Genome**

Genomic Diagnostics: Bio-Informatic Approach to Develop New Tests for Early Detection of Leprosy

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Preclinical M. leprae infection is likely to form a major source for leprosy transmission. Therefore, early detection of individuals infected with M. leprae is crucial. However, to date there are no diagnostic tests available that can identify preclinical leprosy. Newly developed HLA-based bio-informatic tools combined with comparative genomics recently created novel opportunities to help combating this disease and design improved tests for early detection of M. leprae infection. Using this post genomic HLA-based approach, we were able to identify candidate proteins and peptides unique to M. leprae containing predicted T cell epitopes restricted via several major HLA-class I and II alleles. Since the selected genes were of unknown function, their expression in M. leprae bacilli was assessed. Recombinant proteins were used to stimulate PBMC from leprosy patients, household contacts, TB patients and healthy endemic and non-endemic controls individually. Evaluation of the immunogenicity of the antigens in TB patients from a Brazilian population showed that 5 candidate antigens induced significant levels in paucibacillary leprosy patients, reactional leprosy patients and IGFBP-1-boosted healthy controls, but not in most multibacillary leprosy patients, tuberculosis patients or endemic controls. Importantly, among exposed healthy controls 71% had no detectable IgM antibodies to the M. leprae specific PGL-1, but instead responded to one or more M. leprae antigen(s). To improve the diagnostic potential of these M. leprae sequences, synthetic peptides spanning all 5 M. leprae proteins were analyzed similarly. Determination of cumulative T cell responses towards 4 of these peptides that activated PBMC of leprosy patients increased the sensitivity compared to single peptides to 100% in PB, 75% in Rx and 93% in HHC, without compromising specificity. Since diagnostic tools should be applicable in several populations regardless of the genetic background, these M. leprae antigens are also tested in populations on the African (Ethiopia) and Asian (Nepal) continent.

**L-58**

Molecular Epidemiology of Leprosy and Applications in Endemic Situations

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To better describe and compare the factors that lead to continued occurrence and transmission of leprosy against the backdrop of local and global multdrug therapy (MDT) being implemented for nearly 25 years, we have consolidated a collaborative international research program involving endemic countries in Asia (Philippines, India, Thailand and China) and South America (Colombia and Brazil). Observations will be presented regarding the identification and distribution of patients and the Mycobacterium leprae genotypes in various settings to discern transmission patterns and linkages, and on the surveillance of M. leprae resistance to MDT in new and relapsed patients. Strain typing of M. leprae is currently achieved by mapping alleles at a minimum of 15 short tandem repeat (STR) loci and three known single nucleotide polymorphisms (SNPs) using DNA extracts from clinical specimens such as slit skin scrapings and biopsies. Throughput is being enhanced by multiplex PCRs, automated fragment length analyses and other DNA sequencing independent techniques. Variations in the patterns of alleles and their frequencies in M. leprae strains within and between geographically separated populations indicates that STR loci can be suitable for short range transmission, while also separating long range dispersal events. For detection of drug resistance to rifampicin and dapsone, selected regions of the target genes, rpoB and folp1 respectively, are subjected to PCR and DNA sequencing. During the year 2006, rpoB mutations were not detected in patients presenting in a skin clinic in Cebu, Philippines, while 2 cases were found in relapsed patients in a Colombian leprosarium. Common and novel folp1 mutations have been detected in India and China. These efforts are aimed for delivery into the clinical community for routine diagnosis, patient care and effective leprosy control. This research is supported by grants from the National Institute of Allergy and Infectious Diseases, NIH, and the Heiser Program for Research in Leprosy and Tuberculosis through IDEAL.
Analysis of Genes of Mycobacterium Leprae Associated with Drug Resistance in Samples from Brazilian Leprosy Patients

Introduction: Data on the prevalence of drug resistance among leprosy patients are scarce but some reports demonstrate the existence of mono- and multi-drug resistant cases. Objectives: To evaluate the drug resistance rate among Brazilian leprosy patients and the contribution of the latter case to the relapse of the disease. Methodology: Sequence analysis of the genes rpoB, fopA, gyrA and gyrB of Mycobacterium leprae was performed on PCR products generated from a fraction of processed skin biopsy samples collected from leprosy patients diagnosed as part of a prospective study designed for optimal case finding of relapse cases. Results: After one year of sampling, 112 skin biopsies from different patients being considered as relapse cases and from five states of the country were collected. Sixty-three samples were processed and submitted to PCR amplification for analysis of the four genes. At the current stage, part of the PCR products were purified and PCR and sequencing conditions established that generated readable fopA and rpoB sequences. Conclusion: Biopsy processing allowed PCR amplification of the four genes and purification yielded products that at least for two genes resulted in good quality sequences. SNP analysis is underway using SeqScape.

Implications of Gene Expression in Mycobacterium leprae

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Annotation of the M. leprae genome defined a genome with < 50% protein coding capacity and 1133 pseudogenes. To identify the minimal gene set important during infection, we surveyed mRNA transcripts from nude mouse-derived M. leprae using RT-PCR and DNA microarray technologies. Approximately 1350 transcripts were detected, including 55% protein coding genes or open reading frames (ORFs) and 43% pseudogenes in the genome, demonstrating the highest rate of pseudogene transcription to date. ORFs detected are involved in DNA replication, cell division, SecA-dependent protein secretion, energy production, intermediary metabolism, iron transport and storage and genes associated with virulence. Results suggested that M. leprae actively catabolize fatty acids and glucose for energy, produce a wide array of secretory proteins, utilize the limited number of sigma factors (transcription initiators) available, transcribe several genes associated with virulence in M. tuberculosis and produce several proteins involved in iron transport, storage and regulation in the absence of recognizable genes encoding iron scavengers which suggests a novel mechanism of iron scavenging in this bacterium. Since translation of this large number of pseudogene transcripts could impact M. leprae's energy consumption without benefit to its survival, bioinformatics tools were used to identify translational ‘silencing’ mechanisms of these pseudogenes. Results demonstrated that the majority of transcribed pseudogenes lacked translational start codons, lacked strong Shine-Dalgarno sequences, had multiple ‘in-frame’ stop codons, and low predicted functionality. Taken together, these data suggested that one half of the functional genes of M. leprae are expressed during infection and even though a large number of pseudogenes are transcribed in M. leprae, most are phenotypically ‘silent’ and therefore most likely do not impact the infection process.

