



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

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**12th Meeting of the
ILEP Technical Commission**
Thursday, 30th September – 1st October 2008
London, United Kingdom

MINUTES

- 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)
- Secretariat:** Mr Douglas Soutar (DS), Secretary, ITC
Mr Andrew Clark (AC), Assistant General Secretary
Ms Imogen Prickett (IP), Technical and Information Coordinator

1. Approval of the Agenda

The agenda was approved with item 7.5 moved to Issues related to Monitoring: 3.1.ii WHO Informal consultation on innovative approaches to further reduce the burden of leprosy. An addition to AOB was made: 9.1 United Nations call for information on leprosy related discrimination.

2. Matters Arising from Previous ITC Meeting

2.1 ILA – Follow up from Congress

DS reported on the follow up to discussions held at the ILA Congress in Hyderabad in January regarding revitalisation of the ILA organisation and membership. ILEP has been involved with the drafting of a questionnaire to go out to ILA members. DL, DS and the ILA President formulated questions and AC was involved in drafting the forms. Now the questionnaires are with the ILA and are expected to be sent to participants shortly.

DS reported that there had been no update from Salvatore Noto on the development of the ILA website, however SD noted that the development of the website may be in progress. WvB noted that he was involved in producing a revised fee structure for ILA membership, and that NLR had offered the possibility of involving the Infolep Officer in the production of an ILA newsletter, but he had not received feedback on either of these things.

3. Issues related to monitoring

3.1.i Monitoring and analysis of leprosy data WHO/ILEP

ED presented his comments and analysis of the WHO global statistics for 2007. DL noted that she had asked Paul Fine to also produce an analysis of this data which was to be published in the September Leprosy Review. The Chair explained that the task for ED was to interpret the data for the information of ITC and ILEP Members and opened the topic for discussion at the meeting.

There was discussion among members about the variations in data collected not only between countries but also within countries and regions. Looking only at country level data can mask significant variations within countries. There was also discussion on the importance of validation and the shortcomings in validation of the WHO data. HC commented on the issues for countries with very small populations, such as those in Micronesia, which numerically are not significant on a global scale but whose leprosy cases are significant on a local level. Data interpretation for smaller populations is also important. CS noted that the numbers or rate of new cases in the population is the important figure, not the proportion. Grade 2 disability is also important as there is not a stable case detection situation in most countries.

The difficulties in analysing or commenting on country level data were discussed. It was suggested that the regular WER reports on specific countries were a valuable tool, giving more detailed data from which more useful comment and analysis could be made. The issue of drug supply related to data was raised with examples given of recent drug supply problems in India and the Philippines.

ED will give a brief presentation on his analysis of the WHO 2007 data, incorporating some of the points raised by Paul Fine, to the ILEP cooperation meetings to be held after the ITC Meeting.

3.1.ii WHO Informal Consultation on innovative approaches to further reduce the burden of leprosy. (Report of meeting with recommendations and conclusion to follow)

CS provided some background to the consultation. The meeting was called because it was felt that new target strategies were needed in order to ensure the continuation of free drug supply, revitalise the leprosy programme and enhance the ability of National Programme Managers to secure funding for their work. The consultation was called by the WHO South East Asia regional office, chaired by Dr Noordeen in his role as President of the Leprosy Elimination Alliance, and attended by the ITC Chairperson.

CS explained that the members of the consultation had called for realistic measurable targets to be set for the Leprosy Programme for the 2011-2015 period. There was discussion on what the nature of such targets might be. It was noted that case detection targets are easily manipulated and therefore setting a target around Grade 2 disability may be more reliable and also help increase case detection at the same time.

CS noted that there would be a larger International forum to develop a plan of action for the Global Leprosy Programme for 2011-2015. This would involve

key National Programme Managers, the WHO TAG and the ILEP Technical Commission. It would be funded by the Nippon Foundation and held in Delhi sometime in the first quarter of 2009. Other issues on the agenda for this meeting would include: chemoprophylaxis for household contacts and chemotherapy trials in anticipation of the possible threat of rifampicin resistance.

