



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

234 Blythe Road
London, W14 0HJ, UK

Tel: +44 (0)20 7602 6925
Fax: +44 (0)20 7371 1621
E-mail: ilep@ilep.org.uk
Web site: www.ilep.org.uk

7th Meeting of the ILEP Technical Commission

Tuesday 3rd October 2006

London, UK

MINUTES

In the Chair: Dr Pieter Feenstra (PF)

Present: Dr Guido Groenen (GG), Mr Ernst Hisch (EH),
Professor Baohong Ji (BJ), Dr Padebattu Krishnamurthy (PK),
Dr Diana Lockwood (DL), Dr Paul Saunderson (PS)
Dr Vijay Pannikar (VP), Team Leader, Global Leprosy
Programme, World Health Organization (WHO)

Secretariat: Ms Susan Lord (SL), Mr Doug Soutar (DS)
Mr Andrew Clark (AC)

The Chair welcomed everyone to the Meeting. Dr Montserrat Pérez (MP) had advised the Secretary of her absence.
The Chair mentioned that SL will be leaving ILEP at the end of the year, and thanked her for her work with the Commission. He suggested that DS take over the role as Secretary to the Technical Commission as an experiment for a year.
It was agreed that Dr Pannikar should no longer be designated as a guest at these meetings.

1. Approval of the Agenda

The Agenda was approved with minor additions.

2. Points arising from the Minutes of the previous Meeting

No points were raised.

3. Follow-up of Action Points arising from the Minutes of the previous 5th and 6th Meetings

As the action points of the 5th Meeting had not been addressed at the 6th Meeting due to its extraordinary nature, action points from both previous meetings were addressed.

Action points that had been completed and did not require further action were not discussed. Those action points that required further discussion, and fell within the ITC Programme of Work, were deferred to be discussed at the appropriate point in the Agenda.

The following points from the 5th meeting were included for information only:

Item 3 Advice from the ITC to TLMI on the place of pentoxifylline in the management of ENL.

The ITC advised that pentoxifylline may potentially be useful in the management of ENL, but that there is currently very little data on its use as only a few small studies have been conducted with limited documentation of the outcomes. A much larger prospective study is required with larger patient numbers, and better measurement of outcomes before any further recommendation can be made.

Item 4.9.2 Advice from the ITC and response from NLR on the Lateral Flow Test.

The ITC advised that based on current scientific results, it is premature to consider the application of the ML Flow test as a tool for leprosy control programs. Full endorsement of the follow-up of contacts in Brazil and Nepal was given.

The following point from the 5th meeting minutes was discussed:

Item 4.9.4.a Recommendation sought by the INFIR group for ILEP to fund an International Workshop on Neurological Aspects of Leprosy.

The ITC provided advice on this project in the form of a letter from PS to Dr Wim van Brakel. Dr van Brakel has responded by submitting a fuller proposal. However, the meeting felt that the original concerns of the ITC had not been adequately addressed, namely, 1) that an ILEP Member should be approached first as sponsor of the meeting and 2) that the workshop should go further than simply producing a report on neuropathology in leprosy and its implication for the treatment of nerve damage. The group concluded that the ITC response to the current proposal should include a recommendation that in addition to the need to address the two points mentioned above, an organising committee should be appointed to produce clear objectives for the workshop and to set the criteria for whom should be invited.

It was noted that this workshop and the meeting on Reactions in Leprosy, which is being organised by WHO and the Blue Peter Research Centre in Hyderabad for February 2007, should be closely coordinated.

Action point:

SL on behalf of the Chair to write to Dr Wim van Brakel (done)

4. Update of Plan of Work (see Appendix 1)

4.3 Appropriate strategies for treatment

4.3.1 Review evidence on MB relapse rates after MDT, particularly after 12 month MDT

It was agreed to keep the Discussion Document on *Review of evidence on MB relapse rate after MDT*, prepared by BJ, posted on the ILEP website.

4.4 Prevention of Disability

4.4.1 Produce guidelines on POD including advice on organisation of self-care groups

Learning Guide Four: Prevention of Disability in Leprosy by Hugh Cross, Margaret Mahato and Paul Saunderson.

