# MESSAGE FROM THE ILEP PRESIDENT "WORKING TOGETHER FOR A WORLD WITHOUT LEPROSY"

The last twenty years have seen great progress in the treatment of leprosy. These days treatment for leprosy with multi-drug therapy is straightforward and can usually be completed within a year of diagnosis. Early diagnosis and treatment means that people affected by leprosy suffer less nerve damage and disability than in the past treatment allows people to lead a normal life.

All this means that gradually the perception of leprosy is changing and the stigma attached to the disease is slowly diminishing. People increasingly understand that leprosy is a bacterial infection, which is easily treated and not very contagious.

Does this mean we will soon be able to forget about leprosy? In fact, we are at a critical time in the history of leprosy. Shorter, more effective treatment has meant that the number of people registered for leprosy treatment has fallen dramatically. However, the number of people found to have leprosy each year has not yet fallen in the same way. In addition, many people who have had leprosy, including a proportion of the people receiving treatment now and in the future, will suffer nerve damage and possible disability. In some cases these people may still experience serious social or economic disadvantage.

We are at a point where decisions about the future of leprosy services need to be made with intelligence and care. We need to build on achievements so that in the future, people with leprosy will be able to rely on good quality services for treatment, prevention of disability and rehabilitation. We need to do this by careful analysis of needs, thoughtful and strategic planning and effective monitoring of programs. We need to make accurate diagnoses before treatment. We need to support the capacity of governments to provide leprosy care through general health services to achieve increased effective coverage of the population, and to make the services more sustainable. We also need to maintain specialist expertise in leprosy. Above all, we need to remain responsive to changing needs.

ILEP Members know that leprosy is not a high-profile disease, but we know too the devastating consequences people can experience where care is inadequate.

By working together with governments and other agencies, ILEP commitment to work for a world without leprosy, will help ensure the provision of sustainable, quality services for the treatment and care of people affected by leprosy for as long as they are needed.

President

-Terry Vasey

## Minutes of the Pre-Congress ILA Council Meeting

3 August 2002 and 7 August 2002 Salvador, Brazil

### **Participants:**

*Officers:* Y. Yuasa, (President); P. Feenstra (Secretary); W.F. Ross (Treasurer); H.J.S. Kawuma, S.K Noordeen, W.C.S. Smith (Vice-presidents).

#### Councilors:

A. Guedenon, P.K. Gopal, B. Ji, J. Justice, J.W. König, M. Leide de Oliveira, T. Shwe, J. Terencio de las Aguas; A. Tiendrebeogo, C.S. Walter. Absent: R. C. Hastings (regrets), Li Huan Ying (regrets), R.R. Jacobson (regrets), W.M. Meyers (regrets), M. Virmond (regrets), R. Day Syarafuddin, T.O. Sofola, F. Vasquez Bozzo.

#### Invited members:

M.F. Lechat (president emeritus); P.S. Saunderson, D.M. Scollard.

1. The meeting was opened by the President.

2. Secretary's report

Since the Council meeting after the ILC in Beijing on 12 September 1998, the Council has met at two other occasions:

17 November 1999, Abijan Ivory Coast: Informal brainstorming meeting on the future of ILA:

#### 13 November 2000 Agra, India:

During the Agra meeting a working group was set up (P. Saunderson, chair, P. Feenstra, S.K Noordeen, W.C.S. Smith) to submit detailed proposals regarding the future of the journal, including related changes required in the Constitution and Bylaws. Moreover, the Council agreed that there is a need to organize a Technical Forum which would review the major technical issues related to the elimination of leprosy and would prepare recommendations to be discussed in detail during the next ILC in Brazil. Dr. B. Ji was requested to prepare a detailed proposal and to submit this to the President and Secretary, who then should decide on further action to be taken.

The meeting of the ILA Technical Forum was held from 25–28 Feb, Paris, after two preparatory meetings of the organizing committee. The report of the ILA Technical Forum was published in the IJL, Leprosy Review, the Indian Journal of Leprosy and Le Bulletin de l'ALLF (in French).

