



Fédération Internationale des Associations contre la Lèpre  
International Federation of Anti-Leprosy Associations

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## 11<sup>th</sup> Meeting of the ILEP Technical Commission

Thursday, 27<sup>th</sup> March 2008

London, United Kingdom

### MINUTES

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**In the Chair:** Professor Cairns Smith (CS)

**Present:** Dr Hugh Cross (HC), Dr Etienne Declercq (ED), Dr Sunil Deepak (SD), Dr Augustin Guédénon (AG), Professor Diana Lockwood (DL), Dr Paul Saunderson (PS), Dr Wim van Brakel (WvB), Dr Myo Htoon (MH) of the WHO Global Leprosy Programme

**Secretariat:** Mr Douglas Soutar (DS), Secretary, ITC  
Mr Andrew Clark (AC), Assistant General Secretary  
Ms Felicity Bonham (FB), PA to the General Secretary

#### 1. Approval of the Agenda

*The agenda was approved with an addition to Any Other Business: a forthcoming Global Dermatology Congress in Genoa.*

#### 2. Matters Arising from Previous ITC Meeting

*Commission members were asked to inform FB of any changes that should be introduced to the listing of their contact details.*

#### 3. Updates on Technical Expert Groups (TEGs)

##### 3.i Update on TEG on CBR

Attention was drawn to the recently published WHO-ILEP Technical Guide On Community-Based Rehabilitation (CBR) and Leprosy and the letter received from Alana Officer, Co-ordinator, Disability and Rehabilitation (DAR) inviting joint discussion on implementing the guidelines detailed in this Guide.

The ITC members were informed that permission to translate a WHO/ILEP joint publication into the official languages of the WHO (English, French and Spanish) has to be sought and the translators vetted and approved before translation can begin. MH said that the WHO regional offices have authority to translate publications and that ILEP could perhaps usefully make contact with them about translating the new CBR guide into French and Spanish (thereby expediting the process).

It was noted that this TEG has been disbanded.

*The Secretariat to pursue possibility of working with the WHO regional offices to produce translations of the CBR Guide into French and Spanish. Portuguese translators to be identified also.*

### **3.ii Update on TEG on Data and Data Collection**

AC reported that the new Questionnaires had been circulated to all Members. Reminders to ensure the Secretariat is sent data for processing and analysis over the summer will be sent to Members in April.

### **3.iii Update on TEG on Information (ILEP/Infolep Collaboration)**

AC reminded the ITC of the decision to end this TEG. He said that the designers were currently signing the site up to a host and that it would be possible to make the new ILEP website live as soon as a few technical matters are resolved (such as fonts and font colours, accents and spacing).

Opinions were exchanged about the utility of making more language versions of publications available from the ILEP website. CS stated that this was an important consideration in view of high staff turnover in National Programmes.

*The Secretariat is to liaise with the designers to ensure the new ILEP website comes high on lists produced by Internet search engines.*

*When the ILEP website has been made live, the Secretariat will invite feedback and comments from the members of the ITC.*

## **4. Issues Related to Collaboration Between ILEP, WHO, ILA**

### **4.i Feedback from WHO 9<sup>th</sup> Technical Advisory Group (TAG) Meeting, Cairo, Egypt, 6<sup>th</sup> – 7<sup>th</sup> March 2008**

CS, DL and PS commented on the productiveness of the most recent meeting of the TAG. CS summarised the key points of discussion as:

- the quality of case detection data over time and from country to country;
- the importance of reporting relapses annually
- recommendations about drug resistance in leprosy.
- the endorsement of the training for the current global leprosy strategy;
- the issue of leprosy, HIV/AIDS co-infection and HAART
- future chemotherapy based on simplified regimens;
- the management of new tools;
- some recommendations on self-care approaches;
- recommendations on further research and social action on stigma

Eradication of leprosy was a focus of debate. It was clear that some National Leprosy Programme Managers would still welcome quantitative targets. However, it was concluded and recommended that any eradication strategy cannot be justified based on current evidence as leprosy does not meet the feasibility criteria for eradication.

DS informed ITC members that Dr Vijaykumar Pannikar had invited ILEP to suggest nominations to the next TAG. Dr Pannikar reiterated his keenness for the technical bodies of the two organisations to continue to work closely

together.

MH said it was possible there would be another TAG Meeting towards the end of 2008. DS made the point it would be good to have confirmation as soon as possible as participation of ITC members had implications for the ILEP budget.

#### **4.ii Progress on Training for the Operational Guidelines**

MH briefed the Commission members on the planned future training programmes, which are exclusively for National Leprosy Programme Managers. There are to be five workshops this year (two in the African region, one in the American region and one in South-East Asia). It is hoped there will be three in 2009 (one in the African region and two in the Western Pacific and as yet un-funded). He stated that WHO would like its partners to assist with the rolling out of these training workshops.

