



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

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10th Meeting of the ILEP Technical Commission

Wednesday 5 December 2007

London, United Kingdom

MINUTES

In the Chair: Prof Cairns Smith (CS)

Present: Dr Paul Saunderson (PS), Prof Diana Lockwood (DL), Dr Etienne Declerq (ED), Dr Wim van Brakel (WvB), Dr Sunil Deepak (SD), Dr Augustin Guédénon (AG) *via telephone*, Mr Douglas Soutar (DS), Mr Andrew Clark (AC), Ms Imogen Prickett (IP)

Apologies: Dr Hugh Cross (HC), Dr Vijay Pannikar (VP) *WHO Global Leprosy Programme*.

1. Approval of Agenda

The agenda was approved with the following additional agenda items added:

- 8.1 International Leprosy Congress
- 10.3 ILEP Training Catalogue pages (IP)
- 10.4 Leprosy Journals

2. Welcome and Introductions

The Chair welcomed participants to the first meeting of the new ITC at the beginning of their four-year term. The Chair asked participants for an indication of what they felt were the most important topics for this the meeting; it was agreed that an overview of the work of the previous Commission and issues which are still current, and the question of how to prepare for the Technical Forum were the two most important issues.

3. Orientation and role of the ITC

DS explained the process of appointing the new Commission. This Commission is the second ILEP Technical Commission, as the group was formerly called the ILEP Medical Commission and then ILEP Socio-Medical Commission. The new

Commission was appointed by the Board through consensus, which was useful in that it helped encourage Board Members to think about what the purpose and function of the ITC is. The new Commission Members were appointed on the basis of their skills as generalists; possessing both field experience and a particular area of expertise. The eight-members were appointed from a field of 16 potential candidates.

3.1 Process for the Technical Forum in March 2008

DS presented a summary of the format and expected outcomes of the Forum, referring to the document entitled 'What is a Technical Forum'. ILEP Members will be sent questionnaires in January asking them what they think are the priority issues for the ITC to focus on over the next four years. These responses as well as the outcomes of the WHO TAG meeting in early March will feed into the Forum. The Forum will take place on Wednesday 26 March, and the ITC will meet on Thursday 27 March to draw together all inputs and draft a Work Plan setting out their priorities for the four-year term. This draft will be presented to the ILEP Board on Friday 28 March.

With reference to the 'What is a Technical Forum?' document, WvB noted that POD is separate from CBR and should be added to the list of broad areas for discussion to 'set the scene' within leprosy.

N.B Please refer to agenda item 10.1 as further discussion on preparation for the Technical Forum was held later in the meeting.

3.2 Programme of work for the new ITC

The programme of work debated at the Technical Forum will also be defined by what the ITC Members themselves see as priorities or areas for the focus for the Commission and in this sense the questionnaire sent out to ILEP Members should include some guidance along the lines of priorities identified by the ITC. CS asked each Member to briefly highlight their priorities for the work of the Commission:

- Ensuring that leprosy remains on the agenda of governments and policy-makers. (ED)
- Ensuring that POD activities are effective, especially in integrated field programmes. (ED)
- Integration –there is a need to understand what is really happening as there is often a conflict between what is reported and what is observed during field visits. (SD)
- Exploring new technologies, such as email and the Internet – What positive impacts are they having on Leprosy work? To promote these technologies and understand them further. (SD)
- Recognising that POD is undertaken with all sorts of different groups outside of leprosy – How do we learn from examples of POD in other contexts? (SD)
- Research should be seen as a cross-cutting issue; it should be a component of and a continuous thread running through all the topics addressed by the ITC, instead of being viewed as something separate. (DL)
- POD should include the results of the Cebu conference. Appropriate technologies for control of nerve damage. (WvB)
- Identifying areas of common interest with other fields/disciplines; looking for areas where collaboration could occur. (WvB)
- Encouraging support and capacity building for Self-help groups and collaboration with other Disabled People's Organisations. It is important for leprosy affected people to have a voice at a national level and within the wider disabilities networks. (WvB)
- Looking at specific issues for low endemic countries especially how to sustain quality services (WvB)
- Data collection and analysis; collection of federation level data has been simplified. There is a role for the Commission to make comments on international and national level epidemiological data and provide some

analysis. (AC) Finding a standardised way of validating the data across WHO statistics is important as ILEP no longer collects this. (WvB)