R-2: Community Based Rehabilitation

Economic Advancement Movement in Korea

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The Economic Advancement Movement (EAM) in Korea has uniquely compared to other countries and has received attractive attention from many all over the world. This is a remarkable movement—winning out on two fronts: medical treatment and social aspects. Both of them are key in eliminating Hansen’s Disease (H.D.). By creating a framework of self-support and government support, those who were fit for work escaped from living in a group home or being compulsorily segregated, took the first step for EAM in Korea. However, we encountered many problems, but solved within the current system centering around government and academic circles. Once a forceful crackdown on begging increased, taking these problems into our hands with an internal clean-up, we were able to restore dignity by ourselves which was beginning of EAM. We have achieved self-support with 40 years of painstaking efforts and assistance from others, whose goal is elimination of H.D. Currently we are deeply involved in Korea government’s policy decision on H.D. freely extending our opinions.
Disabled in Health, But not in Spirit

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I was born in 1955 and finished high school in 1972. But before I could even picture my future, it had already been ruined by leprosy. In merely two years the illness got worse and worse and I developed disabilities in my eyes, hands, and feet. It took nearly 10 years for me to be cured. In 1983 I was able to go back to my hometown. My disabilities deprived me of the chance to participate in farming, nevertheless I did not give up. I raised ducks, I sold aquaculture products, and I traded waste materials. Although social discrimination and physical disability resulted in many difficulties, I never gave up and after some years' effort I even achieved the financial ability to help others. I began to raise cattle at the end of 1993, even though I had lost a leg by this time. After being successfully fitted with a prosthesis, I restarted my career to seek a meaningful and independent life. I started raising cattle from scratch and before long I expanded the business into cattle-trading. With the support of HANDA's Economic Rehabilitation Project I established the Center for Cattle Trading. After several years' effort, the Center has developed abundant experience in cattle raising and trading. Now its annual amount of raised and traded cattle has reached more than 200; and the associated income has also increased several times. It not only provides me a sufficient life, but also enables me to help many others who also facing the challenges of leprosy. In order to promote interactive support among the people affected by leprosy in my city, in 2002 HANDA Honghu Branch was established. My own experience received recognition and I was elected as president. From then on the people affected by leprosy in Honghu have had the opportunity to gather together and help each other. The members often visit the people to find out their difficulties and needs and encourage them to begin some economic development programs. With the support of the HANDA small loan project, they not only successfully launched activities like domestic livestock-raising and earned a better living, but also regained self-dignity and recognition from neighboring villagers. Several years' endeavor and practice have taught us that the only way for the person affected by leprosy to live with dignity is through unity, mutual support and self-esteem. We must rely on ourselves rather than others. The welfare from the government is limited, and help from relatives and friends is also limited. Dependence on the aid and sympathy of others tends to aggravate social discrimination. Only if we become self-confident and mutually supportive and empowering, can we receive social recognition and regain dignity.

Women's Self Support Programmes in Nigeria

Mary Amylike
Self Support Programmes in India

Prakash Patil
Dr. Minoo Mehta, Apangoddhar Sahkari Audhyogik Utpadak Sanstha Maryadit No. 7, Yewiewadi, Tal Haveli, Pune 411048, India

1. Common Vocational Training Project (CVTPH) was established in 1982 under the guidance of late Mr. & Mrs. Moolgaonkar and late Dr. Jal Mehta with an aim to provide training and rehabilitate the leprosy cured patients and to prove that handicapped persons are also capable of quality production in an Automobile Industry.

2. Due to the social stigma, these cured persons were kept aloof from the society till 1987. In order to overcome this stigma, late Dr. Jal Mehta with his untiring effort started this society, (Dr. Minoo Mehta Society) comprising of 56 society members.

3. Later on reputed companies like Tata Motors (TML) Lucas TVS, Poonawalla group known for their generosity in promoting this noble cause came forward and extended help by giving us work for their companies. With this help the society has a turn over of 3 – 4 lakhs per month (labour charges only) at that time.

4. Due to the sudden demise of Dr. Jal Mehta in 2001 the society was under a new management from 2002 to 2004. Unfazed by this loss the society carried on the good work and attained ISO 9001-2000 certificate as required by TML. Unable to cope up, the administrative body handed over the complete working to the society, but unfortunately without any financial aid or help.

5. All type of taxes, such as Excise, VAT Cess, CST, Income Tax are levied on us as no exemption is granted to us. Even then we have not asked for any loan or grant from bank or government of which we are proud.

6. In 2005 we successfully completed “Kaizen Methodology” which guides us for improvement in production. In keeping pace with TML, we also attained TS 16949-2002 certificate (Technical Specifications), the only of its kind to be given to a handicapped society in the world.

7. At present the society comprising 115 society members.

8. A brief production target which we have achieved during the past 3 years.
   a. 2004 – 2005 Annual turnover of Rs.43500000. Rupees four crore thirty five lakhs only.
   b. 2005 – 2006 Annual turnover of Rs.53500000. Rupees five crore thirty five lakhs only.
   c. 2006 – 2007 Annual turnover of Rs.58900000. Rupees five crores eighty nine lakhs only.
   d. 2007 – 2008 Annual turnover of Rs.80000000. Rupees eight crores proposed.

9. In future if we get any financial assistance we will increase the workload and rehabilitate more 300 members.

Community Based Rehabilitation

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Community based rehabilitation (CBR) is defined as a strategy within community development for rehabilitation. It involves equalization of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services”. (1994 Joint position paper of ILO, UNESCO and WHO). In this context there are several people and organizations in India who are promoting CBR activities. A wide range of activities is included beyond medical care and rehabilitation. Among these our organization is involved in preventing the causes of disabilities, providing rehabilitation services, facilitating education and training opportunities and supporting micro and macro income generation opportunities. Rehabilitation is envisaged as providing disabled people with tools they require to attain independence and self determination, including compensation for loss of function. There is no better example than development of grip-aids and continued research in ergonomic independence. Novartis Foundation developed the Modular grip-aids for advanced hand deformities in orthopedic and leprosy handicap. Local organizations used the epoxy resins available in the local market, to help their patients. The latest grip-aid made of Velcro-
**R-3 : HIV and Leprosy Co-Infections**

**Leprosy- HIV Co-Infection Overview**

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There is an interesting and still evolving interaction between leprosy and HIV. I shall review the effects of leprosy-HIV co-infection on the manifestations of leprosy. Being HIV positive does not appear to put patients at greater risk of developing leprosy. However, the published epidemiological studies are all small, poorly designed and done in the 1990's with often inadequate HIV testing. The histopathological appearance of leprosy lesions shows the same spectrum and the same range of granulomatous appearances as in patients without HIV infection. This even applies to lesions seen in patients hose with advanced immunodeficiency where CD4 cells are found in leprosy lesions even when there are very low circulating CD4 counts. There is no good data on the progress of skin lesions or nerve function impairment in patients who are co-infected. One might predict that these patients would be at higher risk of developing nerve function impairment. There is some data suggesting that co-infected patients have higher incidence of Type 1 reactions, but this needs to be confirmed. Leprosy has now been reported presenting as immune reconstitution disease among patients commencing highly active antiretroviral treatment (HAART). These reports have come from Brazil, The Caribbean and Europe these patients present weeks after starting HAART when their CD4 counts are increasing and their viral load falling. The treatment of reactions in these patients is potentially complicated since they require more immuno-suppression to control their leprosy reactions. Well designed contemporary studies of the clinical aspects of Leprosy-HIV interaction are needed especially regarding nerve function. These need to be complemented by immunological studies. These studies will generate data that will guide optimal management of these patients and the complications of their diseases.

**References**


**T Cell Responses to Mycobacterial Antigens in HIV Co-Infection**

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Early detection of M. leprae infection is crucial in order to diminish a major source for leprosy transmission formed by preclinical or subclinical leprosy cases. Thus, development of new diagnostic tests for detection of preclinical M. leprae infection is studied by several research groups at the moment. Cell-mediated immunity (CMI) plays a crucial role in the protection against mycobacterial infections, therefore several of these tests are based on T cell responses directed towards mycobacterial antigens. Individuals infected with both HIV and M. leprae are expected to show lack of or severely decreased T cell responses directed against major mycobacterial antigens due to the decreased numbers of CD4+ T cells. In addition the effect of successful restoration of the number of CD4+ T cells by HAART is unclear. However, studies on the effect of HAART in TB co-infection show only partial restoration of anti-mycobacterial immunity. In this presentation some issues that will be studied in leprosy co-infection in order to fill the gaps in our knowledge on T cell responses in HIV/leprosy co-infection will be discussed. Support: Gastmann Wichers Foundation, The Netherlands.

