Editorial

INTERNATIONAL LEPROSY CONGRESS 2002—
LESSONS LEARNED

Introduction

The ILA Congress held in Salvador, Bahia, Brazil in August 2002 was a highly successful Congress in terms of the venue, the programme and the high quality of the presentations and discussions. The presentation of the ILA Technical Forum Report\(^1\) on each of four mornings of the Congress provided an important context to the Congress along with the State of the Art lecturers and the free papers, posters and seminars that were presented. Four of the participants were invited by the organizing committee to present a summary of the lessons learned during the Congress during the last morning of the Congress. These four presentations are summarized below.

Epidemiology and leprosy control: S. K. Noordeen

The ILA Technical Forum report reviewed key issues in the current understanding of the epidemiology of leprosy and issues in the organization of leprosy control activities in endemic countries.

During the Congress, there had been presented important new work on the development of new measures of infection and the development of new diagnostic tools. These new tools, some developing from the opportunities presented by the sequences of the *Mycobacterium leprae* genome, will provide essential new tools for the epidemiological investigation of the transmission and early infection stages of leprosy.

The role of contacts was generating renewed interest in both low and high endemic situations. The risk associated with contact status and both immuno-prophylaxis and chemoprophylaxis are now being investigated using new tools and new chemotherapeutic agents.

New approaches to mathematical models are now being developed which can assess in simulations the impact of interventions such MDT, prophylaxis and other strategies on the transmission and incidence of leprosy.

Leprosy elimination campaign (LEC) findings had been analysed and were of value in assessing potential backlog and hidden cases in the community. Repeating LECs were of value not only in case finding, community education and capacity strengthening, but also were contributing to knowledge about epidemiology of leprosy.
The role of BCG vaccine rather than its efficacy was still under debate and issues of repeated vaccinations. Data on the efficacy in different countries had been available for some years however its role in leprosy control still required further investigation.

Clinical leprosy and therapeutics: Norma Foss

The ideal diagnostic test would be simple, would identify all cases (100% sensitivity) and would be negative in people who do not have leprosy (100% specificity). The diagnosis of leprosy has been based on the presence of one of more of the following features: anaesthetic skin lesions, enlarged peripheral nerves and acid-fast bacilli in skin smears. It has been shown that in experienced hands that these signs represent a reproducible means of diagnosing leprosy. A simplified approach based on the single sign of a skin patch with loss of sensation has been proposed for use in the integration of clinical leprosy services into general health services. This approach could lead to under-diagnosis of MB patients who are a source of infection and who are at increased risk of nerve damage and reaction. Over-diagnosis would result in unnecessary treatment and the psychosocial consequences of the diagnosis of leprosy. The sensitivity of this single criterion is only 70%, with 30% being missed. Thickening of peripheral nerves generally appears later than do skin lesions and to accept as diagnostic should be accompanied by other signs. Slit skin smears are useful in diagnosing MB patients and relapses.

Classification remains important even if a uniformed treatment regimen is developed because of different risks of nerve function impairment association with PB and MB.

A number of the recommendations of the ILA Technical report need to be emphasized. Diagnosis based on the single sign of anaesthetic skin patches will miss around 30% of cases, many of whom may be MB—health workers need to be taught to suspect cases and refer patients to more experienced staff who can assess peripheral nerve thickness. Situations where classification is based on only number of lesions need to take smears on a sample of patients for quality control purposes. Further research is required to develop tests of leprosy infection, disease and for classification. Surveillance for the emergence of rifampicin resistance in relapsed MB patients should be carried out in special centres. Flexible, patient-friendly systems for delivering MDT need to be implemented. Only in exceptional circumstances should more than 1 month’s supply be given or the monthly supervision be compromised. Health workers should actively trace absentees and encourage them to complete MDT rather than passively waiting for them to attend and then removing them from registers. The trial of uniform MDT should be supported as an approach to facilitate integration of leprosy services within general health services.

A quiet revolution in basic research: Warwick Britton

Leprosy is not going to disappear and we still do not understand basic issues in human leprosy. The quality of the basic science presented at this Congress is undoubtedly much higher than previously.