- Ensuring political issues don't swamp the technical/evidence-based focus of the Commission. (DS)
- Ensuring that quality leprosy services are maintained at field level after elimination has been achieved, through continued sensitisation of health authorities and supporting the integration process. (AG)
- Ensuring sufficient and timely drug supply in the field. (AG)
- Providing support for training at relevant levels. (AG)

The Chair gave his input and summarised the issues of concern to ITC Members into main themes:

- **Research and development:** there are lots of interesting ideas, and there is a need to see some of these as innovations and challenges. Research should be viewed as a cross-cutting issue.
- **Sustainability:** maintaining leprosy services and keeping leprosy on the political agenda
- **Dissemination and Communication**
- **Quality and coverage of services**

4. Matters arising from the ITC and Board Meetings

DS presented an overview of the activities of the previous ITC as set out in the document 'ITC Plan of Work 2004-2008'. Discussion was held relating to many of the tasks of the previous ITC and how they might feed into the Technical Forum in March and the programme of work developed by the incoming ITC. Some of the topics discussed are as follows (others have been recorded under the relevant agenda point later in the minutes):

Monitoring of Epidemiological Trends: It was agreed that it was important to analyse data for the purposes of the Federation, and in order to make broad global comparisons. The ITC should work to facilitate and empower people to work on data collection and analysis in their own countries. It was suggested that independent commentary on WHO data could be included in the Leprosy Review. WvB noted that for Members it is important to be able to assess the validity of the data. It was suggested that indicators could be developed for this purpose.

Quality of Diagnosis: The ITC need to include activities in their work plan reflecting the quality of data and how this is monitored.

Appropriate strategies for treatment: Issues for the new ITC to address include relapse rates, rifampicin resistance and UMDT.

Prevention of Disability: It was agreed that the new ITC should now focus on dissemination and promotion of the guidance material already published. There is a need to ensure implementation, follow-up and training. One area for focus is advice on the organisation of self-care groups.

Health Education/IEC: As it is difficult to identify what is important in terms of IEC, this is not an area that the ITC is likely to focus on.

Training, Teaching and Learning materials: WvB suggested that a mechanism could be included on the ILEP website for users to leave feedback on materials.

Organisation and Quality of Services: It was agreed that the Discussion Document on Urban Leprosy Control should be left up on the ILEP website. There is no need to review the document unless it is raised as an issue.

Research: The ITC should broaden its ideas in this area and include operational and action research. Current challenges in research include the 'North-South debate' over who is and who should be leading and driving research. CS noted that support should be given in the form of investment, leadership and capacity building for 'Southern'-lead research. PS noted that it is important to reinforce to ILEP Members how important research is.

It was suggested that ILEP Members could be asked to talk about what they are doing in terms of research at the upcoming Technical Forum. This will increase Member's sense of ownership and raise awareness among Federation Members about what the current activities in research are.

Miscellaneous: The ILEP Secretariat should continue to monitor the use of technical publications, and the ITC should continue to provide technical guidance for the ILEP website.

Action: This discussion should be used to help shape the draft programme of work for the new ITC. ILEP Members will be asked to give a short presentation on their research activities at the Technical Forum in March

5. Updates on Technical Expert Groups (TEGs)

5.1 TEG CBR

The minutes of the last CBR TEG meeting and a progress report from Ernst Hisch, lead member of the CBR TEG, were included in the meeting documents and give an overview of the work of this group.

DS updated the meeting on CBR issues. He reported that the WHO/ILEP Technical Guide on CBR was almost completed and due to be printed within the next couple of weeks. DL reported that the next issue of the Leprosy Review will be focussed on CBR and it was suggested that it would be a good opportunity to write a brief review of the WHO/ILEP Technical Guide on CBR to coincide with the launch of this publication. DL will liaise with Huib Cornielje regarding this task. A pre-congress workshop on CBR will be held before the ILC in Hyderabad in January 2008.

WvB raised the issue of the ITC contributing to the drafting of the WHO World Disability Report. The report is being put together on a chapter by chapter basis and it was suggested that a more formal approach to the subject is needed.

It was agreed that the ITC should focus on follow-up and development of the tools created by the last Commission (namely the WHO/ILEP Technical Guide on CBR).

