



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

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ILEP Technical Forum

Wednesday 26th March 2008

London

REPORT

In the Chair: Professor Cairns Smith, Chair, ILEP Technical Commission
Present: See Appendix 1
Secretary: Mr Douglas Soutar, ILEP General Secretary

1. **Introduction of Participants**
2. **Feedback on Output of the ILEP Technical Commission (ITC) 2004-2007**

Professor Smith drew attention to the programme of work completed by the previous ILEP Technical Commission and documented in the Forum papers.

3. **Setting the Scene**

- 3.i **Setting the Scene within ILEP (Mr Douglas Soutar, General Secretary of ILEP)**

Mr Douglas Soutar gave a brief presentation in which he highlighted the role and function of the ITC and the results of the review of the ITC and the work carried out between 2004 and 2007. He outlined the current structure and Members. He noted again the purpose of the Forum as being to give clear guidance to the ITC on setting their programme of work for the next four year period.

- 3.ii **Setting the Scene within Leprosy:**

Presentations were given by the Members of the ILEP Technical Commission and will be made available on the ILEP website. These included the following:

- Overview of Current Issues – Professor Cairns Smith
- Promotion of the Global Leprosy Strategy and Collaboration with the World Health Organization (WHO) – Dr Myo Htoon
- Research Issues – Professor Diana Lockwood
- Socio-Economic and Community-Based Rehabilitation Issues – Dr Sunil Deepak
- Sustainability – Dr Etienne Declercq
- Training – Dr Paul Saunderson & Dr Augustin Guédénon
- Stigma – Dr Wim van Brakel
- Prevention of Disability – Dr Hugh Cross

4. Presentation of Research Policies of Members

Presentations were made by the following Associations:

- Netherlands Leprosy Relief (NLR) – Mr Rens Verstappen
- German Leprosy and Tuberculosis Relief (GLRA) – Dr Adolf Diefenhardt
- The Leprosy Mission International (TLMI) – Mr Geoff Warne
- Fondation Raoul Follereau (FRF) – Professor Baohong Ji

Papers were provided by Associazione Italiana Amici di Raoul Follereau (AIFO), GLRA and NLR which outlined their current research policies and priorities and gave some indication of the levels of expenditure on research activities. TLMI in addition noted that their research policy was currently under review and would be available in the next six months. FRF also outlined their current areas of research in leprosy and Buruli ulcer.

5. Presentation of Tasks Following on from the Previous ILEP Technical Commission 2004-2007 and Requests for Advice from ILEP Members

All Members present were asked to highlight the priority areas from those they had submitted and these were as follows:

Damien Foundation Belgium (DFB): Prevention of disability (POD) activities – how to implement self-care, how to get started and get people to take over responsibility. Sustainability.

American Leprosy Missions (ALM): POD. Diagnostic tests – bringing together and monitoring the different developments and how they can best be utilised. Rifampicin resistance and dapsone allergy.

Fontilles Lucha contra la Lepra (SF): Testing for sub-clinical leprosy and advice on molecular epidemiology.

Comité International de l'Ordre de Malte (CIOMAL): Research on transmission, reversal reactions and facilitating access to services.

LEPRA – Health in Action (LEPRA): Early diagnosis and treatment of reactions. How to organise people affected in self-care initiatives. Need to address high turnover of staff and provide retraining to sustain skills.

Fondation Raoul Follereau (FRF): Assessing quality of services including diagnosis, treatment and POD.

AIFO: Early diagnosis, need to be more informed on results from Initiative for Diagnostic and Epidemiological Assays for Leprosy (IDEAL) and other efforts in this field keeping in mind disability. More advice on how to deal with stigma.

Aide aux Lépreux Emmaüs-Suisse (ALES): Need for quality indicators. Research to determine the true figures and a need for solid recommendations on how to carry out studies in this area most effectively.

NLR: Moving more into CBR so how to monitor and evaluate CBR projects – need better indicators. Case finding in low endemic areas. Developing minimum acceptable standards. Patient charters. Geographic information systems (GISs).

TLMI: With decline in global expertise the role of ITC was key. Needed evidence of usefulness of joint Leprosy/tuberculosis (TB) programmes. Importance of counselling. How to include leprosy CBR into mainstream CBR. Use of chemoprophylaxis and alternative drug regimens.

