Special Inaugural Session on “Key Issues”

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Leprosy has been eliminated as a public health problem in every country except Nepal, Mozambique, the Democratic Republic of Congo and Brazil. While these four strive to reach this milestone, others work to sustain the achievement, further reduce the number of new cases and tackle other leprosy-related problems. In order to “eliminate” leprosy in the true sense of the word, we cannot focus on the medical aspects of the disease alone. We must also deal with the social aspects, such as the associated stigma and discrimination. Ignorance and myths surrounding leprosy over the centuries have helped perpetuate prejudice, marginalizing people affected by the disease. Once affected, a person, and often his or her family members, remains stigmatized and ostracized, even after being cured. As a motorcycle needs two wheels of an equal size to function, there should be a good balance between a front wheel of medical treatment and a rear wheel of social intervention if there is to be a complete cure. Belatedly, I realized the importance of addressing the social aspects of leprosy. First, I visited the UN Office of the High Commissioner for Human Rights in 2003 to draw attention to the issue. Subsequently, I lobbied the then-UN Human Rights Commission and its Sub-Commission. This led to three non-binding resolutions at the Sub-Commission requesting governments and international agencies to take actions to abolish social discrimination against people affected by leprosy and their families. Together with the Japanese Government, which has echoed my efforts, I am now asking the recently constituted UN Human Rights Council to discuss the issue as a formal agenda item, and hope that eventually the UN General Assembly will pass a binding resolution and set guidelines for protecting the human rights of leprosy-affected people. Approaches such as this at the policy-making level are not enough, however. We also need to carry out activities on the ground. These include: a) disseminating correct information about leprosy; b) campaigning to abolish discriminatory social customs such as use of the word “leper”; and c) providing opportunities for education and employment for people affected by leprosy (the aim of the recently established Sasakawa-India Leprosy Foundation). In these efforts to bring about social change from both “above” and “below,” people affected by leprosy must be partners in this process. Over time, I wish to see them play the leading role. This is the way forward for people affected by leprosy to achieve social integration and economic independence, and regain their dignity.

Making Leprosy History

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This is a historic moment: leprosy, a disease already mentioned in texts more than 2000 years ago, is on the brink of elimination. This month the last International Leprosy Congress will be held in Hyderabad. Scientists, politicians, the World Health Organization (WHO), nongovernmental organizations (NGOs) and private-sector foundations have combined their efforts for a final push against the disease. These groups have worked together to make leprosy diagnosis and free treatment available at the village level within primary health facilities in areas where the disease occurs. This approach has proved to be a highly effective way to treat patients, and has led to one of the greatest public health success stories in the world. Today there are only four countries in the world where the prevalence of leprosy exceeds one case per 10 000 inhabitants, compared to 122 countries in 1985. Globally, we have made tremendous progress, but the battle has not yet been completely won. Tackling residual problems requires learning from past successes and failures, as well as having a clear understanding of the remaining obstacles. The changing face of leprosy: Leprosy has always been more than just an infectious disease. It was considered to be a malady of the whole body as well as a disease of the soul, with disastrous consequences for those who became infected. It was a shameful
affliction, brought about by wrongdoing in a previous life, through a curse of God or witchcraft – in short, a punishment. Sufferers were ashamed of their condition and tried to hide the disease for fear of social repercussions. Lack of treatment or delayed treatment increased the risk of disabilities that, in turn, strengthened and perpetuated the stigma of the disease – a vicious cycle. Before we developed an effective cure for leprosy, society dealt with the disease by isolating leprosy patients. In virtually every society, those affected by the disease were cast out of their families and communities to live in leprosaria, segregated villages, for fear of the disease spreading. Leprosy affected most often the poorest of the poor, leaving them without means to support themselves and forced to depend on underfinanced and understaffed leprosy colonies for their care.

