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

15th Meeting of the ILEP Technical Commission

25th March 2010

London, UK

MINUTES

In the Chair: Prof Cairns Smith

Present:
Dr Wim van Brakel
Dr Hugh Cross
Dr Etienne Declercq
Dr Sunil Deepak
Dr Myo Htoon
Prof Diana Lockwood

Secretariat:
Mr Douglas Soutar
Mr Andrew Clark
Dr Lenka Nahodilova

Apologies: Dr Paul Saunderson

Dr Augustin Guédénon and Professor Baohong Ji

Dr Augustin Guédénon, Consultant/Medical Advisor to FRF and member of ITC, died in a car accident in Abomey, Benin, on 12th January 2010.

Professor Baohong Ji, Professor at the Faculté de Médecine Pitié-Salpetrière, Medical Advisor to FRF and past member of the ITC, died in Paris on 10th February 2010.

Both had made a very significant contribution to the ILEP Technical Commission over many years.

1. Approval of Agenda

The Chair welcomed everyone to the 15th ITC meeting.

The agenda was approved.

2. Matters arising from previous ITC meeting

The effectiveness of the teleconference was reviewed. The principle was good, but it would be useful to research also other systems. 'Adobe' and 'E-luminate' were suggested. When choosing a new system it would be good to trial it first.

Minutes of the 14th meeting were approved.

3. Updates on Plan of Work 2008- 2011

3.1 Monitoring

It was noted that Dr Declercq (ED) had written a commentary on the WER data in Leprosy Review and Professor Lockwood (DL) reported that this was useful in raising the issues with the data. While noting that there were limitations in the data Dr Htoon (MH) asked that suggestions be made to find solutions and ways to improve the data.

MH indicated that integration has made some of the data collection more problematic when leprosy data is collected alongside other disease data. There is a need for WHO and partners to help national programme managers to improve data collection and reporting. Feedback to them can be a part of this. DS noted that trends in data are important and updating data in retrospect is more useful rather than continuing to publish partial data at the end of the reporting year. It was agreed that Country specific WERs are important for this and ILEP Members can take an active part in encouraging this. Previous country specific WERs had been published on leprosy trends in Yemen, Vietnam and Thailand and one was forthcoming on China. It was agreed that one on Brazil should be encouraged.

There was discussion of the new indicators in the Enhanced Global Strategy and it was noted that the G2 Disability target encourages a proportional reduction in new cases with G2D per population rather than setting a specific number to be reached. DL suggested an editorial in Leprosy Review could be used to explain the new indicator. WB also suggested encouraging the use of data at local level to help focus attention on the data collection process and engender a sense of pride and ownership in the data.

The risks of under-diagnosis or over-diagnosis of G2 disability were noted and the importance stressed of having an assessment of disability at the time of detection. MH made the point that originally G2 disability amongst new cases was created as an indicator of early diagnosis but that it has also been used as a measure of the burden of disease.

It was agreed that the General Secretary (DS) and the GLP (MH) would encourage a WER on the leprosy trends in Brazil.

3.2.1. Implementation : WHO Training and Capacity Development Strategy

MH gave an update regarding the 'Capacity Development Strategy in

Leprosy Control' document (linked to the EGS for Further Reducing the Disease Burden due to Leprosy 2011-2015). He noted that Henk Eggens (HE) would incorporate suggestions and comments made at the Forum.

The final draft of the capacity development document will be circulated to the ITC members by e-mail and comments fed back to HE.

MH introduced a discussion on the international training centres emphasising the need for these.
WB suggested that training centres can only plan training courses if there is a demand. The Chair (CS) suggested a scenario where high level courses might be put together by bringing in training expertise rather than trying to maintain the high level of training staff on a permanent basis at the centres.
MH asked who would tell training centres that they should plan in that way. The Chair pointed out that this has to be driven by demand and although it is a 'chicken and egg' situation the starting point has to be established if there are sufficient people who would pay to go on the training courses.

It was decided that the ILEP Secretariat would request ILEP Members to give an indication of demand for such a training course. This would also be raised at the ILEP Board Meeting.

3.2.2. Toolkit for Quality Indicators

LN gave a summary of the progress so far and indicated that the plan is to be in contact with PS before mid April to complete work on the Quality Indicators Toolkit. This could then be written in the form of a Technical Bulletin in a similar format to previous advice from the Commission.

It was agreed that when the Toolkit is in the form of a draft bulletin it should be circulated to the rest of the Commission for comment. It will then need a pilot process before finalising it prior to publication. DS will follow up on this.