The meeting returned to this agenda item the following day. ED felt that the quality of services might suffer if case detection targets were applied and wondered if it were possible to have additional indicators such as disability at release from treatment. PS felt it would be important to look at a reduction in disability by a percentage over time. A cohort study to monitor the development of disability over a period of time would not be so easy to manipulate.

It was agreed that in order to prepare for this meeting it would be important to try and find data on disability from ILEP projects which showed disability records and trends.

Chemoprophylaxis would require a proactive approach since it is necessary to know how many household contacts you have to provide it to. It might be better and more useful to focus on the programmatic issue of following up household contacts. WvB mentioned experience gained in SE Asia of household contact follow-up where many new cases were found.

It was noted the stigma is also an issue in chemoprophylaxis and is an important consideration when planning the methodology for follow up of contacts. HC indicated that rifampicin resistance might be encouraged by single dose chemoprophylaxis and also possible resistance in TB cases where there is already a problem, although chemotherapy experts considered this was not a problem.

3.2 Lot Quality Assurance Sampling (LQAS) study in India

CS reported to the group that ALES and Novartis will make a presentation at the cooperation meetings about this proposed research. The research involves surveys and then comparison with reported data. ALES is interested in involving more ILEP Members in this project. Members agreed that although there were always numbers of undetected cases which could be found with studies like this, there are problems around how to interpret this. It was agreed that the ITC should be involved at this stage in order to have constructive input into the objectives and nature of further studies.

3.3 LEM Exercise in Mozambique

DS noted that there were some concerns about the fact this report had some quality issues. ILEP had been referred to as a joint participant in this study, however only one ILEP Member representative in Mozambique had been involved and then only to a very limited extent.

SD reported that although he had sent ITC comments to Mozambique regarding the LEM exercise report, he had had no feedback. This is possibly because ILEP Members have not had a strong voice recently in Mozambique.

4. Issues related to Implementation

4.1 Training of National Programme Managers in the Operational Guidelines.

AG summarised the training of National Programme Managers that had taken place in 2008 and is still planned over the coming months. AG, ED and DS attended the training session in Addis Ababa and reported that the workshops were well presented. There were some concerns that many of the workshop attendees were from countries in Africa with very little or no leprosy (for example Namibia, Botswana, Swaziland and Zimbabwe). It was noted that DFB will organise a training workshop in DR Congo early next year and attendance will be by invitation only. It was also noted that a workshop had been held in India's north eastern states following the training session in Addis Ababa.

Two further workshops are to be held in Bamako in December 2008 and in Cairo in February 2009. Workshops are also planned to be held in South East Asia and the Western Pacific regions in early 2009.

4.2 Development of a tool-kit of quality indicators

PS presented his brief paper on developing quality indicators, explaining that there were various different possible indicators and that targets were needed. Quantitative approaches focus on collecting data, while more qualitative approaches looked at the health worker/client relationship. WvB noted that there is a 'Patients Perspectives' booklet which could be helpful as it sets out guidelines for the standard assessment of patients treatment. PS also mentioned the need for a health systems approach as it reflects the difference in different contexts and brings the focus back on patients. CS suggested that both quantitative and qualitative indicators are needed as they monitor different things.

PS will start by contacting ILEP Members to establish if there are general indicators used and will compile these to get an idea of good practice already existing within the Federation. He will look at methods for measuring qualitative progress.

4.3 Improving the quality and coverage of POD activities

HC presented his paper on improving the coverage and quality of POD activities to the group. There are three initiatives of interest, two of which are in the planning phase and one of which has started.

- a) A survey had been sent to programme managers to assess how POD is being done in different countries. 17 countries had responded so far.
- b) A Delphi exercise had been used to get a consensus view on the skills required for the PHC worker to properly assess nerve function impairment.
- c) A situational analysis of leprosy services in Nepal was being carried out.