PS and DS described how the post Cebu Guidelines is more straightforward and user-friendly than the previous version, although few changes have been made other than the addition of a foreword prepared by DS. It was agreed that plans to include the full Consensus Statement should be changed, and that reference to the full statement in *Leprosy Review* would be sufficient with a summary of the Statement included as an Annex in the Guide. The Learning Guide will be published later this year. Concern was expressed that the current response of a printing requirement of hundreds rather than thousands was disappointing and not reflective of the need, and that the Membership should be alerted to this point. (This point was mentioned to the Members at the feedback session held the following day).

Action point:

DS to amend the forward of the Guide in line with the ITC advice, and proceed to publication.

DS to check printing requirements with Members.

4.5 Community Based Rehabilitation/SER

4.5.1 Produce guidelines on how to assess the impact of CBR, including review of B3 indicators. Explore and promote the involvement of people affected by leprosy.

EH reported on the progress being made by the CBR-TEG towards the provision of the requested guidelines. Two

initiatives are underway that will provide the basis of the guidelines 1) a chapter on *Monitoring and Evaluation* for the WHO, ILA, UNESCO Guidelines on CBR and 2) NGO-IDEAS, a cooperation of 32 Indian and 14 German NGOs with a main focus on identifying and improving NGO tools for impact monitoring and evaluation, specifically in the area of savings and credit.

The 8-page chapter on leprosy for inclusion in the WHO CBR Guidelines has been completed by the CBR-TEG.

The CBR-TEG requested that a formal letter be written by the General Secretary to Dr Federico Montero, Head of the Disability and Rehabilitation Group at WHO, supporting the current collaboration with WHO within the ILEP CBR-TEG, and expressing enthusiasm for future collaborations. The ITC approved this request.

The CBR-TEG had recommended holding a consensus meeting on CBR and Dr Wim van Brakel and Mr Chapal Khasnabis had put forward alternate proposals for holding the meeting in the course of 2007. The ITC agreed that the preparation required to organise a consensus meeting is immense, and that this is not something that can be arranged quickly. Therefore, such a meeting at TATCOT in Tanzania, as proposed by Mr Khasnabis or indeed a meeting in Europe before 2008 as proposed by Dr van Brakel, can not be supported. This will be an issue that the CBR-TEG will discuss further.

Action points:

The General Secretary to write to Dr Federico Montero

SL to convey decision of the ITC concerning a CBR consensus meeting to Chapal Khasnabis and Wim van Brakel.

4.5.2 Provide advice at field level on how to meet the needs of people affected by leprosy through CBR

The content of the ILEP CBR Guide, which is expected to be officially approved by the WHO, has been agreed upon by the WHO-DAR and the ILEP CBR editorial group. Final editing is now underway to be followed by the WHO approval process. It is expected that the Guide will be published in February 2007.

Action point:

SL to arrange the further edits, prepare camera ready copy, and submit to WHO for approval.

4.6 Health Education/IEC

4.6.1 Review the evidence for effective IEC and identify appropriate methods, if possible giving advice on training methods in this field.

PS reported that he has reduced his expectation of the

output for this task, and recommends that a literature review should be sufficient to provide appropriate advice to the Members as there is a lot of material on this topic in fields other than leprosy that can be transposed into the leprosy context. Where possible, evidence-based information will be provided. It was acknowledged that ILEP Members have substantial budgets for IEC and advice by the ITC on this area of work would be greatly appreciated.

Action point:

PS to instigate a literature review.

4.7 Training, and Teaching and Learning Materials

4.7.1 Collect information and prepare a resource on existing training and learning resources

The draft of the Grid of Essential Texts, previously prepared for collating information, was reviewed again, and it was agreed that reference to the Operational Guidelines should be added. Further suggestions are required for specific book chapters, rather than entire books, to cover some subjects; ideally, these chapters will be hosted on the ILEP website or be hyperlinked to a location where the chapter can be found. It was agreed that the Grid will be posted on the website, requesting suggested input.

Information concerning the amount of visitors to specific publications on the website was presented. The Commission concluded that the website statistics is interesting information and requested that the Secretariat circulate this to them periodically. They also recommended that a search facility be added to the website if possible.