Since the early 1980s, the face of leprosy has changed dramatically, however, thanks to the development of a curative treatment and its increasing availability, free of charge, to patients. Multi-drug therapy (MDT), the treatment recommended by the WHO, cures leprosy patients, interrupting transmission of the disease after the first dose of medication and preventing disabilities. Even patients with the severest form of the disease experience visible clinical improvement within weeks of starting treatment. Around the world, various groups have made an effort to change the image of leprosy and encourage patients to seek timely treatment. To remove the stigma associated with deformities, their prevention, correction and rehabilitation are being integrated into general health services. Innovative communication approaches, including mass media, combined with improved access to treatment have both heightened awareness of the free and effective cure and dispelled some of the disease's stigma. As a result, patients are seeking diagnosis and treatment at an earlier stage. Hopelessness and despair are giving way to the idea that leprosy can be just another chapter in a person’s life. As communities witness the impact of MDT, age-old prejudices have begun to change and, with them, societal norms. Discriminating customs are fading in communities that have seen people cured through MDT. Based on estimates from the WHO, Novartis MDT donation helped cure about 4.5 million patients in the past seven years. Nearly all of the global supply of MDT is provided by a collaboration between the WHO and Novartis, a Swiss healthcare company. Since 2000, Novartis has supplied more than 37 million blister packs at a cost of about USD 64 million. The company has committed to work with the WHO to provide free treatment for all leprosy patients in the world at least through the end of 2018.

Adequate supplies of free, high-quality MDT will help to ensure that the remaining endemic countries reach the elimination target, and that other countries continue their progress. In line with the disease burden, most of the MDT medicines are destined for Asia, with a substantial share for India, which until recently accounted for about two-thirds of new leprosy cases worldwide. While India’s outstanding success over the last five years in reducing its share in the global burden of the disease has proven the essential soundness of the elimination strategy, the country still produces a significant number of new leprosy cases each year.

A hopeful new outlook in India: Throughout its involvement in leprosy treatment and control, the Novartis Foundation for Sustainable Development has pioneered unconventional approaches with a profound impact on the way the disease is combated. Many of these approaches are now incorporated into the disability care packages of both the government and NGOs in India. In addition, the Novartis Comprehensive Leprosy Care Association (NCLCA) pioneered a system of prevention, correction, care and rehabilitation based on simple modalities that can be mastered by general healthcare staff. Since its inception, NCLCA has worked to integrate disability care into mainstream health services. The program provides integrated leprosy care, including improved access to MDT treatment, field-based disability care services and reconstructive surgery and rehabilitation where required. The social and economic reintegration of patients into their communities is also an important objective for the NCLCA. Disabilities remain the most important factor for social stigmatization of leprosy. By far the best way to prevent these is through early detection of the disease and treatment with MDT. However, because of delays in starting treatment, improper management of leprosy reactions and patients from the pre-MDT period, India is still home to many patients disabled by leprosy. Depending on the nature of the disability, most can be corrected or cared for and any further physical deterioration prevented, but the requirement is substantial as each disabled person may have more than one deformity and may need multiple services. Training surgeons in reconstructive surgery, conducting camps and workshops, devising simple techniques and transferring technology have all served to bring treatment closer to the leprosy-disabled and have accelerated their integration into the general health services. Services from the NCLCA have benefited thousands of patients who would have developed inoperable deformities and handicaps without help.

The NCLCA’s focus on income generation and moral support for economic rehabilitation has transformed the lives of many of the poorest of the poor affected by leprosy. As these patients gain the ability to earn a living and support themselves, social acceptance and integration back into their communities improves drastically. The work of the NCLCA is far from over but its efforts have ensured that, thanks to comprehensive care, leprosy in India is no longer a life sentence.

Moving toward eradication of leprosy: The progress we have made in curing leprosy and caring for leprosy-affected patients would not have been possible without a team of dedicated, talented people. By bringing such diverse groups together and involving them in the entire process – from drug development to free provision to leprosy patients worldwide – we have transformed leprosy treatment. The teamwork between the WHO, health ministries, NGOs and communities has broken new ground in building public-private partnerships.
Leprosy elimination is indeed a major public health success story. About 20 years ago, fewer than 5% of patients were on treatment with MDT; today, every patient in the world is receiving MDT free of charge through the WHO-Novartis collaboration. As Mahatma Gandhi recognized, “Leprosy work is not merely medical relief; it is transforming frustration of life into joy of dedication, personal ambition into selfless service.”