#### **4.iii Feedback from International Leprosy Congress (ILC), Hyderabad, India, 30<sup>th</sup> January – 3<sup>rd</sup> February 2008**

CS reported that the International Congress in Hyderabad had been one of the best he had ever attended and noted the positive engagement by young field workers in the poster and oral presentations.

Attention was drawn to the new leadership of ILA and the seemingly positive attempt to resuscitate the organisation. It was agreed that ILEP should continue to support and facilitate this process wherever possible. It was noted that ILEP Members would have to be convinced of clear benefits of membership and Wim Van Brakel noted that he had been involved on behalf of the ILA council in drafting a new tariff of Membership fees. It was also noted that the ILEP General Secretary had approached Salvatore Noto (the ILA Vice-President for Communications) to encourage close collaboration with ILEP in the development of any new website and newsletter.

### **5. Development of Programme of Work**

CS introduced the draft outline of the Programme of Work following the previous day's Technical Forum. The key areas within which discussion was focused were Monitoring, Implementation, Research and Development, Stigma and Discrimination and Liaison with ILEP Members. The draft Programme of Work indicated the broad area of activity, what the end product or outcomes might be, the planned working methods and at least one lead member tasked to take this work forward. This draft Programme of Work is attached to these minutes having been approved by the ILEP Board on 28<sup>th</sup> March 2008.

#### **1. Monitoring**

1. This primarily related to the analysis of epidemiological trends and a review of global and other data both from the WHO and elsewhere. Dr Htoon stressed the importance of the analysis needed at country level through regular programme reviews. It was agreed that ED would aim to review the *Weekly Epidemiological Record* data for the September meeting.

## **2. Implementation**

1. Training - The rolling out of the training of National Programme Managers is extremely important and ILEP Members should be encouraged to support this process. ED and AG were identified as lead persons to monitor and report on progress.

2. Indicators – Discussion focused on the need for quality indicators and establishment of Minimum Acceptable Standards. It was agreed that a toolkit of different quality indicators and methods for their use be developed for programme managers. PS agreed to take a lead in identifying potential indicators in collaboration with WHO and to look at their development and testing on behalf of the ITC.

3. Implementation of Prevention of Disability (POD) to Improve Coverage and Quality – The key was to identify the constraints and barriers to implementation of POD activities and it was agreed that tackling this through dialogue at various levels would be vital. This consultation phase with ILEP Programme experts would be begun by HC with a view to planning a workshop for managers and experts during 2009.

4. Implementation of CBR Guidelines- It was agreed that there was a need to collate information on where ILEP Members were doing CBR work and what those activities included. Guidance would be needed on how to improve coverage, quality and impact of CBR. It was agreed that ILEP Members should be encouraged to participate in the WHO First Asian Pacific CBR Conference in Bangkok in December and try to develop its participation in the follow up of the WHO CBR guidelines to be published in December 2008. SD was tasked to take the lead on this area of work.

## **3. Research and Development**

CS outlined the key areas within research and development that needed to be addressed - strategy, coordination, advocacy, funding and gaps. While it was agreed that research was a cross-cutting issue, three priority areas were outlined in the programme:

1. Reviewing main findings which have implications for field implementation including on the question of chemotherapy. It was agreed that a forum for evidence based leprosy policy and practice might be planned for in 2009 similar to that held in Paris in 2002.
2. Advice was needed on the application of new methods of early diagnosis and sub clinical infection and it was agreed that there should be close liaison with the IDEAL consortium and others on potential standardisation of methods. CS would take a lead on both these areas.
3. A neuropathology workshop in 2007 had made an extensive set of recommendations which the ITC now agreed needed to be followed up on. WvB and DL agreed to take the lead on this topic.

## **4. Stigma**

It was agreed that a Temporary Expert Group should be set up to look at stigma and make recommendations on what areas needed further research and on measurement and best practice for interventions. WvB would take a lead on this area of work.

## **5. Liaison with ILEP Members**

It was agreed that it would be vital to liaise with ILEP Members and to review

the programme of work in light of any emerging issues. A further Forum might be useful around the midpoint of the programme in 2010.

## **7. Any Other Business**

### **7.i Drug Supply issues**

DS noted that a number of problems had been reported over the last two years in relation to problems with supply of both MDT and Clofazimine. Examples were given of Brazil, Madagascar and Indonesia. It was agreed that ILEP should do whatever it can to strengthen the capacity of National Programme Managers to deal with appropriate drug ordering and distribution. DS would continue to ask ILEP Members to report any continuing problems.