**Clinical Experiences with Co-Infection in Brazil**

P Deps

**Clinical Experiences with Co-Infection in Ethiopia**

E Bizuneh
HIV and Leprosy Co-Infection in India – Clinical Experiences

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Tuberculosis is an important opportunistic infection among HIV infected persons and the course of the diseases is altered by HIV co-infection and vice versa. It is also reported that in HIV infected persons latent tuberculosis may manifest as clinically relevant disease. Treatment of this co-infection (especially TB and AIDS) may have to be modified due to the associated interaction of drugs used for the treatment of these diseases and also the changes in the immunity of the individual due to the co-infection. There is substantial scientific interest in leprosy and HIV co-infection due to the several similarities of leprosy and tuberculosis namely both caused by the same group of microbes which are relatively slow growing (although leprosy bacillus cannot be cultured in artificial medium); have a long incubation period; bacilli may remain dormant for variable duration; changes in host CMI affect the outcome of the diseases; most of the drugs used for treatment are the same but with a different dosage schedule; endemic in developing countries and affecting the poor strata of the society. There have been several case reports of leprosy and HIV co-infection in the past decade. Most of the reports do suggest that clinical disease of leprosy was manifested after varying time interval of HIV co-infection and also after clinical manifestation of AIDS. This was associated with demonstrable sero-positivity to HIV as well as decrease in CD4 counts in patients presenting with AIDS. There were some alterations in the response of the patients, like precipitation of reactions and/or worsening of the diseases in some cases, but it is not clear whether it was due to the institution of HAART or recrudescence of the disease. With the recognition of Immune Reconstitution Inflammatory Syndrome (IRIS) after successful implementation of HAART, it has become very difficult to distinguish between the two. Never the less it is important to from the treatment point of view to diagnose these co-infections. Workers have estimated the HIV prevalence in leprosy patients in some of the endemic countries. Some have reported a rise in the HIV sero-prevalence in leprosy patients, this is probably is of much less magnitude as compared to the HIV sero-positivity present in the non-leprosy disease affected population. More over there was no change in natural course of the disease in the studies carried out in Ethiopia. Overall, relationship of HIV with leprosy has been observed to be quite different compared to co-infection in HIV and tuberculosis. We have studied the HIV sero-prevalence in leprosy patients in two phases between 1989-1993 and 1999-2004 on different group of leprosy patients attending the out patient department of our Institute. There was a marginal rise in the sero-prevalence from 0.12% to 0.37% in the second phase. All the sero-positive cases are being followed up six monthly for noting the disease progression as well as the serological status. The CD4 counts were also done in these sero-positive patients. At present all the patients have responded to the standard MDT regimen, there has been no relapses or increase in severity or incidence of reactions in these patients. CD4 counts were also found to be normal in these sero-positive leprosy patients. In none of them the disease has progressed to AIDS. There is paucity of data from India about complications like IRIS and situation needs to be closely monitored by creating awareness among clinicians to diagnose leprosy in HIV–AIDS cases.

Future Challenges

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HIV and leprosy co-infection is likely to become more common in the future. HIV infection is increasing in India, which accounts for 70% of incident leprosy cases worldwide, as well as in other countries with a significant leprosy burden, such as Brazil and Nepal. The implementation of anti-retroviral therapy (ART) in these countries and those of sub-Saharan Africa, which have experienced longstanding HIV epidemics, means that subjects with HIV and leprosy co-infection will live longer, giving opportunity for the two infections to interact over a more protracted period. Until the present time, epidemiological and clinical studies have suggested that HIV co-infection does not have a marked effect on the risk of developing clinical leprosy, the pattern of leprosy or the frequency of leprosy reactions. These studies, however, have been limited in size and design (reviewed in Ustianowski), and with the increased frequency and length of co-infection, it is possible that HIV may be found to have a more significant effect on disease caused by M. leprae. To understand the longterm implications of co-infection, it will be important to conduct large, prospective case/control studies to determine if HIV increases the risk of leprosy or leprosy reactions and clinical-pathological studies to determine of HIV co-infection changes systemic or local immune responses to M. leprae. The optimal treatment of reactions with corticosteroid therapy and its attendant risks of Tuberculosis and other opportunistic infections in the presence of HIV have yet to be defined. Further, it is clear that treatment of highly immuno-suppressed HIV/AIDS patients, who are harbouring M. leprae infection, with ART may precipitate Immune Reconstitution Inflammatory Syndrome (IRIS) in the
form of severe reversal reactions in the skin and nerves. In addition to increasing awareness of this possibility in leprosy endemic areas, it will be important to understand the immuno-pathogenesis of skin and nerve damage during “leprosy IRIS” and to define its optimal therapy, which may differ to that for uncomplicated Type 1 reactions. Finally the reliability of serological testing for HIV in multibacillary leprosy must be established. There are major challenges in conducting these studies in a timely manner. The prevalence of leprosy is less than that of tuberculosis and other infections in countries where HIV is major threat to health, and with integration of health services the expertise in leprosy required to conduct these studies may be limited. The following are required to address these challenges:

1. design of multi-centre studies to aid the recruitment of leprosy/HIV co-infected patients and the applicability of findings across regions;
2. agreement on criteria for definition of leprosy, leprosy/HIV co-infected cases and control subjects for epidemiological studies, and on case definitions for leprosy reactions and “leprosy IRIS” for use in immuno-pathological studies;
3. availability of high quality HIV laboratory services to confirm the diagnosis of HIV infection, using confirmatory serological and viral DNA assays, and to measure CD4 T cell levels in co-infected patients;
4. availability of laboratory services to monitor histological and immunological changes in co-infected leprosy patients during ART;
5. agreement on treatment and outcome measures for leprosy reactions and “leprosy IRIS” in co-infected patients to permit comparison of outcomes in different centres.

These activities would be facilitated by the formation of an interest group to study leprosy and HIV co-infection.


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**R-4: Empowerment**

**An Empowered Woman is a Woman Capable of Clothing Herself with Dignity**

BORGES, Zilda Maria

IDEA's International Women's Opportunities Program - IDEA, Brazil

There are thousands of historical reasons for the submission of women. Although the struggle for equal rights and dignity is recognized, the disempowerment of women is present in the every day lives of poor women and is increased in many of them due to the fact that they have carried the Hansen’s disease bacillus in their bodies. With the physical signs of the disease and hidden lives in their homes, many women who were affected by Hansen’s disease began to group themselves in wide circles of conversation, where they could talk about themselves and for themselves. This discussion circle is like a garden, full of flowers and hope, a place where the women can let loose the words and feelings imprisoned in their hearts. Very slowly they loosen the knot that held their lives in anonymity, in fear, and from the deafening suffering that disempowerment provokes. The freedom to be and to talk about themselves and for themselves enables the creation of the capacity to clothe oneself with dignity, dignity that is based on one’s own convictions. New spaces were occupied outside their homes. The women joined other groups in the community. A woman clothed with dignity is capable of generating economic independence. A woman clothed with dignity is capable of generating ethics in human relations, lightness and beauty in the empowerment of Being Herself. A woman clothed in dignity loves gratuitously. She defends her rights – the instrument of her struggle and the foundation for her self-empowerment.