We regard it as a privilege to contribute in the effort to realize the vision of a world without leprosy. This will require a continued, concerted effort by all parties to sustain the substantial gains made so far and to take leprosy elimination to the next step and focus on elimination at the sub-national level. We must retain a sense of urgency as we only have a small window of opportunity to do so in view of other pressing health demands.

Leprosy control is at a critical juncture: the disease has a very limited spread, and thus the level of international attention and political commitment tends to be lowering. However, the disease still exists and can resurge. The next step in leprosy control is to move toward eradication. Working together with governments and partners should make it possible to eradicate leprosy and consign the disease to history.

Noorein Kaleeba

Key Issues in Leprosy Control – An ILEP Perspective

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Over the last 40 years, ILEP Members have helped cure many millions of people affected by leprosy and continue to support vital leprosy work in more than 80 countries. In addition to the treatment provided, ILEP Members have also helped to prevent disability, reduce stigma and discrimination, and restore dignity to those affected. A significant development in the continuing fight against leprosy has been the collaboration and sharing of expertise between the World Health Organization, ILEP and other leading authorities, on the promotion of Operational Guidelines to implement the WHO Global Strategy for Further reducing the Leprosy Burden and Sustaining Leprosy Control Activities: 2006-2010. These Guidelines represent an important tool with which to continue the integration of sustainable leprosy activities with other health services. For ILEP, the Strategy’s aim of further reducing the leprosy burden demands four key elements be pursued: • Maintenance of essential leprosy services and diagnostic and treatment skills. • Emphasis on the WHO Global Strategy indicators of New Case detection and Treatment Completion. • Avoidance of prevalence or case detection based operational targets for field workers and emphasis instead on achieving quality targets which can reflect both the timeliness of detection and the quality of patient management. • Increased efforts to prevent disability, assist with rehabilitation and fight against stigma. ILEP continues to promote and stimulate collaboration between all stakeholders involved in leprosy work. Members work closely with associations of leprosy affected people, non-governmental organizations and governments of endemic countries. In all of these collaborative partnerships, ILEP maintains an evidence-based and patient-centred, holistic approach. Scientific research, in its basic, applied and operational aspects, remains a vital element of ILEP-supported work. Human rights are central to the approach of ILEP Members and more needs to be done to promote the rights of people affected by leprosy within the broader context of the important new Convention on the Rights of People with Disabilities adopted by the United Nations General Assembly in 2006. ILEP also continues to build on its long-term goal of a world without leprosy by promoting broader support to development issues. Conscious of the links between poverty and leprosy, ILEP Members are working for the achievement of the United Nations.

M Htoo
SEARO-WHO, New Delhi, India
Guest Lectures

Understanding Pain

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Pain is defined by IASP as "...an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage". Pain can be classified in relation to its physiopathologic mechanism as: nociceptive is pain due to activation of peripheral nociceptive nerve terminals, neuropathic is pain due to lesion or dysfunction of the nervous system and psychogenic pain is rare and the diagnosis must be founded on positive psychopathogenic bases.

Diagnosis: For nociceptive pain, diagnosis is done through clinical history, with questions trying to enumerate the subjacent causes of pain, such as inflammatory pathologie. For neuropathic pain, in spite of the large number of etiologies, clinical manifestations of the syndromes are relatively uniform. Nervous lesions that lead to neuropathic pain can vary, occurring in the peripheral as well as in the central nervous systems, and often concomitantly. Nociceptive Pain Mechanism: The first step is the transformation of intense physical or chemical environmental stimuli in action potentials, which are carried from free nerve endings through fine nerve fibers to the central nervous system, where they are modulated, integrated in different levels of the neuroaxis and finally interpreted in the cerebral cortex. In tissue lesion, countless substances are released (bradykinin, acetylcholine, glutamate, adenosine, prostaglandins, etc). When the inflammatory process lasts, changes in the plasticity of the central and peripheral nervous systems occur, facilitating the perpetuation of pain independent of the stimulus intensity.