3.2.3 POD Activities

HC gave a progress report but noted that plans to generate a set of guidelines based on good practice had stalled because of funding issues. In order to bring together countries identified as providing good POD programmes there would have to be some funding available (£10 000 - £12 000). The countries suggested were Brazil, Indonesia, Viet Nam, Myanmar.

It was agreed to consider whether ILEP could facilitate this around the times of the October ILEP Cooperation meetings. HC and DS to follow up.

3.2.4 CBR Guidelines

The question was raised as to what both WHO and ILEP might offer to national programmes managers regarding CBR. SD noted that it is important that national managers continue to train staff about CBR and ILEP Members need to promote a discussion between CBR and leprosy programmes.

DS mentioned that there is a regular contact with DAR in Geneva to keep each other briefed on related activities.

WB mentioned a summer school on Disability and Development in Jakarta to which Members are welcomed.

It was agreed to have a Cooperation meeting in October to allow ILEP Members to explain what CBR meant to them and to invite someone from DAR (Chapal Khasnabis) to participate in this and also to feedback from the Africa Region CBR Congress planned in Nigeria from 3-5 October.

3. 3. Research and Development

Literature Review
The Chair was happy with the level of discussion at the Forum. Both the Chair and HC suggested that an interface between evidence and implementation is needed and that it will be necessary to examine the evidence necessary for making recommendations. The value of evidence grading and the need to unify the evidence grading system for the reviewed literature was discussed, as well as the methodology of using such an evidence grading system for different types of evidence and for non-medical research.
There was also some discussion concerning the placement of the grading tables and standardising their structure; whether to use appendices for the tables, etc. DL suggested that each section needed tables at the end but it was recognised that this would greatly increase the size of the final document.

Some disappointment was expressed regarding the lack of attendance at the Technical Forum although the Chair felt that the discussion was good even if the number of participants was low. DS indicated the clash with the Buruli Ulcer meeting was one reason for low attendance.

It was decided:
(1)that the draft final report will be edited by the Chair by end April for circulation and supplemented with recommendations for implementation using three categories (Evidence base, Best Practice and Further research). The ITC members will have one month to look at it and the final report will be finished in June.
(2) that the tables will be produced in a common format using the form HC and WB used and will be included as an appendix also by end April.
(3) that structural revision for consistency will be done, and
(4) that the review will be finalised for publication in Leprosy Review and inclusion on the ILEP website.

The ITC can comment on the draft report before it is finalized by June.

Members Questions addressed to the Technical Forum

1. SMHF
DS will liaise with SMHF and draft a response as discussed during the TF.

2. DAHW
Request for some evaluation of earlier training workshops on the global Strategy and operational guidelines. MH suggested that it is difficult to provide evidence based impact evaluation following the training courses that had taken place.

WB suggested a technique of evaluation called 'Most significant change' noting what has happened as a result of attending the training, could be used for processes when it is difficult to get quantitative indicators. Participants could be asked to give their own evaluation of the personal impact of the training. *It was agreed that WB will find a student who could conduct this and MH will provide a list of participants to be contacted.*

3. TLMI - question on new drugs.
The discussion started by MH indicating that because of the closure of the mouse foot pad labs we are losing technology for testing new drugs. Piet Both in the Forum had pointed out the importance of maintaining a network of experts. The Chair pointed out the need for collaboration.
MH informed that sentinel survey sites for monitoring drug resistance have WHO funds to buy alternative drugs if resistance is found. This is done on an individual case by case basis. On a national programme basis it represents a problem – it is costly.

PB had also noted that alternative drugs are available only in certain countries. DL gave an example of Sri Lanka where minocycline, is not allowed or available.

3. 4. Issues Related to Stigma

3.4.1. Temporary Expert Group on Stigma

WB indicated that it had been difficult to get feedback in time for this ITC meeting and that the process of having virtual groups without actually meeting had not been very productive. A literature review had been done on stigma measurements in HIV stigma, leprosy stigma and mental health stigma, and in the fields of non- HIV, non-leprosy and non-mental health stigma. There is no literature on stigma interventions in leprosy, although there is in similar fields such as HIV.

Planning is going ahead for a bigger workshop 11th -13th October 2010 in the Netherlands. Guidelines will be drafted prior to the workshop to help participants prepare. Funding for the workshop will come from NLR and there will be approximately 40 participants. The final product should be in the form of guidelines for ILEP Members, plus a scientific paper on each topic. This will be probably be "best practice" based advice.

HC queried whether it would be possible to come up with recommendation guidelines for stigma interventions. WB noted that there has been an assumption that if we do leprosy control then stigma will disappear but this is not the case. So it is necessary to do specific stigma prevention and he considered that we can produce guidelines for this.