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**Political Empowerment**

Veldenora Da Cruz Rodrigues

Brazil
Grassroots Empowerment in Ghana

Kofi Nyarko
IDEA Ghana

I tried to start our empowerment efforts with radio stations, but I saw that this would not solve our problems for many people in Ghana do not have radios and televisions. Even if they have them, how many people will listen to me on the radio at a specific time? So I needed to reach people in their communities by seeing the chiefs of the communities or the elders of the families. They gave me authority and the time that was OK for me to meet with them and at that time I went. I visited so many places in Ghana, camp by camp and community by community, school by school and door by door! And these visits brought attention and many people got to know what IDEA GHANA’s teachings are about! This door to door grass roots empowerment did not help only those who had Hansen’s disease but also those who have HIV. I had many experiences when I was doing this grassroots empowerment. I met many people who have been rejected for so many years. I also got to know that some of the people who had this disease thought that since they have had leprosy they will be rejected even after they have finished the treatment. But with the help of IDEA, when they got back to their families and communities, they welcomed them and there is no discrimination anymore. At first those who had leprosy had their own schools within the leprosy camps or in their hospitals, but now they can go to any school without any problem. In Ghana these days people have the belief that if something has happened to you today anything can happen to me tomorrow, so they should not discriminate against anybody, no matter if they have Leprosy or HIV or any kind of disease or disability. So I can say people in Ghana are now free and I hope they will be free for ever! And also this grassroots empowerment did not end in Ghana. We went to DR Congo and I wish you were there to see how happy the people of DR Congo were and how they welcomed us. “Ah, we have been waiting for this for 30 years now” said one man. And we were able to establish IDEA DR Congo west and east.

Empowerment Through Education of Children

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Children are the promise of humanity for tomorrow. Education plays a pivotal role in the growth and development of any society and nation. The persons affected by leprosy were thrown out and used to settle down by themselves and families in places called as leprosy colonies. The children of leprosy patients as well as children affected by the disease needed financial support to pursue their education. Due to the difficulties in finding resources they used to drop out from schools. Just because the parents are affected by leprosy and unable to support their children, the normal growth of these children should not be affected. If no intervention is done to support them, then they will become a burden to the society in the future. To overcome the above scenario IDEA India had launched the children education programme and support over 1200 children every year who live in the leprosy colonies and in the community.

Children who had completed their education were placed in good jobs after completing their education. They support their parents. After employment they have taken back their parents from the Government leprosy Homes to live with them. Various educational support rendered through IDEA India have enabled the families to get empowered, to improve their quality of lives to have an integrated life in the society with dignity. Providing education to the future generation is a genuine need and desire of human society. It gave many opportunities for them. We thank Sasakiwa Memorial Health Foundation, Japan, IDEA International, Emmaus Switzerland Leprosy Relief Organisation who are providing their support for implementation of this programme.

Overcoming Discrimination Against Women in Nepal

Parwati Oli
IDEA Nepal

There are innumerable problems related to the fundamental rights of women in Nepal. Women are deprived of their basic rights. They have not been able to utilize their rights as men can. Nepal is a male-dominated country, therefore many decisions are made in favor of men and women are not involved in different social activities. Women are limited in household work and their work is devalued and felt to be worthless. Most Nepalese families are uneducated. They do not know the importance of education, so they rarely send their daughters to school for education. Women are deprived of education and other social and political rights. Widows are not allowed to get remarried. They have to sustain their life without marriage after the death of their husbands, whereas a husband can get married after the death of his wife. Widows cannot expose their internal feelings in society. They are to hide their feelings inside their hearts. In the context of Nepal, when a woman suffers from leprosy, she is sent out of the village. She is hated in society. She is thought to be cursed by god. Due to lack of education and knowledge, it is not known that leprosy can be cured with treatment. A woman has to divorce her husband when she has leprosy. Women have to leave their homes even when they are pregnant. Therefore it is said that the life of a woman with leprosy becomes pitiable and miserable after marriage. After the advent of democracy in Nepal, the status of women is being improved. Their rights are also being saved. Women are raising their voices to better their conditions. IDEA Nepal is working for the empowerment of women for example through the First Empowerment Workshop for Women that was held in 2006. IDEA Nepal is trying to remove discrimination against women and help women to realize their rights. Education brings change in society. Unless people are educated, their problems will remain the same in the future.
R-5 Pathology of Leprosy

Immune Mechanisms in Reactions

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Leprosy reactions are responsible for a major component of nerve damage and morbidity in leprosy. A detailed understanding of the immune mechanisms underlying these reactions is essential to devise more effective control measures. Type I or Reversal Reactions (T1R) are caused by increased cellular immune responses to *M. leprae* antigens in the skin and nerves, marked by infiltration of activated CD4 T lymphocytes and macrophages. Studies in the last five years have demonstrated the increased expression of pro-inflammatory cytokines, TNF, IL-1β, IL-6, IFN-γ and IL-12, and immunoregulatory cytokines, TGF-β and IL-10, in reactional skin lesions, along with evidence of macrophage activation. Although there is a fall in lesional cytokine mRNA levels with corticosteroid therapy, there is still increased expression of some cytokines at 6 months. Changes in plasma cytokine levels are not consistently associated with T1Rs, however IFN-γ and TNF responses of peripheral blood lymphocyte to *M. leprae* antigens are increased in T1Rs, fall with therapy, but rise again as corticosteroids are withdrawn. Patients with poor neurological outcome and increased clinical symptoms have sustained increases in *M. leprae*-induced TNF responses during therapy. These studies highlight that the increased inflammatory response in T1Rs may persist for >6 months and is consistent with the recent evidence for increased effectiveness of longer duration corticosteroid therapy for T1Rs. Type 2 Reactions (T2R) or Erythema Nodosum Leprosum (ENL) are a generalised inflammatory response involving the skin, nerves and other organs in LL and BL leprosy patients with a high bacillary load. The histological appearance is of a small vessel vasculitis with neutrophil infiltration, and the original studies showed localised deposition of immunoglobulin and complement in ENL lesions, consistent with immune complex formation as the principal pathogenesis. There are additional features of the immune response in ENL. First, there is marked disorganization of TNF production, in excess of that observed in other immune complex mediated diseases to viral or self antigens. There is marked elevation is serum TNF and increased TNF mRNA and protein production by macrophages and lymphocytes in response to *M. leprae* components in some, but not, all ENL patients. Second, there is evidence of activated T cells in the ENL skin lesions, with increased mRNA for IL-12 and local changes in lymphocyte subsets compared to nonreactional lepromatous patients. The preferential response to thalidomide in ENL is different to that in other immune complex mediated diseases, and this involves both inhibition of TNF production and changes in immune regulation. Recent clinical studies have highlighted that the majority of ENL reactions persist for >6 months, consistent with ongoing immune stimulation by persisting *M. leprae* antigens in the tissues. The evidence for persistent immune activation in both types of reaction supports the notion that the management of leprosy reactions should be similar to that for other chronic immune-mediated inflammatory diseases, such as vasculitis, rather than as acute episodes. The optimal management requires “Induction” therapy to suppress both T cell activation and cytokine production and the resulting tissue inflammation, and then “Maintenance” therapy to allow maximal functional recovery and to prevent recurrence.