Neuropathic Pain Mechanisms: In the PNS neuropathic pain can appear as a consequence of direct lesion of the axons. Such lesion can lead to ectopic discharges which will reach the central nervous system, where they will be interpreted as pain originating in the region of the corresponding innervations. The central mechanisms involved in the neuropathic pain are related to an unbalance between the pain impulse inhibition control and transmission facilitation mechanisms. Clinical Condition: Nociceptive pain may present a "mechanical" when pain is worsened during the day or an "inflammatory" rhythm when pain is aggravated during rest. Neuropathic pain can present itself spontaneously, continuously, generally described as a "burning or undefined sensation" or paroxysmal as "shocking, stitching, shooting or acute", or still in both forms concomitantly. Physical Exam: Physical and neurological exam will determine the topography of the lesion, the level of damage and the type of the damaged nervous fibers. By testing sensitivity, we can also identify conditions of hyperalgia and allodynia. Treatment: Pharmacological therapy is the first strategy to fight pain but not the only one, and there is evidence suggesting that early treatment of acute pain may prevent the development of chronic pain. Pain treatment should not be restricted to analgesic drugs. Physical medicine and rehabilitation programs, as well as several psychotherapy support techniques or surgeries in the pain modulation centers and even some alternative therapies in their due cultural contexts may benefit the patient in the recovery of their bio-psycho-social well-being.

Bibliography:
Genomics and the Origin of Leprosy

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Leprosy, a chronic, neurological human disease, results from infection with the obligate intracellular pathogen *Mycobacterium leprae*, a close relative of the tubercle bacillus. *M. leprae* has the longest doubling time of all known bacteria and has never been cultured in the laboratory. Comparison of the 3.27 Mb genome sequence of an armadillo-derived Indian isolate of the leprosy bacillus with that of *Mycobacterium tuberculosis* provides clear explanations for these properties, revealing an extreme case of reductive evolution. Less than half of the genome contains functional genes while pseudogenes, with intact counterparts in *M. tuberculosis*, are abundant. Gene deletion and decay have eliminated many important metabolic activities including siderophore production, part of the oxidative, and all of the miroaerophilic and anaerobic respiratory chains, together with numerous, alternative catalytic systems and their regulatory circuits. Genome decay has thus led to metabolic crippling. In the 1990s, it was thought that the elimination of leprosy was possible thanks to the massive implementation of multidrug therapy by the World Health Organisation. While over twelve million patients were cured, the incidence of the disease has not declined and remains stubbornly high at around 600,000 new cases annually. Better means of diagnosis and improved understanding of transmission are thus required. Using post-genomic approaches we are developing both an immunodiagnostic test for infection and epidemiological tools. Diagnosing leprosy is often difficult as the disease exists in different forms. At one end of the spectrum is lepromatous leprosy, characterised by numerous lesions, a high bacillary load and humoral but not cell-mediated immunity, while tuberculoid leprosy is at the other. Patients with the tuberculoid form of disease present with few lesions, where bacteria are seldom detectable, and have weak antibody responses but strong cellular immunity. Comparative genomics led to the identification of antigenic proteins that are restricted to the leprosy bacillus or of limited distribution, and these have been used in a whole blood assay to stimulate antigen-specific interferon-gamma production by lymphocytes. In conjunction with an antibody-based test for lepromatous leprosy it is now possible to detect most forms of the disease although there are still problems distinguishing between cases of infection or simple exposure to the pathogen. Indeed, the remarkable frequency of immune responses in healthy contacts suggests that transmission of *M. leprae* is far more common than believed and this underlines the necessity for improved means for tracking the disease. To develop tools for molecular epidemiology, we sequenced the genome of a Brazilian isolate of *M. leprae*, chosen because of the high prevalence of leprosy in that country and its great distance from India. In light of the extensive gene decay observed in the Indian strain multiple examples of pseudogene formation and numerous single nucleotide polymorphisms (SNP) were expected. Astonishingly, the two genome sequences were nearly identical differing by a single pseudogene and a mere 118 SNP, distributed almost equally between genes and pseudogenes. On surveying over 300 leprosy biopsies, 78 SNP were found to be informative. Phylogenetic studies revealed that all extant cases of leprosy are attributable to a single clone of *M. leprae* whose dissemination worldwide could be retraced from SNP analysis. The disease seems to have originated in Eastern Africa or the Near East and spread with successive human migrations. Europeans or North Africans appear to have introduced leprosy into West Africa and the Americas within the past 500 years.
**Positional Cloning of Major Leprosy Genetic Risk Factors**