The sequencing of the genome of \textit{M. leprae} has been a major development, perhaps the most important ever in leprosy. It now permits the definition of the genes essential for the organism, the cell wall structure, new targets for drugs, virulence factors, and proteins
specific to *M. leprae*. There now exists the possibility of identifying strain variation, which genes are expressing in ‘living’ *M. leprae* and methods of assessing *M. leprae* survival in culture.

Further advances in understanding host responses to *M. leprae* have been made through work on genetic susceptibility to leprosy (variations in TLR2 and the influences of TBF, IL-10 polymorphisms), stimulating immune response to *M. leprae* through T cell response and molecular signals to activate T cells, and cytokine responses to leprosy.

Work with Schwann cells has identified laminin–dystroglycan complex as the ‘receptor’ for *M. leprae*. Important questions concern how Schwann cells phagocyte *M. leprae* and their molecular responses. Schwann cells as antigen presenting cells may contribute to the immunopathology in nerves.

Informative clinical and laboratory studies have investigated single skin lesion leprosy, the cellular and cytokine basis of reversal reactions and cytokine responses as predictors of recurrent reactions.

While there no diagnostic tests for immediate application in the field, there are tools for asking specific questions about disease and infection. Serology can assist in classification, but is not yet at a stage for use in mass screening. PCR is proving a useful research tool in PB and single skin lesion leprosy and in environmental studies. PCR methods to identify dapsone and rifampicin resistance have been developed and these need to be compared with traditional mouse foot pad studies. Testing of the first generation of skin test antigens has started.

There is a quiet revolution in the ‘who and where’ of basic research in leprosy. There is now a group of new, young investigators. There are new groups in endemic countries as well as the established laboratories. New research partnerships have been established with field and laboratory groups, between research institutes in different countries and ILEP support groupings.

A commitment to eradicate leprosy involves a commitment to understand it. This requires integration of leprosy research with mainstream molecular biology, immunology and other disciplines. It requires innovative approaches to strengthening and funding for basic research, and not only through the TDR programme. Finally, partnership of laboratory and field to define the questions and to develop applications is essential.

**Prevention of disability, social aspects and rehabilitation: W. C. S. Smith**

This Congress has demonstrated that research in these aspects has significantly increased in quality and quantity since the previous congress in Beijing, 1998. The need for research in this area was recognized as being important, but that it lacked the support necessary for its development. Attempts were made following the Beijing Congress to develop a network but these proved unsuccessful. However, a number of research initiatives funded by ILEP members have been productive in bring people together and creating the opportunity for research.

The socio-economic rehabilitation guidelines work brought people in the field together to share their experiences and this led to a publication that was widely disseminated. The qualitative work as part of the INFR programme has created a network of people engaged in addressing issues in delayed diagnosis using qualitative methods. The work on A (activity) and P (participation) scales is having a similar effect. The output from these initiatives has been seen throughout the Congress.
A further catalyst was the special issue of *Leprosy Review* that was allocated by the Editorial Board to the topic of social aspects of leprosy. This opportunity brought together a variety of submissions for that special issue and hopefully will now be followed by an increase in the number of papers submitted in the field. The appointment of the new Editor for the *International Journal of Leprosy* will hopefully lead to a broader acceptance of the importance of social research in leprosy.

The Salvador Congress has seen evidence of a real momentum in social science research through papers presented, discussions, debates and ideas. The fact that the Congress was held in South America, where social science research is strong, has undoubtedly enhanced this.

The approach of listening and reflecting on what patients say, families and community say is an important principle in qualitative methods helping health workers to recognize that they do not have all the answers. This will challenge our current, accepted approaches to all aspects of leprosy work from case finding to reconstructive surgery. These challenges are healthy and necessary at a time of transition in leprosy. We are now entering a new era; some call it the ‘post-elimination’ era. It is not the end but the beginning of a new phase. The concentrated efforts of the elimination strategy were like a 100-metre race to a deadline—it was important and it took us to a new level. But we are now at the start of a new race, a 10,000 km race, a much longer one that requires different approaches that are long term, sustainable and integrated. We need greater simplification and demystification of leprosy activities. We need the strengths of the integrated programmes and of communities to help us adapt to new approaches. We need the resources, ideas and input of patients and their communities. That is why social science is now important—the strengths we need to make programmes sustainable lie in the people and their communities and not with medial experts and external donors. It is important that this approach, which is now gathering momentum, is maintained.

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**References**