Global Collaboration in Leprosy Research – INFIR Study

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Recent trends in the organisation, funding and conduct of medical research are towards multidisciplinary, international collaborations that seek to address the key questions that would make a difference to the global health. This trend results in large programmes of research targeted to priorities agreed by communities, funding organisations and the scientists. INFIR is an example of this trend and more such initiatives are needed that make major advances that benefit patients and their communities. INFIR is the ILEP Co-ordinated Programme of Research on Nerve Function Impairment and Reactions in Leprosy. The need for research in nerve damage and reactions was identified at an ILEP working session in December 1997, an expert workshop was conducted in June 1998 to develop proposals which were approved for funding by Follereau Luxembourg with support from LEpra UK, and TLMI in December 1998. A steering group was established in February 1999 chaired by Jo Colston. The programme involved co-operation between field centres, field laboratories and Universities with field work in Asia, Africa and South America. INFIR had 4 components: a Cohort study to investigate prediction, detection, and pathogenesis of nerve impairment in new patients, trials of new treatments for reactions, a study of recurrent and late reactions, and studies of delay in detection and treatment of leprosy. One important product was the development of standardised methods that are now in
widespread use in leprosy research. Findings from the cohort study include the relationship between monofilaments and voluntary muscle testing and neurophysiology. Neurophysiology studies show nerve damage is much more widespread than is clinically apparent, nerve conduction and temperature testing are important, and nerve function improves with MDT. The treatment trials demonstrated that steroids remain the first line therapy with second line drugs such azathioprine and cyclosporin having steroid sparing benefits. Recurrent reaction and chronic reaction have been defined and methods developed are now being used in research. Methods to study delay were developed based on field studies conducted in Bangladesh, Nepal, India, Ethiopia, Malawi, Brazil, and Paraguay. A booklet has been produced for field programmes on how to find the reasons for delay. INH is has been a highly productive research initiative that contributes to prevention of nerve function impairment and better treatment of reactions. The ILP co-ordination model adds value to research in development of standardised methods, multi-disciplinary approaches and international collaboration. A similar model has been adopted by the IDEAL project to develop tests for early diagnosis and understand transmission. New research of this nature is vital in leprosy.

Serum Proteomics of Leprosy Patients and M. leprae Infected Mice

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Proteome profiling allows better understanding of disease progression, subtype classification, susceptibility patterns and disease prognosis. Leprosy is a spectrum disease with clinically, histologically, immunologically and bacteriologically distinguishable subtypes. In addition, a significant fraction of patients undergo immune mediated reactions even after multidrug therapy (MDT). Erythema nodosum leprosum (ENL) is an immune complex mediated reational condition in leprosy, characterized by a systemic inflammatory condition afflicting borderline lepromatous (BL) and lepromatous leprosy (LL) patients. We have analyzed serum proteome of leprosy patients undergoing ENL reactions and compared it with that of healthy noncontact controls. After depletion of albumin and immunoglobulin G (IgG), two dimensional gel electrophoresis (2DE) of these serum samples was performed. Differentially expressed proteins were identified by MALDI-TOF and MALDI-TOF MS/MS mass spectrometry. Significant increase in one of the isofoms of alpha 2 chain of haptoglobin was observed in ENL condition. In addition, haptoglobin phenotype was determined for healthy controls and leprosy patients. Hp 0-0 phenotype was detected in 21.4% of ENL patients undergoing treatment, which on follow up examination showed typical phenotype thus showing a condition of acquired anhaptoglobinemia. Since ENL still remains a threat of leprosy disease management, the above finding provides new insights in understanding the development and progression of this inflammatory condition. In order to examine the plasma proteome profile a complementary study was initiated using plasma from mice infected with M.leprae. Analysis revealed disease specific changes in the in the infected mice plasma. The proteins showing changes in expression level were quantified using DIGE analysis. MALDI TOF mass spectrometry and MS/MS analysis were done to identify the proteins which showed significant changes. These results will be discussed in the broader perspective of proteome analysis in infecitomycosis.

Kineomics in Leprosy Pathology : Limitations and Prospects

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Despite advances in the knowledge of the key players viz. resident and immune cells and their associated soluble products, the understanding of the patholgy of the unique leprosy spectrum and associated reactions remains enigmatic. In the last decades, investigators have studied the role of cytokines and chemokines in the evolution of leprosy pathology or in the search for suitable biomarkers of the disease activity. These studies demonstrated the association of these molecules with leprosy as compared to healthy controls and contacts. However different studies have shown considerable variation with respect to their association with the leprosy spectrum and reactions. Furthermore, no strict cytokine and/or chemokine profile could be specifically associated with leprosy as compared to other infections or inflammatory conditions. Our studies in circulation and within tissues assert the fact that evaluation of cytokine profiles and soluble factors is useful in monitoring disease activity and of limited value in either predictive diagnosis or elucidation of the complex pathology. These limitations arise probably due to both individual variations within a population and between different populations. Despite these limitations, research should continue using modern technologies like cytokine and tissue arrays as “kineomics” in parallel to proteomics and genomics. Keywords: Pathology, cytokines, chemokines, biomarkers.
R-6 : Diagnostics

Diagnostics ; Challenges in Clinical Diagnosis

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Leprosy is a disease affecting mankind since times immemorial. It still continues to be an enigmatic disease even after the genome of leprosy bacillus has been fully deciphered. Despite several advances made in understanding this disease many issues still remain and among them one most important is establishing a definitive diagnosis of the disease in specially early stages. As *M. leprae* the causative organism of leprosy cannot be grown in any artificial culture medium, the diagnosis of disease in the present settings is based primarily on the clinical appearance and criteria. There are inherent problems of clinical diagnosis which include inter observer variability, eliciting the co-operation of the patient for testing of neurological deficit as perception threshold varies from individual to individual, overlap of several types of symptoms and absence of definitive signs and confirmatory evidence for definitive diagnosis in early forms of disease. Depending upon the endemicity one has to take into consideration the different conditions which come in the differential diagnosis like post kalaazar dermal leishmaniasis (PKDL), fungal infections and other dermatological/neurological disorders. In the pre-elimination phase the clinical acumen and experience of treating doctors as well as close follow-up of difficult to diagnose cases was used to clinch the diagnosis. In the post-elimination era, with the merger of the leprosy services with the primary health care centres, definitive tests for diagnosis are essential to maintain the elimination phase as well as steer the programme towards total eradication of the disease. With the progress made in deciphering the *M. leprae* genome some progress has been made towards the use of molecular probes and amplification techniques in demonstrating genes/their products in tissue specimens. Attempts have been made in establishing the viability of the detected organisms by the use of RNA based probe and amplification methods. Strain differences in the species identified. Some of these tests need to further simplified and validated. However, several easy and simple, tests are urgently required for solving the dilemmas still associated with the disease: Differentiating sub clinical and self healing disease from disease which requires treatment. Effective and reproducible tools for mapping of impairment of sensation and nerve impairments. Easy tests for assessing autonomic dysfunction Accurate assessment of bacterial load and viability. Tests to monitor progress of patients on treatment Distinguishing relapse from reactions etc.