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Leprosy is a chronic infectious disease with a strong host genetic component caused by *Mycobacterium leprae*. By employing forward genetics approaches, we have been able to identify two major genetic risk factors of leprosy susceptibility. A first set of risk factors is located in the PARK2/PACRG shared promoter region on chromosome region 6p25. In addition, the investigation of a linkage peak (LOD=2.7) on chromosome region 6p21 identified in a previous genome-wide linkage scan led to the identification of a second genetic risk factor. In 194 Vietnamese simplex families, the initial association scan of a 10.4 megabase region underlying the linkage peak targeted the *lymphotoxin-a (LTA)* gene for high-resolution association studies. All SNPs in the bin containing the functional LTA+80 variant (AA/AC vs. CC P=0.007; OR=1.74 [1.16-2.60]) were associated with leprosy. The association of LTA+80A was replicated in a second independent sample of 104 Vietnamese simplex families (P=0.003; OR=2.34 [1.27-4.31]). When stratifying on age at diagnosis, the association of LTA+80 was captured almost entirely by cases diagnosed before age 16 (P=0.00004), reflecting significant genetic heterogeneity of the LTA+80 effect between cases <16 years and those >16 years (P=0.00054). In the second Vietnamese sample, the odds ratio similarly increased in cases <16 years (OR=5.31 [1.19-23.60]) resulting again in significant evidence for heterogeneity (P=0.04). When both samples were combined, the evidence for association overall and in cases <16 years was very strong (P=0.000024 and P=0.0000004, respectively). In a third sample of 364 cases and 371 controls from Northern India, the association of LTA+80A was replicated (P=0.01; OR=1.60 [1.10-2.33]) using multivariate analysis. The strength of association increased in the youngest age group (P=0.004; OR=2.95 [1.32-6.58]) replicating the age-effect and genetic heterogeneity (P=0.003) observed in the Vietnamese samples. A careful comparison of linkage disequilibrium pattern of SNPs in the LTA region between the Vietnamese and Indian samples provide further support for LTA+80A as the causative leprosy susceptibility variant.