Action: DL will follow up with Huib Cornielje regarding including information about the WHO/ILEP CBR Guide in the next Leprosy Review. WvB will approach WHO DAR and chapter authors individually to see how leprosy can be effectively included in the World Disability Report. It was agreed that as this group no longer has a clear mandate following the completion of the CBR Guide, it will be disbanded.

5.2 TEG Data and Data Collection

AC updated the group on the activities of the TEG and the revision of the ILEP Data collection forms. He reported that the former ILEP A and B questionnaires have been revised following the decision to cease collection of routine epidemiological field data. The Project Profile (formerly the A questionnaire) will collect basic information on the location, organisation and activities of each project. The ILEP Annual Project Report (formerly the B questionnaire) will collect information designed to show broadly the range of work ILEP Members are involved in and its impact. The Annual Project report will be sent shortly to ILEP Members to be completed for 2007 projects along with a short questionnaire asking for feedback on the new forms (*N.B these were sent on Friday 7 December*). This will be a transition year and 2008 is expected to be the first full reporting year.

DS noted that it is hoped that the new forms will continue to generate data which can be usefully analysed by the ITC. SD questioned how many people/Members actually use these forms.

Action: AC will undertake an analysis of data and form use and feed it back to the ITC. The TEG on Data and Data Collection will not continue as its function was to develop and disseminate the new forms; this task has now been completed.

5.3 TEG on Information (ILEP/Infolep collaboration)

AC updated the meeting on the activities of the TEG and the amalgamation of the ILEP and Infolep sites. The new site is at the design-stage at present and it is hoped that there will be something ready to show participants at the ILC, even if the site is not 'live' by then.

IP will be attending the ILC, and will be promoting and demonstrating the new site and the services provided by Infolep at the ILEP stand. Infolep are planning a brochure presenting information about the new site and its resources and services, which will also be available for distribution at the conference.

6. Teaching, training and learning materials

6.1 Grid of Essential Texts

The group were informed of the current status of the Grid which lists the most important leprosy texts for various audiences. DS recommended that the task of reviewing and upgrading this Grid will be ongoing for the ITC.

7. Issues related to collaboration between WHO and ILEP

DS reported that relations between ILEP and WHO have improved dramatically over the past four years, with ILEP re-entering official relations status with WHO. Staff from the WHO Global Leprosy Programme have participated in ITC meetings and it is hoped that they will continue to do so. The ITC also have an open invitation to attend TAG meetings so there is a great deal of collaboration. DS asked that the Secretariat be kept informed of all joint activities of ITC Members and WHO (including Geneva and all regional offices) as this information is needed for the purposes of reporting back to WHO.

7.1 WHO TAG Meeting

Following the cancellation of the TAG meeting in Burma/Myanmar, the next meeting is now scheduled to take place in Cairo in March 2008, and will focus on Human

Rights and stigma issues. There may be an opportunity for the ITC to input into the agenda of this meeting.

It was agreed that it is not necessary for all ITC Members to be present at all TAG meetings. CS and PS are members of the TAG already and the ITC should aim to have two representatives attending each TAG meeting according to their experience relative to the theme or focus of each meeting.

Action: DS will discuss the nature of ITC involvement in future TAG meetings with Dr Vijay Pannikar of WHO Global Leprosy Programme.

7.2 Progress on training for the Operational Guidelines

WvB reported that ten countries have agreed to send participants to take part in training on the implementation of the Operational Guidelines which is to be held in ALERT, Ethiopia. Ten people have also been invited to act as observers, including Dr Leide of the Government of Brazil and Dr Joshi of the Government of India.

It was agreed that the training programme has been prepared to a high standard and detail and the ITC extend its compliments to those who worked on this project.

8. Meetings Update

8.1 International Leprosy Congress, India

PS and DL reported on the progress of organisation and planning for the Congress. The ITC discussed the participation of the ITC in the Congress and received information on the ILA.

Action: CS will circulate notes on his presentation to the First Plenary Session of the ILC to ITC Members for their information and feedback. WvB will write to ILA Council Members supporting the suggestion that ILEP and the Global Leprosy Programme be included in the invitation to give key note addresses to the Inaugural Session of the ILC.

8.2 Report on Workshop on 'Monitoring and Evaluation of Epidemiology in the Post-Elimination Era', India.

DS reported on the workshop and concluded that this was a very positive step for India.