WB also announced the establishment of an e-journal on stigma entitled 'Stigma Intervention and Action'.

Upcoming research meetings:

IDEAL - next meeting August 2010 (last week 23rd/24th), Beijing.

Vaccine IDRI/ALM, April (24th/ 25th) 2010, Washington.

SARI stigma prevention trial starting mid 2010, Ethiopia, India.

TENLEP meeting, NLR August (2nd week) 2010, Netherlands.

` **4. Enhanced Global Strategy (2011-2015) and Operational Guidelines**

4.1. 4.1.1. Implications of EGS and Operational Guidelines

ILEP project data collection
-ILEP Project Data Collection
- Monitoring EGS in ILEP supported projects
SD formulated a request about how to collect information from the projects. DS noted that there had been a Temporary Expert Group to review report format and that had resulted in the current "new" reporting forms. He noted however that some references had been made in the ILEP strategy review responses as to the usefulness or otherwise of the ILEP data. SD suggested it would be good to give Members a recommendation on what kind of data to collect. DL noted that ILEP forms do not provide enough information for interpretation of the data.
AC noted that ITC should advise on the kind of data which should be collected. There still remains the question how to evaluate the data from the ILEP Annual Project Report. WB asked whether the Members find it useful. The Chair said that an added value of data collection from ILEP Members is that it gives an amalgamate overview of the whole country.

The Chair suggested that it would be useful to have overview of data on the national level for the next ITC Meeting in order to see what kind of picture it can give on the country level and discuss how to use and analyse it.

4.1.2. a) Relapses versus reactions in multibacillary leprosy
DL commented on the relapse paper pointing out that it did not have enough histological evidence and therefore no "gold standard".
WB pointed out that the paper doesn't have bacteriological reporting.

ITC will write a note that the paper was received.

b) DAHW guideline for Treatment of Severe Leprosy Reactions

WB commenting on the paper indicated that although there was some evidence that duration of treatment might have a better effect, there was no evidence to support higher doses. He wouldn't recommend the paper for dissemination. The Chair pointed out that the ITC needed to be careful not to endorse something that was different from the WHO Operational Guidelines unless there was very good evidence, and noted that the DAHW paper doesn't have any references and no clear evidence base for the recommendations.

DL suggested that they could provide feedback on the paucity of references which was in any case discussed at the Forum, where doses of prednisolone were discussed.

The Commission agreed that while there is a value in producing something which goes beyond the guidance in the OGs, the ITC endorses the OGs and notes some concern regarding the lack of references and notes the importance of establishing the evidence base for high level dosages proposed. It was agreed that DS would draft a suitable response along these lines.

5. Report on ILEP/Infolep Information Portal Project

Portal Project has been reported at the TF.

6. AOB

6.1. India National Sample Survey

There plans for a India National sample Survey were noted, the findings would inform the post-elimination strategy

ITC noted the initiative and awaited the results.

6.2. New ITC Member

The Commission felt that it was important to fill the gap that had been left by Dr. Augustine Guédénon and tribute was paid to his perseverance and representation of the field.
The Commission also paid tribute to Dr Ji, his great contribution to leprosy work and to ILEP over many years. His death will leave a major gap in the field of chemotherapy.

The Commission suggested that a new ITC member should be someone from francophone Africa, filling the gap not only on the regional level but also on the level of expertise. (The ILEP board subsequently appointed Dr Christian Johnson (Benin) of Follereau France to fill this position until the end of the current Commission.

Next Meeting:

AFRO, Brazzaville, June 22-24. MH pointed out that it would be good to have an ITC representative at this meeting.

Next ITC meeting will be on 5th October 2010.

Document distribution:
Board
ITC
ILEP representatives

Acronyms used in this report:

AFRO	WHO African Regional Office
CBR	Community Based Rehabilitation
CHP	Chemoprophylaxis
DAHW	Deutsche Lepra und Tuberkulosehilfe
DAR	Disability and Rehabilitation Unit
EGS	Enhanced Global Strategy for Further Reducing the Disease Burden Due to Leprosy, plan period 2011-2015.
IDEAL	Initiative for Diagnostic and Epidemiological Assays for Leprosy
ILEP	Federation of Anti-Leprosy Associations
ITC	ILEP Technical Commission
NLR	Netherlands Leprosy Relief
POD	Prevention of Disability
SMHF	Sasakawa Memorial Heath Foundation
TLMI	The Leprosy Mission International
TEG	Technical Expert Group
TF	Technical Forum
WHO	World Health Organization