Novel Immuno - Molecular Approaches

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The availability of the whole genome sequences of *Mycobacterium leprae* and several principal members of the *M. tuberculosis* complex has revolutionized research for immunodiagnostic tools for leprosy. In combination with the miniaturization and simplification of test platforms as well as other developments such as microarrays, immunological rapid tests and new molecular/cellular methods, this has recently provided unique opportunities to renew investigations of unsolved issues in leprosy, including : 1. Early diagnosis of (sub)clinical leprosy patients, in particular PB leprosy. 2. Identification of *M. leprae* infected persons using new field-applicable diagnostic tests. Serological testing has been in use for more than 20 years. Until recently these tests were mainly ELISA-based test formats for the detection anti-phenolic-glycolipid-I (PGL-I) IgM antibodies. This type of test has a role to play in the confirmation of the diagnosis of MB leprosy, in classification and for the identification of contacts that are at an increased risk of developing leprosy in future, but its widespread use is hampered by the need of relatively sophisticated laboratory infrastructure and by the fact that results are only available after 24 hours. Two novel, promising developments may revive and expand the use of serology: 1. The availability of rapid tests, which can be applied by health workers with limited training and give results in 10 minutes; and 2. The identification of antigens that may be suitable for PB leprosy and possibly even sub-clinically infected individuals. It is well known that the cellular immune response plays a crucial role in (protection against) leprosy. However, tests to detect and quantify this type of immune response in leprosy have been of limited use because of widespread cross-reactivity with other mycobacteria (in particular TB) and technical complexity. The results of whole genome sequencing have opened up the possibility to identify and study *M. leprae*-specific antigens and peptides. From TB we have learnt that it should be possible to develop antigen-based tests (such as the Quantiferon test), but further development and evaluation will be necessary to make tests that are sensitive, specific and applicable in routine leprosy control programmes. New antigenic targets are being identified which could, after validation, serve as the basis of a diagnostic test capable of revealing infection before clinical symptoms are apparent or of detecting disease in PB patients. Earlier disease detection will result in prompt intervention in the form of chemoprophylaxis or MDT, thereby increasing the likelihood that both the prevalence and incidence of leprosy can be further reduced.

[43]
Lessons Learnt from TB in Immunodiagnostics

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Immunodiagnosis of leprosy has been one of the main research agenda last couple of decades but is still far from satisfactory. In comparison, immunodiagnosis of tuberculosis (TB), mainly IFN-gamma assays, has been successfully adopted as a tool of detecting Mycobacterium tuberculosis infection leading to chemoprophylaxis at least in some countries. While serological tests were main streams for immunodiagnosis of leprosy, IFN-gamma assays replacing the PPD tuberculin test was major focus in TB although there were also tremendous efforts in serodiagnosis of TB. Despite some weak points such as suboptimal specificity, PPD tuberculin test has been widely used for diagnosis of TB in combination with clinical and chest X-ray findings and for detecting latent M. tuberculosis infection which requires preventive therapy in certain settings. With discovery of M. tuberculosis-specific antigens such as ESAT-6 and CFP-10, more specific IFN-gamma or ELISPOT assays were developed and have been widely used for detecting latent TB infection. However, these T cell-based assays need to be further evaluated in the areas with high prevalence of TB before implementing those assays to TB control programs. High cost will be also another factor for making difficult to implement T cell-based assays in the areas with limited resources. Considering a wide spectrum of host immune responses to mycobacterial infections, it is impossible to detect all subjects infected with mycobacteria by immunodiagnostic assays even if combinations of antibody and T cell-based assays. With advantages of simplicity and low cost, several serological tests have been available as commercial kits for immunodiagnosis of TB. Test formats ranged from ELISA, immunochromatography or lateral flow tests, and dot-ELISA using protein and glycolipid antigens and lipoarabinomannan, etc. However, the serological tests have not been widely used in diagnostic laboratories as a confirmatory test for diagnosis of TB, mainly because of unsatisfactory sensitivity and specificity. In addition, there was a wide variation in sensitivity and specificity among studies depending on geographical areas. Heterogeneity of antibody responses to various antigens among TB patients makes it more difficult to develop single antigen-based test. Instead, multiple antigens need to be used in a test to maximize sensitivity despite loss of some specificity. Such serological tests need to be evaluated for their efficiency in detecting latent M. tuberculosis infection and active TB in comparison with T cell-based assays. In summary, PPD tuberculin test is still the method of choice for immunodiagnosis of TB while new and more specific T cell-based assays have been gradually adopted for detection of latent TB in the areas with low prevalence of the disease. Serological tests employing more than one antigen still need to be improved and evaluated further for potential use in immunodiagnosis of TB.

International Consortium – The IDEAL (Initiative for Diagnostic and Epidemiological Assays for Leprosy) Consortium

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The “Initiative for Diagnostic and Epidemiological Assays for Leprosy” (IDEAL) resulted from two workshops held under the auspices of the TDR programme of WHO, in 2002 and 2003, and set itself the mission of coordinating and facilitating research leading to new tools for leprosy control, and, specifically, the development of new tests, arising from knowledge of the genome of Mycobacterium leprae, addressing transmission and infection. Both tests will be developed using well-characterised clinical samples, evaluated in the field and used to gain insight into leprosy transmission and infection. The combination of the two approaches (early diagnosis and transmission studies) will for the first time allow the development of rational interventions for the prevention of leprosy which can then be aimed at those people who are at the highest risk of developing leprosy. The IDEAL Consortium consists of approximately 30 partners in endemic and non-endemic countries with backgrounds in laboratory- and field-based research. A Steering Committee (chair: Prof. P. J. Brennan; co-chair: Prof. H. Dockrell; secretary: Dr. L. Oskam; members: Dr. A. Aseffa, Dr. C. Pessolani, Prof. R. Hussain, Dr. A. Joseph, Dr. J.H. Richardus) was appointed to coordinate efforts to obtain funding and coordinate the activities. In 2004, 2005, 2006, and at this ILC, workshops were organized for IDEAL partners at which activities were identified and assigned. Research development will be reported at various junctures during this Congress. Generous grants were obtained from the Heiser Program for Research in Leprosy and Tuberculosis of the New York Community Trust to support the research and workshops, and the Steering Committee is actively pursuing further funding. For further information on IDEAL please contact the Secretary Dr. Linda Oskam at l.oskam@kit.nl.
R-7 : Health Education and Health Promotion

Using the Public Media to Present Your Message

Manoj Verghese

Effective Communication

Fione Post

Psychological Support as Part of Health Education

Zilda Maria Borges,
IDEA’s International Women’s Opportunities Program

Several years’ experience with psychological support of people affected by Hansen’s disease has revealed many problems, including thoughts of suicide, profound indifference in relationships, symptoms of self-abandonment, depression, restrictions in social life, and issues of self-segregation. How does one conduct effective health education under these circumstances? There is no possibility of conducting health education in these circumstances without actively involving the person rather than simply providing information. Health education should be born within the people affected by Hansen’s disease. The function of the educator, the friend, of relatives, is to be like a midwife — to help a person to be reborn. To help the person to give new significance to psychological feelings that are triggered by the disease. We need help to be born and for a person who has profound psychological changes to be reborn, they need a lot of support and they need to be listened to. They need someone to walk with them. An important component of health education needs to be creating a network of psychology professionals who are available to help at specific moments such as in chronic cases of depression and attempted suicide after a person is diagnosed with Hansen’s disease. At the same time, it is important to create a network of people connected by hearts, that stimulates friendship and a network of friends. It is also helpful to create a network of women, who with their sharp intuition, help to pay attention to the details, to the needs of people who isolate themselves and who are afraid of rejection. There is no medication for emotional pain. Baccarau says that what heals emotional pain is love — love that revives social relations and gives security to people. Love diminishes the profound fear of being abandoned, of suffering prejudice and being stigmatized. Love helps people to regain their identity with dignity. It increases, without a doubt, the desire to live. In our work of psychological support, we also listen to people who have never had the disease. We have found people who had correct information about the disease and the possibility of a cure and also those who were afraid and rejected people because of the disease, who kept away from people even after they were cured. This led us to conclude that the health education process has to go beyond merely providing information. It must help each person change their attitude. It requires an opening up of one’s BEING to universal love.