9. Research Update

9.1 Research priorities and current opportunities

CS presented his paper which was written to inform the EU on the current situation within research on Leprosy. WvB noted that stigma and Human Rights are points not well covered in the paper, which CS acknowledged. The group discussed whether the ITC should be proactively promoting initiatives which need to be continued with funding. CS raised the issue of whether the term 'research' should be widened to 'research and development', and asked if this describes this field more successfully. It was felt that this was not an option since there may be too much confusion over the meaning of the word 'development'.

WvB mentioned a grid developed by NLR dealing with promoting research priorities. This may be something useful for the ITC.

Action: NLR will be asked to give a presentation on their research activities at the Technical Forum, including an overview of the grid which they have developed.

10. Any Other Business

10.1 Preparation for the Technical Forum in March 2008

The Chair asked the group for further ideas for the Technical Forum at the end of the meeting. The following issues were raised: implementation of training materials; promotion of the ILEP website and Infolep; and an overview of training and technical guidance available from Members.

At the beginning of the Forum the ITC Members will make presentations of ten minutes each in order to 'set the scene', mapping out the achievements of the previous ITC and the challenges ahead. ITC Members will be responsible for the following topics:

- Overview of the trends in the latest data – Cairns Smith and Vijay Pannikar
- Promotion of the Global Strategy and collaboration with WHO – Vijay Pannikar
- Research issues – Diana Lockwood
- Socio-economic and CBR issues – Sunil Deepak
- Sustainability of integrated leprosy services– Etienne Declerq
- Training issues – Paul Saunderson and Augustin Guédéon
- Stigma and Disability – Wim van Brakel
- Prevention of Disability – Hugh Cross

Action: ITC Members will prepare their presentations ahead of the Technical Forum in March 2008. The Secretariat will write to ILEP Members in January 2008, asking them to decide on three key points to bring to the Forum. The Secretariat will draft a Forum agenda, and formulate a list of the contact details of ITC Members for circulation among the group.

10.2 Clofazimine and MDT Supply

AG explained that in the field there are often situations where there are no drugs available in the region or district. ED reported that in the Congo, supply is also an issue as the number of detected cases has increased in recent years due to the cessation of conflict. In some cases orders have been 'corrected' in order to decrease the numbers of recorded cases. DS outlined the ongoing issues of drug supply that the Secretariat has been made aware of. Although MDT and Clofazimine are available from WHO free of cost, some ILEP Members have purchased their own supplies in order ensure availability in the field. WHO maintain that it is the responsibility of National Programme Managers to plan ahead and request MDT and Clofazimine supplies from WHO in advance. It was noted that the issue of management, supply, control and distribution is covered in the training modules for the Operational Guidelines. It was agreed that ILEP Members should work closely with Government counterparts on this issue.

10.3 Training Catalogue information pages

IP informed the meeting that guidance from the ITC on important technical resources has previously been included at the back of the Training Catalogue. It was agreed that the Grid of Essential Texts should be included from now on.

Action: IP will update the Training Catalogue to include the Grid of Essential Texts

10.4 Leprosy Journals

Before all the participants of the meeting had arrived, a short discussion took place regarding the different Leprosy-related journals and their geographical/linguistic coverage. As a result of this discussion it was suggested that DL as the editor of Leprosy Review would contact the editors of the French Leprosy Bulletin to offer Leprosy Review articles for publication in French. It was also suggested that a list of journals, similar to that recently published on the Noto Leprosy Mailing List, should be included for reference purposes on the ILEP website.

Action: These suggestions will be followed up by DL and the Secretariat.

11. Next Meeting

The next ITC Meeting will be held on Thursday 27 March 2008, following the Technical Forum the previous day.

Acronyms used in this report:

CBR: Community Based Rehabilitation
DAR: Disability and Rehabilitation (a unit of WHO)
EU: European Union
IEC: Information Education Communication
ILA: International Leprosy Association
ILC: International Leprosy Congress
ILEP: International Federation of Anti-Leprosy Associations
ITC: ILEP Technical Commission
NLR: Netherlands Leprosy Relief
MDT: Multi-Drug Therapy
POD: Prevention of Disability
TAG: Technical Advisory Group (WHO)
TEG: Technical Expert Group
WHO: World Health Organisation