



Fédération Internationale des Associations contre la lèpre
International Federation of Anti-Leprosy Associations
Internationale Vereinigung der Leprahilfswerke

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1st Meeting of the ILEP Technical Commission

Thursday February 19th 2004

Irish Centre, London

MINUTES

Chair ad interim: Dr Pieter Feenstra

Present: Dr Guido Groenen, Mr Ernst Hisch, Prof. Baohong Ji, Dr Padebattu Krishnamurthy, Dr Diana Lockwood, Dr Montserrat Pérez, Dr Paul Saunderson

Secretariat: Mr Andrew Clark

Secretary: Ms Penny Holzmann

Dr Feenstra opened the meeting and welcomed everyone onto the Commission. Participants each gave a brief introduction. Dr Feenstra expressed pleasure at the wide range of expertise and wealth of experience that was represented, and in particular at the election of the two female members. It was noted that Commission members participate in an individual capacity, advising according to their technical expertise rather than the policy of their parent organisations.

1. Approval of the agenda

The agenda was approved.

2. Responsibilities, tasks and procedures of the ITC

Dr Feenstra referred to the *Extract from ILEP Bye-Laws*, and the *Proposal for the structure and functioning of the ITC*, which was approved by the Standing Committee in March 2003. He noted that these two documents give an idea of what others in ILEP expect from the ITC. He also referred members to other background documents, such as the job description of the ITC secretary, documents on the GAEL and the General Assembly minutes.

Andrew Clark described the way in which ILEP works as a federation, and how the ITC functions within that structure. The fundamental role of the ITC is to provide technical advice to ILEP Members, who can therefore suggest areas of advice for the ITC to focus on. In terms of reporting, the ITC reports to the Standing Committee, to which the ILEP federation delegates responsibility for decision making and action during the year. Policy decisions have to be ratified by ILEP Members at the General Assembly.

On a day-to-day basis, the Chair of the ITC works through the Secretariat to report to the Standing Committee. The role of the Secretariat is to organise meetings and produce reports pertaining to ILEP projects and related activities. One member of the Secretariat – the ITC secretary – is appointed to the ITC, and s/he reports both to the General Secretary and to the ITC Chair. Work given to the Secretariat passes through the Chair, rather than coming directly from individual ITC members.

The ITC meets twice a year, in the week of the second Monday in June (in London) and December (when it is usually hosted by an ILEP Member). Meetings are linked to the Working Sessions and Mid-Year Meeting.

3. Discussion of minutes of MSC meeting in December 2003

The Commission discussed items from the minutes of the last MSC meeting which were not tabled as outstanding tasks for the ITC. These were as follows.

- **Training at ALERT:** It was noted that training at ALERT continues successfully, according to information received from GLRA. Dr Lockwood, having recently visited the ALERT training centre, reported that this is largely due to the determination of Drs Krishnan and Ruth, who receive little support in terms of secretarial or other assistance. Mr Hisch offered to discuss the issue of lack of support when he visits in October 2004.

As one of the outstanding tasks for the ITC is a review of international training in leprosy, it was suggested that the same sub-group could look into the form of support which ILEP could most effectively give ALERT.

- **Prevention of blindness in leprosy (Paul Courtright):** Dr Saunderson reported that production of this booklet by ALM was being pursued, with work still required on layout and photographs before printing.

Dr Feenstra noted that, in parallel to the ITC's role as facilitator for specialised publications such as this, one of the ITC's outstanding tasks is to review the 'basic materials' list, i.e. to identify gaps in the literature and where necessary to fill those gaps. It was also pointed out that specialised publications, or details of where they can be obtained, can be made available on ILEP's web site.

- **U-MDT research proposal:** Dr Feenstra described the background to the KIT/MoH Brazil/University of Brasilia proposal, which offers an alternative protocol to that of the WHO-sponsored trial for assessing the efficacy of a U-MDT 6-month regimen. ITC members were referred to a recent letter from Dr Klatser in which he responds to the recommendations made by the Temporary Expert Group (TEG) in January 2004.

The Commission discussed how the proposal should best proceed. It was noted that the Commission had agreed at the last MSC meeting that it should not involve itself with the funding, monitoring or supervision of specific research proposals, other than through the provision of general comments. As the Commission had now done this, it was felt that the proposal should now proceed through the usual channels, and should be submitted to potentially interested ILEP Members. It was suggested that the TEG report, and Dr Klatser's response to it, could be included as supplementary documents alongside the proposal itself.

Action: The Chair will reply formally to Dr Klatser, explaining the ITC's position and advising him to submit the proposal to an ILEP Member.

