

## **AWARENESS AND MANAGEMENT OF A RARE DISEASE - LEPROSY - IN THE U.S.**

ORDR scientific conference support (April 16-17, 2009) - Dr. Steven M. Holland, LCID, NIAID, NIH

### **Final Report:**

This NIH-sponsored training event included updates and reviews on current topics in Leprosy-related diagnosis, management, and research. The event represented also a joint effort between the Laboratory of Clinical Infectious Diseases, LCID, NIH and the National Hansen's Disease Program (NHDP). The event was attended by about 47 participants including biology.

Participants will include NIAID and NCI intramural and extramural physicians, immunologists, pathologists, dermatologists, mycobacterial specialists, infectious diseases specialists, nurses and students from academic, research and primary care institutions, including Walter Reed, Bethesda Naval, Johns Hopkins, and the Clinical Research center (CRC) / NIH. Invited speakers were mainly US researchers and clinical experts on the field as well as leprosy specialists from the Leprosy Laboratory, Oswaldo Cruz Foundation, Brazil.

The meeting comprised a total of 16 presentations during one and a half day and was subdivided in two major sections: 1- Clinical; 2-Scientific research.

1 - The Clinical presentations outlined: a) An overview of the NHDP program, world & U.S. epidemiology of the Hansen's Disease; b) Microbiology of the *M. leprae* and the use of the armadillo as an animal model for the disease; c) Clinical/immuno/histo-pathological spectrum of Hansen's Disease; d) Treatment and management of leprosy reactions; e) Presentation and discussion of two clinical leprosy cases that were diagnosed and have been treated at the NIH Clinical Center.

There were discussions after each section, and one major outcome was to teach staff how to recognize, treat, and understand this important but still under-diagnosed and under-recognized disease here in the US. The major complications that are frequently observed during the development of leprosy reactions and how to recognize reactions as it frequently shows as the first manifestation of the disease were also discussed.

2- The Scientific section included discussions on major topics of Leprosy research since leprosy and its mechanisms are critical for a better understanding of the disease and its importance is central to the NIAID Clinical Research Mission. Major topics discussed in the meeting were: a) Genomics of *M. leprae*: Gene expression, vaccine development, strain typing; b) Knock-out mouse strains as models for the spectrum of leprosy; c) Mycobacteria infection and modulation of Schwann cell function; d) Innate Immunity Variation, TLR-Dependent Cytokine Production and mycobacterial susceptibility (for Leprosy and Tuberculosis) associated gene polymorphisms, SNPs; e) Immunology of leprosy reactions - Potential Markers and HIV and leprosy co-infection; f) *M. leprae* cell wall associated lipids.

There was much discussion on the clinical and immunological aspects of disease mainly applied to clinical diagnosis and management. An overview report and discussion is being elaborated for publication and optimal submission date is expected for December of the current year.

In addition, joint efforts among the participants include acknowledge to the NHDP for their continuously support of live *M. leprae* to the research community inside and outside the US, and to outline collaborative communication in the fields of clinical expertise.