### **7.ii First Global Dermatology Conference in Genoa, 23<sup>rd</sup> – 26<sup>th</sup> April 2008**

SD brought this to the attention of the ITC. DS noted that the organisers had asked for ILEP assistance in facilitating Professor Paul Fine to make a presentation on eradication. It was agreed that since Professor Fine was busy his presentation given to the recent TAG might be shared and the key issues presented by someone else already attending such as SD.

## **8. Next Meeting**

Initially this was noted as being on 23<sup>rd</sup> and 24th September 2008. Subsequent changes were required to be made and the date is now confirmed as 30<sup>th</sup> September and 1<sup>st</sup> October 2008.

### ***Appendix: ITC Plan of Work 2008 – 2011 (approved by ILEP Board)***

#### Document distribution:

Board  
ITC  
ILEP Representatives

#### Acronyms used in this report:

AIDS acquired immune deficiency syndrome  
CBR community-based rehabilitation  
DAR Disability and Rehabilitation Unit (WHO)  
HAART Highly active antiretroviral therapy  
HIV human immunodeficiency virus  
IDEAL Initiative for Diagnostic and Epidemiological Assays for Leprosy  
ILA International Leprosy Association  
ILC International Leprosy Congress  
ITC ILEP Technical Commission  
MDT multi-drug therapy  
POD prevention of disability  
TAG Technical Advisory Group (WHO)  
TEG Temporary Expert Group  
WHO World Health Organization

# ILEP TECHNICAL COMMISSION PLAN OF WORK 2008-2011

Date: 31<sup>st</sup> March 2008

*Prepared by Professor Cairns Smith  
and the members of the ILEP Technical Commission*



<i>Activity Advice requested by Members</i>	<i>Freque ncy</i>	<i>Product</i>	<i>Working Method</i>	<i>Lead member</i>	<i>Date due</i>	<i>Present status/notes</i>
<b>1. MONITORING</b>						
1. Advise on the monitoring of routine and ad hoc data on leprosy. Respond to specific requests for advice on data quality.	Annual	Review and analysis of most recent WHO and other data. Response to specific requests from Members.	Analysis of data and critical review including HIV co-infection and GIS.	ED		
<b>2. IMPLEMENTATION</b>						
1. Training of national programme managers in the operational guide for the Global Strategy. Support for sustainability and other aspects of training such as dermatology and referral.	5 in 2008/9	Training programmes in 2008 and 2009. Other training to support sustainability.	Participation and support for regional WHO training programmes.	ED/AG		
2. Development of a tool kit of indicators of quality for use in leprosy programmes.	Once	Tool kit of different quality indicators and methods for use by programme managers.	Identification of potential indicators and their development and testing by ITC. Work in collaboration with WHO.	PS		
3. Implementation of prevention of disability to improve coverage and quality.	Cont.	Identification of barriers and facilitators for extending POD coverage. Follow-up of recommendations.	Consultation with ILEP programme experts and workshop with programme managers & ILEP experts in 2009.	HC		

<i>Activity Advice requested by Members</i>	<i>Freque ncy</i>	<i>Product</i>	<i>Working Method</i>	<i>Lead member</i>	<i>Date due</i>	<i>Present status/notes</i>
4. Implementation of community based rehabilitation guidelines.	Cont.	Guidance on Improving coverage, quality and impact of CBR. Follow-up of recommendations.	Workshop in Bangkok linked to New WHO CBR guidelines in December 2008 with DAR.	SD		
<b>3. RESEARCH AND DEVELOPMENT</b>						
1.Synthesis of research findings for implementation and development of research strategy based on priority research questions including chemotherapy.	Once	Synthesis of current research and new research strategy. Implementation of research findings.	Identify key questions. Systematic review of evidence. Forum for evidence-based leprosy policy and practice in 2009.	WCS		
2. Advise ILEP on use of new methods of early diagnosis of leprosy and sub-clinical infection.	Cont.	Advice on application of new methods.	Liaise with IDEAL project on standardisation of methods.	WCS		
3. Support the develop of research in reactions and nerve damage based on recommendations of neurology workshop in 2007.	Cont.	Support and advocacy for research in reactions and nerve damage.	Work within ITC.	WvB/ DL		
<b>4. STIGMA</b>						
1. Identify research needs and develop best practice in the measurement and interventions to reduce stigma including the role of counselling.	Cont.	Recommendations on measurement of stigma and best practice for interventions.	TEG.	WvB		
<b>5. LIAISE WITH ILEP MEMBERS</b>						
Liaise with ILEP Members through ILEP Forum and e-mail to review programme of work in light of emerging issues.		Revise programme of work after e-mail consultation with Forum in 2010.	Continuing communication with Members. E-mail circulation of Forum members at mid-point (2010).	WCS		