- **MB-MDT correspondence:** The Commission discussed the concerns raised at the last MSC meeting that some countries were being pressurised to adopt a 12-month MDT regimen for all MB patients. The correspondence between Dr Feenstra and Dr Daumerie at WHO on the subject revealed that the programme managers at the MoH in Bangladesh and China have not experienced pressure from WHO to adopt the 12-month MDT treatment policy for MB cases by providing a supply that is only sufficient for 12 months of treatment.

The problem of obtaining loose clofazamine for individual patients outside programmes was also discussed, for example in the USA, for which clofazamine is supplied under licence by two companies in India and where it is difficult for patients to obtain it.

- **Accompanied-MDT (A-MDT):** Dr Krishnamurthy described a study in the state of Bihar, India which sought to look at the relative compliance for A-MDT compared to regular MDT. Bihar is an under-developed state which has a low ratio of health centres to population, and access to health centres is disrupted seasonally by flooding. Seven areas were randomly divided into two groups: one received A-MDT and the other

received regular MDT over 6 months. Both groups were given the same counselling. Patients were asked to keep all their empty blister packs so that consumption could be estimated at the end of the study.

For PB cases, all six packs had been consumed by about 80% of A-MDT patients, compared to about 50% of regular MDT patients. For MB cases, all six packs had been taken by about 80% of A-MDT patients, compared to about 60% of regular MDT patients.

The conclusions of the study were firstly that flexibility in the availability of MDT seemed to have a favourable impact on compliance in areas which have poor seasonal access, and secondly that counselling was found to be important in ensuring compliance.

The Commission discussed the study. It was noted that a regular programme would include a defaulter retrieval element which was absent from this programme. It was suggested that the results could be stratified for patients with relatively good access to acceptable quality health services and those with bad access to such services. The Commission concluded that it was an interesting study which confirmed that well-counselled patients in inaccessible areas comply well, but hoped that the results would not be generalised to imply that A-MDT could be recommended as the standard for treatment delivery in all circumstances.

- **Revised B form:** definitions have been drafted by the Secretariat to accord with the data items on the new B form and Commission members were invited to consider them.

Action: Commission members will submit comments on the proposed definitions to Dr Feenstra, who will then draft the final versions.

4. List of outstanding tasks

Dr Feenstra noted that the aim of the meeting is to identify those tasks of highest priority, and to allocate responsibility for each of these to one or more Commission members. He also pointed out that while every ITC member was elected according to a particular cluster, this does not necessarily mean that that member's activities should be limited to that cluster.

4-1 Standing invitation to WHO

Dr Feenstra described the basis of the standing invitation to WHO to MSC meetings, in that it was felt important that the door between the Commission and WHO should be kept open. He reported that Dr Endo had invited a representative of the ITC to the TAG meeting in February 2004 but that unfortunately it had not been possible for a representative to attend.

Members of the Commission stressed the importance of a bi-directional exchange of ideas and the need for consensus on technical advice for people working in the field. The Commission agreed that WHO should continue to be invited to its meetings.

4-2 Coverage indicator

This was identified as a pending issue that may require consultation with WHO and postponed to the next meeting

4-3 ILEP research information system

Action: Dr Lockwood and Dr Ji will formulate a proposal on this issue for the meeting in June 2004.

4-4 ILEP strategy

Commission members were invited to submit comments in an individual capacity on the document *Consultation of Members on the ILEP Strategic Review* to Dr Feenstra by 28th February 2004, who will then forward them directly to the General Secretary. (ITC members can also, or alternatively, respond through their parent organisations.) Responses will be discussed by the Standing Committee at their meeting in March 2004.

The Commission felt that the draft strategy document produced as a result of these consultations should be reviewed by the ITC on its technical content before completion and release.

The possibility of producing a position paper on the future of leprosy control was also considered. This would involve a review of current leprosy control activities, identification of the major challenges and the development of a future strategy, and would ideally be produced by the end of 2004. A combined meeting with WHO on this was suggested.

4-5 ILEP web site

Andrew Clark clarified the work involved in producing the proposed summary page on leprosy; the main work will be in drafting the page, and then updating it as necessary to include ongoing developments within the field.

Action: Dr Saunderson will draft a summary page, incorporating links to key sites, and email it to ITC members for comment.

4-6 Technical Bulletin on Urban Leprosy Control

Dr Feenstra described the background to the bulletin and the direction in which it was currently being revised by Dr Babu. The Commission felt that the draft would be rendered more substantial through the inclusion of examples of how problems specific to the urban environment were tackled in different situations. This could be presented according to the questions in the questionnaire.