Health Education in the Community

CS Cheriyan

Introduction: Health Education in leprosy parlance is a dynamic, multi-faceted, information dissemination and communication process. The affected person is the central figure, whose cooperation is the most decisive factor in Health Education program and process. My first experience when heard that I had leprosy… was bewilderment and dismay: I felt as though the whole world was shaking and collapsing in front of me. I felt as though the ground underfoot had caved in and I was swallowed live by Earth. I felt totally lost and threatened. It took quite some time for me to recover from that instant shock. That was the first time I became aware of the fact that I had leprosy. The messages that hit home to me were: 1. The need and importance of remaining ulcer-free for better social acceptance. 2. The need and importance of specially made protective footwear/prosthetic and orthotic appliances. 3. The scope for rehabilitation and re-integration into the natural environment. They had truly helped me to come this far and continue to exist without any further damage or deteriorations in my physical and mental conditions (except ageing process and disuse atrophies). I continue to benefit from the above till date personally. The FAB walker that was specially made for me by a German Volunteer in 1976, I am proud to state that I am on with the very same one at this moment and continue hopefully till I exist. How Health Education affected me personally relates to my personal experiences at Karigiri in the
early 70's from where I received the first ever human touch after my disease was confirmed as leprosy. The wonderful ambience and dedicated staff at Karigiri had given me the most essential love and understanding support when I needed them most. I can confidently say that I am a successfully launched product of Karigiri. Impact of Health Education: I am happy to inform this august gathering that after 50 years of living with leprosy and after having spent most part of it as a health worker; I have learnt to transform all kinds of bitterness leprosy had brought to me into sweetness. I am really enjoying every moment of my refocused life through IDEA has been providing me with. Conclusion: Let us usher in a dawn of hope for those persons cured of leprosy to enable them to lead a life with dignity, honour and self respect. History beckons us. Let us work “TOWARDS A WORLD WITHOUT LEPROSY”. Let us not consider a person cured of leprosy as a ‘LEPER’ and denigrate humanity. Let us leave a legacy that can honourably be enshrined as an ever-lasting tribute to human dignity, as a covetous legacy of this Congress. Let us continue to dream for all that are good for human life and make leprosy work as one such. “LOKA SAMASTHA SUKHINO BHAVANTHU”.

Experience with Telehansen in Brazil

Faustino Francisco

Advocacy in Global Setting

Jose Ramirez

R-8 : Future of the Last Leprosy Communities

Resisting Closure of Lo Sheng in Taiwan

Tien-Pei Lee

Future of the Last Leprosy Communities in China

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Like many other countries, China’s leprosy control policy was to establish leprosy hospitals in remote areas. As a result, more than 1,000 such hospitals were built between the 1950’s and 1970’s. I was only 14 when I was admitted to the Qingyuan leprosy hospital in 1956 and it never occurred to me that this hospital would become my home forever and I would have to spend the rest of my life there. The land on which many once-remote leprosy villages are located has now become valuable as resort areas or parts of economic development zones. Many land developers have shown their interest in these locations and, as a result, many leprosy villages have been or are about to be relocated. In provinces like Guangdong and Guangxi, many people are concerned about being merged and relocated. The villages in Huadu, Nanhai, Qingyuan and Sanshui have been removed and the original sites have been converted to golf courses, automobile factories or are being developed by real estate. Some villages have seen their conditions improved through relocation, like safer housing and better transportation. Unfortunately, some villages have been forced to move to more isolated and inconvenient places. Though leprosy villages in economically backward areas have not been forced to move due to economic development, their living conditions have lagged behind because of social isolation. Many villages still have no water, no electricity, inadequate medication and healthcare, and poor transportation. In contrast to rapid economic development, the people affected by leprosy are facing the great challenge of being further marginalized. In Qingyuan, we have new houses equipped with kitchens and toilets. However, we were never consulted and were not asked for any suggestion about the new houses. As a result, though the new houses look good from outside, they are not suitable for us. The doors inside the house are not wide enough for wheelchairs. Squat toilets were installed, but most of our villagers with disability are not able to use them. Furthermore, the water heaters were changed from solar-powered to gas-powered, which has not only added to the villagers’ financial burden, but also increased their safety concerns. The government has spent a huge amount of money on these new facilities, yet they have failed to solve our problems and meet our needs. I believe that four things should be seriously considered: 1. Consult and respect our opinions before shutting down any leprosy village. We were once forced to leave our own homes because of misunderstanding about leprosy. Now that society has become more open-minded, we don’t want to be forced to leave our second home. 2. Preserve some villages. They are a witness to our history and bear educational value for future generations. 3. Consult and respect our opinions when helping us address our problems. We know our own difficulties and know best how to solve them. 4. What we urgently need is not safe and comfortable housing. Rather, we need social understanding and acceptance, as well as equal rights and opportunities.
The Future of Hansen's Disease Sanatoria: Current Status and Challenges

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In the 1950s, approximately 12,000 people were forced to live in the 13 national Hansen's Disease sanatoria in Japan. There are now 2,890 of us as of May 1st, 2007. The average age of the residents is 79, and about 200 people die every year. Most of the residents of the sanatoria have lived there for over 50 years. There are hardly any who consider leaving the sanatoria to live in community. There were absolutely no medical reasons for our forced segregation, and yet we were driven out of our hometowns. We were segregated and forced into remote national sanatoria. Family ties were cut, names were erased from census registers, and we were forced to live with false names. We had no freedom, we had no legal rights. We lived as mere shells of people. The HD sanatoria were places where the Japanese constitution had no influence. We used to say sarcastically that the sanatoria were managing the residents in such a way that we were neither alive nor dead. There are three walls affecting the future of the residents of the sanatoria. The first is the law. When the Leprosy Prevention Law was abolished, the new law stated that only those with HD and those who once had it would be allowed to live in the sanatoria, which means they cannot be shared by others. The second wall is discrimination. My niece has had a number of engagements broken off. The only reason is that she has an uncle who lives in a HD sanatorium. There are many family members of those affected by HD who cannot say "come home to us" because they are afraid of social discrimination. The third wall is the national policy. Due to a lack of funds, the nationallyrun medical institutions have been transformed into independent administrative institutions. The government's position is that opening the national HD sanatoria to the public is absolutely impossible. A national association of residents of the 13 national sanatoria was formed in 1951 to work against repression by the authorities. Its purpose was to realise the basic concepts of the constitution of Japan in the sanatoria and to regain our human dignity. This struggle has continued for 56 long years. In our eyes, opening of the sanatoria to the local communities and their reintegration into society is the ultimate goal of our struggle. When this is achieved, then the sanatoria will finally be free from segregation and the residents will be freed from social isolation. Our hope is to submit a draft law in January. We collected the first one million signatures on 15th December. Nevertheless we know that more needs to be done, and we hope that everyone will give us a hand in this battle, so that the law will be enacted, and each sanatorium will be able to choose its own future.