4.4 Improving the quality and impact of CBR activities – CBR & Leprosy Workshop in Bangkok, December 2008

SD presented an overview of the planned CBR Congress in December and progress made towards planning for the Leprosy and CBR Workshop, which will be held following the main Congress sessions. He drew attention to the

feedback received from Congress organisers who feel that the workshop should not be specifically called an 'ILEP' workshop, because it is part of the overall event and will include participants from outside the leprosy field. SD reported that the group involved in organising the workshop (SD, WvB and HC) are still finalising a list of the presenters they would like to be involved in the workshop and noted that it was important to include some people who have been affected by leprosy.

The group will meet after the meeting to finalise their plans for the structure of the workshops and a list of possible presenters. Some of the suggested presenters will need to be contacted in order to ascertain their availability and it may be necessary to seek sponsorship for their attendance.

5. Issues related to Research and Development

5.1 Synthesis of research findings for the development of research strategy

CS reported briefly on progress made in this area. He noted that a research strategy had been prepared in relation to the ILA Forum held in 2002 and the findings of much of this research had now been published in major journals. However, these issues may not be relevant now as questions have moved on.

It was suggested that the ITC use as a base for a research strategy the four areas of priority identified in the Global Strategy and these were discussed by the group in terms of what priorities there may be within these areas and whether any further areas should be added to the list.

- 1. Prevention and management of nerve function impairment and reactions:* This area was still of interest and a synthesis of finding was suggested. DL suggested adding 'the ongoing effects of neuropathic pain' to this area.
- 2. Improved chemotherapy:* It is important to define priorities within this area. Does "improved" mean cheaper, faster acting, fewer reactions? Looking at adverse reactions to the current chemotherapy regime is important, and this also relates to the issue of compliance.
- 3. Development of diagnostic tools to identify individuals at high risk:* Looking at host responses and understanding transmission is a key area. Environments are important in this regard.
- 4. Operational research to improve sustainability and integration:* Quality is now an important part of this area.

Two additional areas of research priority were identified by ITC members:

- 5. Stigma:* The TEG on Stigma will be the mechanism through which this is taken forward.
- 6. Community-based rehabilitation:* The upcoming workshop on CBR and Leprosy in Bangkok will be the starting place for identifying possible lines of research in this area.

5.2 Advice on application of new methods in early diagnosis

CS referred to the IDEAL project and suggested that this could be added to the list of research priorities under development of diagnostic tools. He noted a forthcoming meeting in Cebu in December.

5.3 Follow up on the recommendations from the Neuropathology Workshop

WvB reported that following on from the Workshop, he had prepared a TENLEP (Treatment of Early Neuropathy in Leprosy) proposal which has been sent to various ILEP Members. Seven centres in five countries have agreed to take part in the project. WvB also reported that the publication of INFIR studies was ongoing. DL noted that a study has been published in Leprosy Review covering pathogenesis aspects. Intervention studies have been set up in ALERT, at the Blue Peter Centre in Hyderabad and in Sri Lanka. Neuropathic pain is emerging as an important area of concern.

6. Issues related to Stigma

6.1 Update on TEG Stigma

Before presenting an update on the TEG, WvB noted that there is currently a pilot project in India called SARI, which is looking at stigma in the context of CBR. This study is showing promising results and another set of studies is proposed in Ethiopia, India and Indonesia.

WvB directed the group to look at the four proposed objectives for the TEG and CS noted that they corresponded well with the ITC Workplan. WvB explained his proposal for a bigger TEG than normal with a division of expertise among TEG members in line with the four objectives. It is proposed that the first meeting of the group would correspond with a World Psychiatry Association Conference on Stigma in London in January 2009. This would be a valuable opportunity to create links with people attending the conference and exchange information and ideas. It could also help to cover the costs of the TEG as some of the members may already be attending this conference.