Action: Dr Krishnamurthy will take responsibility for the production of the bulletin, with whatever support is necessary from the Chair.

4-7 Training, and teaching and learning materials

Dr Feenstra referred to the probable need for a TEG for the regular review of teaching and training materials and the importance of involvement of WHO in this activity.

Action: Dr Groenen will prepare a 'road map' and timetable for activities, to be presented at the ITC meeting in June 2004, incorporating the three issues of the development of a method for **reviewing teaching and learning materials, training in Francophone Africa** and a review of the **ILEP training catalogue**.

Wording for local adaptations: The idea of including a disclaimer in publications and translations was endorsed – this would state that the Commission can only endorse the original version in English. Such a disclaimer would give people in the field the freedom to use the material. Minor changes to the wording drafted by the Secretariat were accepted. The agreed text is as follows:

The original text of this publication is in English. Although ILEP is happy to make this available for local adaptations and other language translations, the ILEP Technical Commission can only endorse the original version. For more information contact ilep@ilep.org.uk.

4-8 Learning Guide 4 – SER Guidelines

Mr Hisch described the background to the SER guidelines. He expressed appreciation for the comments received so far. It was noted that in order to conform to the format of the first two learning guides, the text will need to be reduced by about 25%; the number of pages should be a maximum of 50. It will also need to be made more practical, and more suited to general health workers.

Action: Mr Hisch will take responsibility for the production of this guide, which will probably involve forming a small editorial group. The final draft should be sanctioned by the Commission, if possible in June 2004.

4-9 Learning Guide 5 – Prevention of Disability

Dr Saunderson referred to the decision of the last MSC meeting to develop this guide by drawing on materials that have already been produced for other programmes. He

reported that Hugh Cross and Margaret Mahato are ready to progress on producing a draft. He noted that it will be a simple guide, which will include the management of ulcers and will place great emphasis on self-care.

The Commission discussed the extent to which the guides are used. The role of ITC publications as reference material – i.e. to provide input into locally produced guides – was stressed, as was the desire to avoid producing material which is already available.

Action: Dr Saunderson will co-ordinate the production of this guide, with the aim of producing a first draft by June 2004.

4-10 Requirement for Prednipacs

With reference to the letter from Dr Yuasa of SMHF requesting an estimate of global requirements for Prednipacs, the Commission, agreeing that Prednisolone should be made available to trained field workers for treating reactions, discussed the relative advantages and disadvantages of Prednipacs versus loose Prednisolone, and the different ways in which the two forms of drug are regarded and administered in the field. The advantages of blister packs in terms of storage was acknowledged, and the increase in the number of patients who can be treated for reactions because of the availability of Prednipacs was welcomed, but a number of other points were raised:

- The way in which blister packs of different dosages are boxed together can sometimes cause confusion if a reaction has to be treated with a higher dosage available only from a new (and unopened) box.
- Blister packs can have a disempowering effect on patients liable to reactions, who in many cases tend to know how many Prednisolone they need to take. Disregarding this knowledge through the use of blister packs of a standard dosage takes away patients' sense of control over their own medication.
- In many cases, health workers tend to give a lower dose if Prednisolone is administered loosely.
- The differences in packaging, labelling and promotion mean that Prednipacs are sometimes seen as a quite different drug from Prednisolone, and that in some cases health workers reserve the former solely for leprosy reactions. Because of this, other conditions not related to leprosy which require steroids can remain untreated despite the availability of Prednipacs. This is also against the principle of integration.
- Training is very important in the administration of corticosteroids, whether in the form of blister packs or loose Prednisolone.

The need for operational research on the use of Prednipacs in different situations was suggested, and reference was made to the consultation of ILEP Members on drug supply issues carried out at the end of 2003 at the request of the Standing Committee.

Action:

- Dr Pérez will review the consultation document containing the responses of ILEP Members and see if any conclusions can be drawn from Members' replies on the adequacy of the current supply system and whether recommendations could be formulated to improve the system. The review should also incorporate advice on whether Prednisolone should be supplied as loose tablets or as Prednipacs, and how to estimate the requirements for Prednisolone/Prednipacs. Supply of clofazamine will also be considered, although it was not included as a specific question in the questionnaire. Dr Pérez will then formulate a proposal as to how to proceed, including the formulation of recommendations and advice as to whether further research is necessary
- Dr Feenstra will write a formal note to Dr Yuasa to say that the ITC is looking further into the Prednipacs issue.