**Host Genetics of Mycobacterial Infections: Current Concepts**

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Genetic basis for interindividual variation in susceptibility to human diseases involves a complex array of immune regulatory genes with variants that impose subtle but significant consequences on gene expression or protein function. Recent upsurge in knowledge concerning immunological display of antigenic peptides by HLA for T cell recognition is crucial in understanding disease pathogenesis. Other candidate genes like TLR2, PARK2 and PACRG have also been defined for their possible biological role in governing susceptibility/resistance to mycobacterial infections. Further, a non-targeted genome-wide linkage analysis has helped in identification of positional candidates like Chromosome 10p13. A gene that lies at the peak of this linkage is the macrophage mannose receptor (MRC1), which has a role in the processing of glycolipids derived from mycobacteria. Our study deals mainly with the identification of specific HLA motifs and supertypes responsible for restricting T cell responses in infectious diseases and identification of immunogenetic markers, which might be associated with disease susceptibility. Studies from our laboratory have shown existence of several novel alleles and unique haplotypes in the Asian Indian population. This extreme molecular diversity in MHC in Asian Indians has been driven by racial admixture and microbial pressure. The study on the molecular diversity of MHC in mycobacterial diseases in North Indians have delineated an association of HLA-DRB1* 15/16 (DR2) both with tuberculosis as well as leprosy. Further analysis based on HLA-DR restricted supertypes has revealed an important role of negatively charged ‘pocket 4 motif’ residues (D70, E71, A74) in tuberculosis. This is in contrast to our observation in tuberculous leprosy where the pocket 4 binding is influenced predominantly by ‘Arg rich motif’ at position 13,70/71 of the DRB1 molecule. Additionally, we found that the Val/Gly dimorphism of ‘pocket 1’ of the peptide binding groove of HLA-DRB1 influences disease severity. It is possible that the net charge of peptide binding motifs in these pockets might have distinct influence on epitope binding and constitute important information in vaccine design. Our data suggest that the critical epitopes must contain at least three distinct class II MHC binding motif matches for efficient binding. Bioinformatics tools such as Epimatrix and Conservatin to name a few could be applied for identifying unique or multi HLA restricted (promiscuous) T cell epitopes that are conserved across variant strains of the pathogen. These approaches offer a significant advantage to develop novel vaccines/therapeutics for the prevention and treatment of infectious diseases.
Human Genetics of the Mitsuda Reaction

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Introduction: Leprosy is a chronic infectious disease caused by Mycobacterium (M.) leprae. The Mitsuda reaction is a delayed granulomatous skin reaction elicited by intradermal injection of heat-killed M. leprae. Interestingly, even in areas not endemic for M. leprae, results of the Mitsuda test are positive in a substantial proportion of individuals. Like leprosy, the Mitsuda reaction is thought to be genetically controlled, but its mode of inheritance is unknown. Methodology: We performed a model-free genome-wide linkage analysis for the quantitative Mitsuda reaction in 19 large Vietnamese families with a history of leprosy (114 offspring) in order to To identify and locate the major genetic factors influencing the extent of the Mitsuda reaction. Results: We identified 2 regions with suggestive linkage to quantitative Mitsuda reactivity: 17q21-25 and 2q35 (SLC11A1 locus). Notably, the high linkage and heritability for these 2 loci are indicative of large QTL effects. Both regions harbor genes previously reported to be linked and/or associated with mycobacterial or other granulomatous diseases. Interestingly, when the present study performed analyses in the subset of 60 healthy offspring, the same linkage regions were identified—albeit with lower significance because of smaller sample size. Conclusions: These findings, coupled with the observation that, regardless of the endogeneity of leprosy, the distribution of Mitsuda-reaction values is similar across countries [3], support the view that the importance of this phenotype extends well beyond the field of leprosy. Given the high proportion of Mitsuda-reaction variability explained by the 2 regions identified here, additional association studies to identify the underlying genes will be of considerable importance to our understanding of in vivo granuloma formation.

Genetic Background Regulating the Immunological Balance in Mycobacterium leprae Susceptibility

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Leprosy is a complex disease where host genetic background control susceptibility and severity outcome. A balance of efficient cellular immune activation with a predominant production of cytokines from IL-12/23-IFNG axis are critical to control intracellular growth of Mycobacterium leprae as any other intracellular pathogen. Tumor necrosis factor (TNF) is another critical mediator of granuloma formation and control of bacilli spread synergizing with IFNγ/IL-12 to hamper M. leprae infection, while interleukin-10 (IL-10) has an antagonistic role. To evaluate genetic associations in leprosy, studies have been performed based on case-control design using candidate genes like TNF and IL-10. Moreover, genomic scans using family-based designs identified chromosome regions as novel candidates to be tested for association. Thus far, genes clustered in 6p21 region, like tumor necrosis factor (TNF), lymphotoxin-alpha (LTA) and human leukocyte antigen (HLA) have been consistently associated with leprosy in different populations like Indians, Brazilians, and Vietnamese. On the other hand, genetic variations in interleukin-10 (IL-10) were also replicated in association with leprosy. The 6p21 genes and IL-10 are critical immunological regulators, associated with either protective (TNF, LTA, and HLA) or susceptible (IL-10) responses against M. leprae. Thus, epidemiological data suggest that a genetic background regulating the ratio of TNF-LTA/IL-10 could be crucial to outcome of leprosy. Even though, the biological significance by functional studies still needs strong confirmation in order to provide genetic markers to screen high-risk populations and improve prophylactic actions.
Genetic Epidemiology of an Isolated Leprosy Population from Northern Brazil