The proposal for a larger TEG than usual and the associated possible funding issues were discussed. The travel and accommodation for four people (the normal TEG size) could be provided for by ILEP, however sponsorship would then need to be sought from ILEP Members for additional TEG participants. AC noted that there could be room in the ILEP central budget for further support but this depended on costs associated with other meetings.

The ITC supports the proposal with further refinements in terms of funding and timescale. WvB and HC will further develop the proposal with these issues in mind.

7. Meetings Update

7.1 Briefing on 1st Dermatology Conference in Genoa, April 2008

SD reported that there was not a great deal of debate at the conference to report on as it was mostly based on presentations with little discussion.

7.2 Update on ILEP/Infolep collaboration and website

DS reported that new 'country pages' have now been made live on the ILEP website. These pages provide detailed information on ILEP representatives and activities in particular countries as well as statistical data and other qualitative information. There has been some feedback from ILEP Member staff in the field and some suggestions on content. ITC Members were also

asked for their feedback.

Discussions are being held with NLR on the possible development of a database of images of leprosy to be added to the website. The Infollep Officer at NLR is currently developing a proposal for this activity. DS noted that he may request images and links to images from the ITC in the future. DL asserted that links should be the priority as there are already many images available. Finally it was noted that the future development of the ILEP website may include more interactive dimensions.

7.3 Report and follow up on TAG

The group were referred to the report from this meeting included in the papers and noted that this had already been discussed at the March ITC meeting. A new TAG is now being put together and it was reported that inputs from the ILEP on the possible makeup if the new TAG were welcomed by Dr Pannikar at WHO GLP. ITC members were encouraged to submit any thoughts on the new TAG through the General Secretary as soon as possible.

7.4 Eastern Mediterranean Region Programme Managers meeting, July 2008

CS reported that both he and DS had been invited to this meeting. It represented a fairly active group even though the numbers of leprosy affected people are relatively small in most of the region's countries. DS agreed that the official report of the meeting would be circulated once it was received.

8. Update on Teaching and Learning Materials

8.1 Update on translation of the CBR Guide into French, Portuguese and Spanish

DS updated the group on progress made with translations of the CBR Guide. The French translation will be completed by WHO and it is currently with Dr Bide at AFRO for this purpose. The Brazilian Portuguese draft translation has been completed by ILEP Members in Brazil and when it has been proof-read, it will be designed and formatted in London, before being sent back to Brazil for printing and distribution. AIFO will use this version to produce an African Portuguese version. The Spanish version is currently being translated by Fontilles and will also be designed and formatted in London before being sent back to Spain for printing.

9. Any Other Business

9.1 UN letter on Discrimination

DS reported that a letter had been received from the United Nations High Commission for Human Rights calling for information to assist in the preparation of a report on the measures taken by governments to eliminate discrimination against people affected by leprosy and their families. This relates to the UN Human Rights Council Resolution 8/13 passed in June 2008. ILEP Members are encouraged to submit information for this report to the Human Rights Council by 31st October. A copy of the letter was distributed at the meeting.

10. Next Meeting

ITC Members were asked to pencil in the date of Thursday 26 March 2009. It was agreed that this date might change to allow a meeting to be combined with the planned international WHO meeting in Delhi. As this meeting is now tentatively set for 13-15th April, and following discussion with the ITC Chair, it is suggested that the ITC meet briefly on the evening of the 12th April and then again on the 16th following the WHO meeting.

Document distribution:

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ILEP Representatives

Acronyms used in this report:

AIDS acquired immune deficiency syndrome

CBR community-based rehabilitation

DAR Disability and Rehabilitation Unit (WHO)

IDEAL Initiative for Diagnostic and Epidemiological Assays for Leprosy

ILA International Leprosy Association

ILC International Leprosy Congress

INFIR ILEP Nerve function impairment research study

ITC ILEP Technical Commission

MDT multi-drug therapy

POD prevention of disability

SARI Stigma Assessment and reduction of impact

TAG Technical Advisory Group (WHO)

TEG Temporary Expert Group

TENLEP Treatment of early neuropathy in leprosy

WHO World Health Organization