4-11 Monitoring the impact of MSC publications

The Commission discussed the difficulties of assessing how ILEP's publications are used. A number of issues were raised, including the level to which different publications 'trickle down', the role of ILEP publications in national programmes, and the problems involved in collaboration. It was hoped that in the future, technical advice will be issued in collaboration with WHO.

It was suggested that a project be set up involving local medical students in different countries to look at how publications are used. A protocol could be developed involving the use of simple, observational methods.

Action: Dr Groenen will draw up a proposal for the meeting in June 2004, with support from Dr Lockwood.

Provision of drugs by Novartis

The question of the supply of MDT after 2005 was raised. It was reported that Novartis has, through WHO, announced a commitment to production until 2010.

5. Other proposals for future activities

Dr Saunderson suggested that ILEP should be present in some form at the workshops which TDR is co-ordinating on different topics (nerve damage and reactions; transmission and diagnostics; and integration). It was agreed that ITC members who do attend will not do so as representatives of the ITC, but will nevertheless be able to provide useful feedback to the Commission.

6. Organisation of Technical Forum in June 2004

The Commission discussed the agenda for the Forum, and allocated presentations to different ITC members (see Annex). The ITC will be meeting the day before the Forum and presentations will be discussed then. The aim of the presentations is to provide some background and to provoke debate on each of the topics. It was also agreed that ILEP Members will be asked for feedback on the MSC's performance from 2000-2003 by rating on a questionnaire the usefulness of each of the MSC's outputs.

7. ILEP relationships with WHO and other partners

The Commission agreed that dialogue with WHO should be maintained. It was noted that relationships with WHO staff in the field are in most cases excellent. The Commission reiterated its support for the recommendations of the GAEL report, and welcomed the idea that the Standing Committee be more proactive and forceful in its attempts to establish a new partnership with WHO and others. It acknowledged the efforts made by the ILEP President to get the issue of sustaining leprosy services beyond 2005 onto the WHA agenda for 2004/05.

Dr Saunderson gave some feedback from the TAG meeting, reporting that it was a positive and open meeting in which, for example, additional studies on U-MDT (further to the WHO-sponsored trial) were welcomed, and leprosy control strategies beyond 2005 discussed.

8. Election of chair

Dr Feenstra was elected as Chair.

9. Any other business

There was no other business.

10. Date and place of next meeting

The next ITC meeting will take place as follows:

Tuesday 8 th June	– full day's meeting to prepare for the Forum
Wednesday 9 th June	– Forum
Thursday 10 th June (a.m.)	– half day meeting

Abbreviations used in this report:

ALERT	All Africa Leprosy, Tuberculosis and Rehabilitation Training Centre, Ethiopia
ALM	American Leprosy Missions
A-MDT	Accompanied Multi-Drug Therapy
GAEL	Global Alliance for the Elimination of Leprosy
GLRA	German Leprosy Relief Association
ITC	ILEP Technical Commission
KIT	The Royal Tropical Institute, the Netherlands
MB	Multibacillary
MDT	Multi-Drug Therapy
MoH	Ministry of Health
MSC	Medico-Social Commission
PB	Paucibacillary
POD	Prevention of Disabilities
SER	Socio-Economic Rehabilitation
SMHF	Sasakawa Memorial Health Foundation
TAG	Technical Advisory Group
TDR	Special Programme for Research and Training in Tropical Diseases (WHO)
TEG	Temporary Expert Group
ULC	Urban Leprosy Control
U-MDT	Uniform Multi-Drug Therapy
WHO	World Health Organization

Distribution:

ILEP Technical Commission
Standing Committee
ILEP Members
ILEP Representatives

Annex: Draft agenda for Technical Forum, June 9th 2004

Forum
ILEP Technical Commission
Wednesday June 9th 2004
International Methodist Centre, London
DRAFT AGENDA

1. Introduction of participants
2. Feedback on the output of the MSC, 2000-2003
3. Setting the scene within ILEP (*Secretariat*)
4. Setting the scene within leprosy: presentations by members of the ITC
 - 4.1 Overview of current trends in the field of leprosy *Dr Krishnamurthy*
 - 4.2 Sustainability of leprosy services *Dr Feenstra*
 - 4.3 Prevention of disability *Dr Pérez*
 - 4.4 Socio-economic rehabilitation *Mr Ernst Hisch*
 - 4.5 Training issues *Dr Groenen*
 - 4.6 Research issues *Dr Ji/Dr Lockwood*
5. Presentation of requests for advice from Members
6. Open floor discussion on the Commission's priorities
7. Summary: identification of priority topics