Action points:

AC to circulate website statistics and to investigate the provision of the search facility.

SL to add Operational Guidelines to the grid and post the grid on the website.

4.7.2 Identify any gaps in this information and ascertain whether there is a need for these to be filled. Develop a framework to meet these needs.

GG/SL presented feedback from their investigation into the perceived need for a new or revised textbook. It was decided that there is no clear need for a new or revised textbook and that sufficient teaching and learning material exists, but that efforts are required to promote the use and adaptation of this material.

4.8 Organisation and Quality of Services

4.8.1 Advise on effective leprosy control

As the Discussion Document on Urban Leprosy continues to receive an average of 50 visitors per month, it was decided to keep the document on the website even though no feedback is currently being received.

4.9 Research

4.9.1 Inform ILEP Members and field workers on outcomes and implications of important research

It had been suggested at a previous meeting that a 500-word description of recent research results that have implications for the field be included in *Leprosy Review*. However, it was now thought that this was not such a good idea and that guest editorials covering specific topics would be a better approach. Dr Paul Fine is writing an editorial for the December issue on the latest WHO statistics. DL asked for suggestions from the group for topics/authors.

Action point:

ITC to suggest topics for editorials.

4.10 Miscellaneous

4.10.1 Develop and apply systems to monitor the use of ILEP publications

SL reported that she had not been able to obtain more completed questionnaires, which had been prepared to monitor the use of publications in the field. The ITC agreed that expensive and sophisticated approaches would be required to complete this task, and that this falls outside the resource capability of the ITC.

5. Issues related to the Collaboration between ILEP and WHO

It was agreed that it is important to show that ILEP and WHO are working well together, and that Members should emphasise this point to their programme managers.

The next WHO TAG meeting is to be held in Myanmar in October 2007 and will be a combined TAG/ITC meeting. The TAG and ITC will meet together for two days followed by a 1 day meeting of each group separately.

Joint visits of WHO and ILEP are taking place i.e. BJ and WHO in Madagascar, DS and WHO in Maputo, PF and WHO in Indonesia and will continue in 2007.

5.1 Next steps Operational Guidelines

VP explained that the Guidelines are not static, and that feedback will be reviewed and an update will be prepared in 2008 if necessary.

The important point is for the Guidelines to be implemented and to feed into national programmes wherever possible. It has been suggested that courses might be run at ALERT to facilitate this process, although the formulation of the programmes themselves should be done at country level. It was mentioned that Nigeria has already integrated parts of the Guidelines into their National Manual. VP mentioned that a new management module for national programme managers based on the new WHO Strategy and Guidelines is being proposed; this module would be along the same lines of the 1990 WHO modules prepared with KIT. It is hoped that the module will be completed by mid 2007 and that about 12 workshops in different countries will be held between 2007 and 2009.

5.2 Coordination of data collection

A previous meeting of the ITC recommended that ILEP and WHO coordinate their data collection.

AC gave a brief overview of the reasons why ILEP has historically collected data, namely, 1) to give an overview of what each Member does and 2) to gain an epidemiological overview. He has recently visited Members to discuss their information and coordination requirements and reported that some Members have concerns about the quality of the national data and would therefore prefer ILEP to continue collecting their own data.

The ITC suggested that ILEP should work towards strengthening, and possibly monitoring, the National data to improve its quality, and that the ILEP B forms should no longer be used.

The General Secretary put forward his proposal for a TEG to develop a simplified ILEP A form, and a rationalised ILEP B form. The ITC advised that the TEG should report directly to the Board since the TOR are beyond the remit of the ITC. The Chair requested that if a TEG is approved by the Board, PK be included in the group.

The ITC discussed the incredible drop in case detection in India from 617,993 in 2001 to 161,457 in 2005 and concluded that it cannot be attributed primarily to similar drops in incidence/transmission, and that therefore the major explanation can be operational factors and "manipulation" of case definitions and data. There are examples of how this has been done, but these are mostly anecdotal with sources reluctant to be put on the record. It was accepted that it is difficult for ILEP to comment on this situation as ILEP has been blamed for wanting to keep case detection numbers high for fundraising purposes. The proposed editorial by Professor Fine (see 4.9) was warmly welcomed by the ITC in this regard.