GLRA: Implementation - minimum acceptable standards and indicators. Implementation of CBR Guidelines. Validation/verification.

Individual ITC members added comments on the need to tackle the transfer of control of health outcomes; looking beyond leprosy for collaboration in the field of POD and CBR; capacity building for self-help groups and disabled persons organisations (DPOs); referral services and quality indicators – their definition, development and field testing.

6. Open Floor Discussion: Commission's Priorities and Identification of Priority Topics

Professor Smith highlighted that further discussion would be required on quality indicators, the role of the ITC with regard to research and the issue of validation of data. Discussion also focused on those areas where there were clear overlaps of Members' needs and priorities.

It was agreed that quality was a complex issue and it was noted that it would be important to consider patient perspectives and a rights-based approach to the measurement of quality.

Verification of data was similarly complex in that there were many operational factors which made analysis difficult. It was agreed that investment was needed in the reliability of data and that verification should not be about "elimination", but about the accuracy and reliability of data.

It was stressed that research interests discussed reflected both the priorities of Member associations and ITC Members and it was suggested that there should be more effort made to promote and advocate for collaborative ILEP funding of research initiatives.

7. Summary

The key points arising from the discussion were listed as follows and the ITC were asked to take these forward the following day in their discussion and preparation of a draft programme of work.

- POD implementation
- CBR implementation
- Early diagnosis
- Sustainability
- Diagnosis and treatment of reactions
- Quality indicators and surveillance
- Research coordination
- Drugs, resistance, chemoprophylaxis
- Stigma
- Human rights as a cross cutting issue.

Document distribution:

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Acronyms used in this report:

AIFO	Associazione Italiana Amici di Raoul Follereau
ALES	Aide aux Lépreux Emmaüs-Suisse
ALM	American Leprosy Missions
CBR	community-based rehabilitation
CD-ROM	compact disc read-only optical memory
CIOMAL	Comité International de l'Ordre de Malte
DFB	Damien Foundation Belgium
DPO	Disabled Persons Organisation
FRF	Fondation Raoul Follereau
GIS	geographic information system
GLRA	German Leprosy and Tuberculosis Relief Association (DAHW)
IDEAL	Initiative for Diagnostic and Epidemiological Assays for Leprosy
ITC	ILEP Technical Commission
LEPRA	LEPRA – Health in Action
NLR	Netherlands Leprosy Relief
POD	prevention of disability
SF	Fontilles Lucha contra la Lepra
TB	tuberculosis
TLMI	The Leprosy Mission International
WHO	World Health Organization

Auth: DS
Ori: Eng
Date: April 2008

Appendix 1

List of delegates

Amorós, Mr Jose	SF
Both, Dr Piet	TLMI
Braber, Mr Kommer	NLR
Cegolan, Dr Luca	CIOMAL
Cross, Dr Hugh*	*
De Miguel, Mr Eduardo	SF
Declercq, Dr Etienne	*
Deepak, Dr Sunil	*
Diefenhardt, Dr Adolf	GLRA
Guédédon, Dr Augustin	*
Htoon, Dr Myo Thet	* <i>WHO Global Leprosy Programme</i>
Ji, Professor Baohong	FRF
Lockwood, Professor Diana	*
Rao, Dr P V Ranganadha	LEPRA
Saunderson, Dr Paul	*
Smith, Professor Cairns	* <i>Chair, ILEP Technical Commission/ ILEP Technical Forum</i>
Torres, Dr Pedro	SF
Van Brakel, Dr Wim	*
Vargas, Mr René	LEPRA
Verstappen, Mr Rens	NLR
Von Stamm, Dr Thomas	ALES
Warne, Mr Geoff	TLMI

* *Member of the ILEP Technical Commission*

ILEP Secretariat:

Bonham, Ms Felicity	ILEP Secretariat
Clark, Mr Andrew	<i>Assistant General Secretary of ILEP</i>
Soutar, Mr Douglas	<i>General Secretary of ILEP/ Secretary, ILEP Technical Commission/ILEP Technical Forum</i>
St Hill, Ms Beverley	ILEP Secretariat