



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

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8th Meeting of the ILEP Technical Commission

Wednesday 28 -Thursday 29 March 2007

London, United Kingdom

MINUTES

In the Chair: Dr Pieter Feenstra (PF)

Present: Dr Guido Groenen (GG), Professor Baohong Ji (BJ), Dr Padebattu Krishnamurthy (PK), Dr Diana Lockwood (DL), Dr Paul Saunderson (PS), Dr Myo Thet Htoon (MH) *WHO Global Leprosy Programme*, Mr Douglas Soutar (DS), Mr Andrew Clark (AC), Ms Imogen Prickett (IP)

Guest: Professor Hazel Dockrell (HD) *IDEAL Consortium*

Apologies: Dr Ernst Hisch (EH), Dr Monserrat Pérez (MP)

1. Approval of Agenda

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

9.5 Chemoprophylaxis Workshop

13. AOB

14. Next Meeting

2. Points Arising from the Minutes of the Previous Meeting

No points were raised

3. POD

3.1 It was reported that Learning Guide 4 has now been printed. 1,600 copies have been printed and 1,423 copies have been distributed to Members. The French version is with AFRF, and AIFO usually takes on translation of publications into Portuguese. It is ILEP's role to print and distribute the Guide but the responsibility of Members and local users to promote appropriate use of the Guide according to the local context. In this regard, there is a role for ILEP Country Representatives to promote the appropriate use of the Guide.

Action: The Secretariat will follow up on translations of the POD guide into French and Portuguese.

4. CBR

4.1 EH's report on the progress of the TEG on CBR was discussed. The ITC approved the proposal to submit to the TEG on CBR for discussion and recommendation:

- the method employed by members of the NGO-IDEAs in a study to identify and improve NGO-specific tools to monitor and evaluate the impact of projects (See: <http://www.ngo-ideas.net/>); and

- The framework proposed by Cornielje and Velema to gain a better understanding of rehabilitation programmes and of their evaluation (See: Disability and Rehabilitation, 2003 ; Vol. 25, No. 22, 1252-1264).

The Commission agreed that it is important to include a person with real expertise in CBR in the next ITC.

The World Disability Report was discussed. The ITC is sympathetic towards the issue of collecting information to 'measure' the level and burden of disability and the publication of a report, and feels it should be developed, but without a firm proposal it is difficult to endorse at this stage.

4.2 With regards to the CBR Guide Publication, a letter was received from Federico Montero at WHO (the letter was written in the beginning of February but only just arrived) stating that they were willing to go ahead and publish the Guide but were having problems getting the \$45,000 needed to do this. This was surprising and concerning to the ITC as the original budget was estimated at around £4-5000 to print 2000 copies.

Action: The Secretariat will continue follow up on the printing of the CBR Guide with WHO.

4.3 DS reported that, as requested in the last meeting, a letter was sent to Federico Montero, WHO expressing ILEP's satisfaction at the increased collaboration between ILEP and the Disability and Rehabilitation Team at WHO.

5. Health Education/IEC

5.1 The ITC agreed that the Terms of Reference were too ambitious in this area. PS's report was accepted, and it was agreed that this added as an appendix to Technical Bulletin #13 is sufficient in giving basic guidance at this stage

6. Training Teaching and Learning Materials

6.1 The Grid of Essential Texts was discussed. It was agreed that footnotes should be added to all titles with more explanation about their content. All major medical textbooks (e.g. The Oxford Dictionary of Medicine, and major textbooks on infectious diseases) should be added to the Grid with reference to the appropriate chapter/section. IP reported that a request was recently made via Salvatore Noto's list for specific articles or chapters to be suggested for addition to Grid.

Action: IP will continue to update the Grid and work to improve the format for ease of reading/printing on ILEP website. DL will assist IP to include a list of major reference and textbooks.

The current format of the Training Catalogue will be maintained.

6. 2 Statistics on the use of the ILEP website, including most downloaded items, were presented for general information.

6. 3 It was agreed that regular full review of teaching and training materials should be conducted once during each ITC term (four years) in cooperation with WHO. The review should be written into the Work Plan of each ITC. This ongoing process will help to identify any gaps and to address these.

7. Research

7. 1 It was agreed that the current ITC has fulfilled its role in terms of research, which was to identify and inform ILEP Members about research gaps and needs. There is no new action or initiative required by the ITC at this stage. The continuous ongoing review of research and identification of research priorities should remain on the ITC Work Plan as a bi-annual watching brief.

It was suggested that the next research topic for the annual ILEP co-operation meeting could be on the training for operational research, being conducted by NLR.

7.2 Possible topics for articles in *Leprosy Review* and *PLoS Journal on Neglected Tropical Diseases* were discussed. DL is happy to receive suggestions for both journals as she sits on their Editorial Boards. Suggested topics included: Reflections by Indian experts on the India data following the elimination target, Vaccines – including possible TB vaccines and their potential impact on leprosy, Key issues in disability.

7. 3 On the invitation of the ITC, Prof Hazel Dockrell of the IDEAL Consortium gave a presentation on the structure, aims and activities of IDEAL. The Commission feel this is an excellent initiative and a good example of a group of motivated researchers working together sharing common protocols and definitions. The ITC supports the initiative and recommends that if approached, ILEP Members should in principle be interested in co-financing such an endeavour.

8. ILEP/WHO

8.1 This item was moved to agenda point 11.

8. 2 ILEP and WHO have had positive experiences in the past regarding joint visits. The WHO Global Leprosy Programme is interested in joining any ILEP joint evaluation mission, should they be invited. The ITC encourages ILEP Members to be proactive on this.