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Leprosy is a complex disease where host genetic background control susceptibility and severity outcome. A balance of efficient cellular immune activation with a predominant production of cytokines from IL-12/23-IFNG axis are critical to control intracellular growth of Mycobacterium leprae as any other intracellular pathogen. Tumor necrosis factor (TNF) is another critical mediator of granuloma formation and control of bacilli spread synergizing with IFNg/IL-12 to hamper M. leprae infection, while interleukin-10 (IL-10) has an antagonistic role. To evaluate genetic associations in leprosy, studies have been performed based on case-control design using candidate genes like TNF and IL-10. Moreover, genomic scans using family-based designs identified chromosome regions as novel candidates to be tested for association. Thus far, genes clustered in 6p21 region, like tumor necrosis factor (TNF), lymphotixin-alpha (LTA) and human leukocyte antigen (HLA) have been consistently associated with leprosy in different populations like Indians, Brazilians, and Vietnamese. On the other hand, genetic variations in interleukin-10 (IL-10) were also replicated in association with leprosy. The 6p21 genes and IL-10 are critical immunological regulators, associated with either protective (TNF, LTA, and HLA) or susceptible (IL-10) responses against M. leprae. Thus, epidemiological data suggest that a genetic background regulating the ratio of TNF-LTA/IL-10 could be crucial to outcome of leprosy. Even though, the biological significance by functional studies still needs strong confirmation in order to provide genetic markers to screen high-risk populations and improve prophylactic actions.

Nerve Damage and Repair

Gigi Conforti

Transforming a Negative Legacy Into Historical Sites That Benefit Family and Community

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Discrimination against people challenged by leprosy and their families is still widespread in Kenya and throughout the world. In 2007, oral history conducted with individuals in Kenya revealed widespread human rights violations. People are denied the right to decent burial; People are denied the right to property and land ownership; People are denied the right to free movement and association; People are denied the right to an honorable marriage. Dorcas Akoth is a widow who lives in Nyamanga village, Suba District, Kenya. She lives with the family of her younger brother but her house is built away from the main homestead. Her husband died before she contracted leprosy, leaving her with two sons. One of the sons died and the other one abandoned her. She was chased away from the village where she lived with her late husband. When asked why she left her home to live with her brother’s family, she said: “They chased me away and disinherit me of everything. My son was so ashamed of me that he would not call me Mama. He has never come to see me.” When asked what will happen when Dorcas dies, her sister-in-law commented: “When she dies, we will bury her away from the homestead. Her house will be burned, her belongings will be left on the road. It is taboo to inherit anything from somebody with her disease.” In Kenya, we are encouraging young people, the next generation whose parents or grandparents have been challenged by leprosy, to accept their family’s history and discuss it openly without fear. Instead of running away from their history, we are encouraging them to promote their history through tourism. In this way, they can use history to support their families instead of accepting the negative legacy which so often results in poverty and people begging on the streets. The youth were advised to identify sites where their relatives who had leprosy were buried without honor. Currently, some burial sites that were previously abandoned are in the process of being fenced in and promoted for community-based tourism through the Kenya Tourism Trust Fund and the Abasuba Community Peace Museum. Young people have been shown how community-based tourism can change their lives while bringing honor and acceptance to their families. As part of this effort, we have stressed that all of the history of the older generation must be documented for the education of future generations. Through education and tourism, the negative legacy of leprosy can be transformed into a positive message of pride and honor. We hope that this is something that will be carried out by the younger generation on a global level as an important means of removing the stigma of leprosy while at the same time providing a means by which the younger generation can support themselves and their family members who have had leprosy.