The Right to Housing

Malavika Vartak,
COHRE (The Centre on Housing Rights and Evictions)

The Centre on Housing Rights and Evictions (COHRE) is an independent, international, non governmental human rights organisation initially registered in the Netherlands and now based in Geneva, Switzerland. COHRE has registered offices in Australia, Brazil, Ghana, Cambodia and Sri Lanka. COHRE pursues the vision of a world in which everyone fully enjoys housing rights, and promotes practical legal and other solutions to endemic problems of homelessness, inadequate housing and living conditions, forced evictions and other violations of economic, social and cultural rights throughout the world. To this end, COHRE promotes the creative use and application of international human rights law. COHRE's presentation at the 17th International Leprosy Congress will focus on application of international human rights law in the context of forced evictions of persons affected by leprosy due to closure of sanatoria and other leprosy communities around the world. The presentation will therefore be aimed at strengthening the efforts of persons affected by leprosy to realise their human right to adequate housing through the strategic use of international human rights law and the overarching human rights principles of equality and non-discrimination. Forced eviction is a violation of the human right to adequate housing. Beginning with the Universal Declaration on Human Rights 1948, the human right to adequate housing has been reaffirmed in numerous international human rights instruments. COHRE's presentation will highlight Article 11 (1) of the International Covenant on Economic, Social and Cultural Rights, that obliges State parties to respect, protect and fulfil the human right to adequate housing and thus provide protection from forced evictions. The presentation will also discuss in detail the UN Committee on Economic, Social and Cultural Rights' General Comment 7 (1997) on Forced Evictions. General Comment No. 7 lays down: "the State itself must refrain from forced evictions and ensure that the law is enforced against its agents or third parties who carry out forced evictions". Further, General Comment 7 asserts that prior to evictions, State parties must ensure that all feasible alternatives are explored in consultation with affected persons and that legal remedies must be provided to those affected by evictions. Additionally, it declares that evictions must not result in rendering people homeless and that State parties must provide alternative housing or access to productive land to all those affected by evictions. COHRE's presentation will also briefly touch upon General Comment 6 (1995) of the UN Committee on Economic, Social and Cultural Rights, which focuses on the economic, social and cultural rights of older persons. With regard to older persons and the right to adequate housing, General Comment 6 emphasises recommendations of the Vienna International Plan of Action on Aging particularly recommendation 19 that recognises that housing for the elderly, apart from physical, has particular psychological and social significance which should be taken into account and that national policies should help elderly persons to continue to live in their own homes as long as possible, through the restoration, development and improvement of homes.
The Situation in Brazil

Rosa Castalia Franca Ribeiro Soares

The Future of Leprosy Sanitarium Under Low Endemic Situation:
The Philippines Experience

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The 8 leprosy sanitarium played a major role in the elimination of leprosy as a public health problem in the Philippines in 1998, with the successful implementation of Multiple Drug Therapy bringing about marked reduction in sanitarium registry, with old, disabled, poor, stigmatized patients remaining for custodial care. This development has paved the way to the conceptualization and implementation of expanding the role of the sanitarium with the view of maximizing the health staff available and the health care structure and services in the respective area of jurisdiction in support of the DOH thrust and programs. With leprosy being eliminated as a public health problem in the country and with only few old disabled people affected with leprosy being taken care in the sanitarium, the issues of cost effectiveness, efficiency and relevance of leprosy sanitarium under low endemic situation in the Philippines, is now put into questions, considering the economic condition and the many health priorities and emerging diseases that need to be addressed. How and what is the role and contribution of the 8 sanitarium in furtherance of the objectives of sustaining quality leprosy services and further reducing the leprosy burden would be a big boost to its relevance and existence.

Culion: A Mecca

Hilarion M Guia
IDEA Philippines

The promulgation of the Forced Segregation Law of the Philippines and the establishment of Culion island as a “National Reservation for People Sick of Leprosy” in 1906, brought about tremendous miseries and malady not only among the sick but also among their children who were fortunately born free of the disease. The repeal of the Forced Segregation Law in the mid-50's and later the discovery of the Multi Drug Therapy (MDT) inspired the people to crave a change in the status of Culion – to turn it from a leprosarium into a municipality with the status of self-governance. To achieve the desired conversion was, of course, not an easy task. Nevertheless, to hasten the realization of the noble dream, people thought of using a very powerful weapon.....Political Empowerment. The successful implementation of the MDT program contributed much in changing the perspective of the townspeople. Being no longer enslaved to the disease, there developed among them not just the aspiration but the courage to free themselves from the bondage and clutches of the spirit-paralyzing “Scourge”. The residents of Culion radically ventured on a journey to regain their place “under the sun”. They formed and organized a movement and started their way back to the mainstream of the society where they rightfully and lawfully belong as gregarious human beings. Equipped with high hopes and an indomitable spirit, the people of Culion advocated for reintegration into society and I was elected the first Mayor of the Municipality of Culion. The enactment of R.A. 7193 of 1992 was a real deathblow to the 86-year reign of the Department of Health over Culion. It was a resounding victory for Culion and its people, so to speak. Understandably, the good effects of the transformation could not be felt instantaneously. Nevertheless, the fear of being stigmatized, ostracized, discriminated and the like, has eventually eroded so that at this point in time, 12 years after since the Municipality became functional, the fear is on the verge of total obliteration. With the conversion of the Culion Leprosarium into a legitimate local government unit, the residents, regardless of status and condition in life, are made entitled and free to exercise and enjoy their constitutional rights and blessings under the principle that, “All Men Are Created Equal”. Culion is now a blooming and thriving Municipality and residents are free of the stigma, discrimination and ostracism. Today, Culion is a Mecca!
A Matter of Justice

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In 2007, the final residents of Talsi Hospital in Latvia were told that they had one month to get themselves ready to be transferred to an infectious disease hospital in Riga. They felt despair over having to leave their home at Talsi and anxiety over concerns that the infectious disease hospital would force them out because they do not have an infectious disease. Shortly after the residents of Talsi were moved, some 10,000 people on the streets of New York City saw delegates from Lo Sheng Hospital in Taiwan and their supporters walk through the streets chanting “Guarding Lo Sheng. Preserve History, Preserve Dignity.” Living on opposite sides of the world, the concerns of the residents of Talsi and Lo Sheng were the same – they simply asked to live out their lives in the place that had become their home. Hundreds of these communities exist around the world. Many people were forced into them long after a cure had been discovered because society’s response to the disease was allowed to lag far behind the medical advances. Will we approach the final chapter in the lives of these thousands of individuals with a sense of justice and with a sense of responsibility and appreciation, or will we simply act as if they and their history never existed? Clearly our response will say a lot about us as a society. In the words of the late Les Parker, one of the last six residents of St. Giles Home in England: “It is essential that abandoned buildings don’t result in abandoned lives, no matter how small our numbers may be.”