5.3 Report from WHO AFRO Meeting in Maputo 22nd – 24th August, 2006

The General Secretary mentioned the positive action of the organisers postponing the meeting and amending the Agenda so that the Operational Guidelines could be discussed. The Meeting recommended that the main principle of leprosy control should be based on timely detection of new cases and their treatment and that sustained effort is required by everybody for implementation of the Guidelines.

5.4 WHO initiatives

VP described the Special Support to Extraordinary Circumstances (SSEC), which is a fund earmarked for difficult-to-reach areas where special actions are required for leprosy work. A complex proposal is not required to obtain funding from the SSEC. VP encouraged Members to come forward with proposals, and the ITC endorsed this.

A WHO workshop will be held this November in Agra on *Rifampicin Resistance in Leprosy*.

6. Other Issues

6.1 Report on progress of the International Leprosy Congress (ILC), including the role of the International Leprosy Association (ILA)

The Chair circulated a flyer for the Congress and expressed his dissatisfaction with the continued use of the concept of elimination, which was in contradiction to the directive of the new WHO Strategy and Operational Guidelines. In addition, it was reported that it had been pointed out to Dr Noordeen by an ILA Officer that occupying the position of Chair of both the Congress Organizing Committee and the Scientific Committee was somewhat irregular and broke with the long-established tradition of the Congress; Dr Noordeen's reply was that he had been persuaded by others to take on both of these roles. The Chair advised that Dr. Noordeen was widely perceived and reported to be strongly pursuing the continuation of elimination targets. Given this fact, it was considered that if the ILA President were to chair both the ILC Organizing Committee **and** the Scientific Committee, there would be a risk that the ILC may be used to promote continuation of sub-national elimination targets. It was noted that this of course, would be against the ILEP endorsed WHO Global Strategy and indeed would not fit with the resolution adopted by the General Assembly of the ILA during its meeting on 9th August, 2002, at Salvador, Brazil.

Under these circumstances, it was therefore agreed that the three members of the ILC Scientific Committee who are also ITC members, send a letter to Dr Noordeen stating that they want to see at the Congress 1) the goals of the Operational Guidelines and the conclusions of the ILA Technical Forum promoted and upheld, 2) that prevalence-based elimination targets should not be promoted and, 3) that an alternative Chair of the Scientific Committee be appointed. If these points were found to be unacceptable to Dr Noordeen, the ITC thought it would be inappropriate to recommend to Members that they support the Congress by sponsoring attendees and continuing to help with the planning of the Congress.

6.2 ILEP/INFOLEP collaboration

A proposal was presented by the General Secretary to form a small TEG to consider the closer, improved and rationalised collaboration between ILEP and INFOLEP. The ITC agreed that this would be a useful exercise, but that this is really a matter for the Board to approve.

6.3 Scheduled review of ITC

The General Secretary mentioned that an evaluative review of the current ITC would be undertaken in 2007 in order to plan for the next Commission. He suggested that the Technical Forum, usually held after the new ITC was appointed, be brought forward to March 2007 so that feedback from Members as to what advice they require could inform the selection of members of the new ITC.

However, the ITC thought that the Technical Forum should take place, as previously, shortly after the formation of the new ITC as this has worked well for the current ITC. The Forum will therefore take place early in 2008, with the new ITC being appointed in September 2007, and beginning their term in January 2008.

7. Any other business

VP mentioned that ILEP should actively ensure that training in leprosy is maintained.

8. Date and place of next meeting

The next meeting will take place on March 28th, to begin at 2pm to give time for people to travel in the morning, and the whole day of the 29th. A joint meeting of the ITC and the WHO-TAG will take place in October in Mandalay, followed by a separate meeting of the ITC.

Document distribution:

ITC (Dr Pieter Feenstra, Dr Diana Lockwood, Prof. Baohong Ji, Dr Paul Saunderson, Ernst Hisch, Dr P Krishnamurthy, Dr Montserrat Pérez, Dr Guido Groenen, Dr Vijaykumar Pannikar);
ILEP Board; and
ILEP Representatives