Discussion was held regarding Regional Meetings. Following on from the positive experience with input into planning and attendance at the AFRO meeting last year, the ITC wishes to continue this collaboration. ILEP are not just funders but partners with Governments and WHO, and as such they should be involved with organising and planning meetings.

8.3 DS reported that ILEP has been granted official relations status with WHO.

8. 4 MH reported on the training initiative for introducing National Managers to the Operational Guidelines which is being planned with support and funding from GLRA

and NLR. The training agenda will be circulated for comment in May, including to ITC members.

9. Meetings Update

The Commission were updated on important meetings which have taken place since the last meeting and which are upcoming.

10. Temporary Expert Groups

The Commission read and heard reports on the progress of the TEG on Information (ILEP/Infolep), and the TEG on Data and Data Collection. These were both endorsed.

10.1 The TEG on Information (ILEP/Infolep) includes staff from the Secretariat, from NLR (Infolep hosts) and an ITC representative (PS). The group have met twice and the smaller Working group will now look in more detail at what the integrated website will look like and how it will be structured. They will also begin to work with a web designer.

10.2 The TEG on Data and Data Collection has been engaged in looking at ILEP's data collection questionnaires. They are in the process of developing a set of revised and simplified indicators. It was agreed by the Commission that if ILEP needs any data additional to those routinely collected by the national health services, this should not be requested from programmes, but that ILEP should find ways and means to collect this independently.

11. Review of ITC – Structure, Activities and Outcomes 2004 - 2007.

The responses to the review were used as a basis for a discussion and comment by the Commission.

Although the results from the ratings grid (the first section of the review) were difficult to analyse as individual ITC and ILEP member responses are included together, the ratings given by respondents were positive overall.

The form of advice required by the ITC will be moving away from producing documents and publications towards focussing more on updating and maintaining the collection of materials already developed. The next phase will be more about how to implement this advice.

There is a need to continue to work closely and develop the working relationship between ITC and WHO to be even more collaborative and effective.

The ITC should continue to monitor epidemiological trends and provide comment and analysis. A focus on CBR and POD activities, as well as research, should be ensured.

One ILEP Member should be able to have more than one representative on the ITC. The current structure of the ITC in four 'clusters' should remain, including TEGs. 'Development' should be added to the areas of expertise under the Rehabilitation and Social Aspects cluster. Persons elected to the ITC should be generalists as well as having areas of specific expertise. They must have some knowledge of the field situation and of realities in the field. The current make-up of ITC is good in terms of the coverage of knowledge or expertise in a broad range of areas. However, the ITC could have been faster with calling on outside expertise in unfamiliar areas.

ITC activities, including travel and accommodation, should be financed by a budget administered by the Secretariat and contributed to by all Members.

Twice-yearly meetings should be maintained, and timed around ILEP Board Meetings and TAG Meetings where possible.

The New ITC

The ITC also discussed coming to the end of their term, the election of a new ITC and the proposed Technical Forum to set the agenda of work for the next four years.

It was agreed that it could be possible to conduct any remaining business via email and that this may be last meeting of the current ITC. However, as the Board must decide on meeting dates, the Chair asked members to keep 18-19 September 2007 free in the event they do need to meet in person again.

The new ITC should be elected at Board meetings in September 2007. Candidates should be informed in good time to keep meetings dates of the first meeting of the new Commission free. This meeting should take place as soon as possible after the election as the new ITC should preferably be functional as soon as possible after they are elected. The first meeting of the new ITC should take place before the TAG in Myanmar and the ILC in India in order to be prepared to feed into these meetings. At the Technical Forum in March 2008, the new ITC would then be able to draw on issues discussed at the TAG and ILC when formulating their Plan of Work.

Action: The Chair to report this to the Board during their discussion regarding meeting dates and the timing of handover to a new ITC.

12. Other Issues

12.1 DS presented an outline of the planned participation of ILEP in the upcoming ILC in Hyderabad in January 2008, which was supported by the ITC.

12.2 The issues around HIV/Leprosy and Immune Reconstitution Inflammatory Syndrome (IRIS) were discussed. There is currently very little knowledge in this area and urgent research funding is needed. ILEP Members should be willing to consider supporting research in this field.

13. A.O.B

The issue of clofazimine supply was raised. There is currently not enough clofazimine available to treat reactions in Brazil, and supply problems in other parts of the world have also been reported. The issue is in organising and planning stocks in advance for timely procurement and supply through WHO. National Programme managers are responsible for this.

14. Next Meeting

During the Board Meeting of 30 March it was decided that there will be a meeting of the current ITC on the morning of Wednesday 19 September, with co-operation meetings starting that afternoon. On Thursday 20 September, co-operation meetings will continue and there will be time for bilateral meetings that afternoon. The ILEP Board Meeting will be held on Friday 21 September.

Acronyms used in this report:

ILEP: International Federation of Anti-Leprosy Associations

ITC: ILEP Technical Commission

IDEAL: Initiative for Diagnostic and Epidemiological Assays for Leprosy

POD: Prevention of Disability

AFRF: Association Française Raoul Follereau

AIFO: Associazione Italiana Amici di Raoul Follereau

CBR: Community Based Rehabilitation

TEG: Technical Expert Group

WHO: World Health Organisation

IEC: Information Education Communication

NLR: Netherlands Leprosy Relief

PLoS: Public Library of Science

GLRA: German Leprosy Relief and Tuberculosis Association

AFRO: WHO Regional Office for Africa

WHO-TAG: Technical Advisory Group

ILC: International Leprosy Congress

IRIS: Immune Reconstitution Inflammatory Syndrome