Two questionnaires had been circulated among the members:

1. ILC survey. Opinions, comments on the content and organization of the 15th ILC and suggestions for the next ILC were requested to all who attended the 15th in Beijing: the results have been published in the ILA Forum and were taken into account for the organization of the 16th ILC.

2. IJL Survey. In December 2000 questionnaires were sent to all 1010 of the IJL recipients (approximately 300 ILA members and 700 institutions). 160 responses were received. The respondents are resident in 45 different countries, 69% are MDs. The institutions in which they work include 37 medical schools, 43 research centers, and 26 leprosy control programs. 57% want the IJL to be continued as a peer reviewed scientific publication and 29% would like more emphasis on needs on the field. 65% are willing to make a commitment to submit articles for publication to the IJL and 58% to give priority to the IJL for publication of their own articles. 79% agreed that the journal should be published electronically and 73% prefer this to be in conjunction with the printed edition. 79% had, or expect to have within one year, access to the internet.

#### 3. Editor's and Treasurer's Report

In the absence of the Editor the Treasurer reported also on behalf of the Editor.

The average circulation of the IJL over the past three years has been 1044 of which 1000 generated income and 44 were exchange and complimentary copies. 353 journals were sent to ILA Members and 647 to institutions. The journal is distributed to 81 different countries. The annual cost for each recipient is \$129 for four issues.

For the past three years the average annual cost of operating the IJL has been \$129,807 and the average annual income has been \$120,608. The deficit has been made up from reserves accumulated in previous years. The income is comprised of payments from members (\$15,111), from subscribers (\$18,160), from grants and contributions (\$84,570) and miscellaneous income (\$2767).

As these figures make clear the Journal is dependent on grants and contribution, mainly from ILEP member agencies, for 70% of its income.

The costs of publishing the Journal consist of publication and distribution (\$75,359), peer review and editing (\$44,043) and management and auditing (\$10,375). One of the realities of the cost of publishing a journal like the IJL, with relatively small circulation, is the relatively high level of fixed costs not affected by the actual numbers circulated. The costs of editing are entirely in this category. The cost of auditing is fixed and the cost of keeping track of payments and address changes does fall as circulation falls. Mailing costs (\$16,883), comprising approximately \$4 per recipient per mailing, creating the tractile offected by the number

proximately \$4 per recipient per mailing, are clearly directly affected by the number of journals mailed but printing costs, which consist largely of the costs of composition, are little affected. These factors need to be kept in mind when electronic publication is considered. Printing and distributions cost will be eliminated but peer review, editing and management will still be needed.

4. Nomination for Officers for 2002-2006.

The President presented a list of Officers to be proposed for election during the General Meeting of Members. There was a long discussion on the procedure followed regarding the selection of the nominees. The Councilors agreed that in the future the procedure should be more open and democratic with adequate opportunity for the members and councilors to propose nominees. Then the Council discussed the nominations and agreed on the following nominations:

President:	
Secretary:	
Treasurer:	
Editor:	
Vice Presidents	:

S.K. Noordeen C.S. Walter P. Saunderson D.M. Scollard H.J.S. Kawuma (Africa) M. Virmond (Americas) T. Shwe (Asia) W.C.S. Smith (Europe).

After this agenda point was concluded Drs. P. Saunderson and D.M. Scollard were invited to join the meeting.

5. Changes in the Constitution and Bylaws

Based on the recommendations of the special working group regarding the future of the journal, a proposal was prepared by the President and the Secretary, including related changes required in the Constitution and Bylaws. This proposal was discussed in detail after which the Council agreed to propose the following to the General Meeting of Members: Proposed changes to the ILA Constitution.

#### A) Introductory comments

#### Membership

- The constitution already allows for a wide membership, not restricted to doctors; on this basis the membership should be increased by various means, including a possible link to Congress registration. Further efforts should be made to recruit more scientists and doctors, also.
- In future, membership dues should be significantly reduced.

#### The journal

- The journal will be published online, with a transitional period of at least one year. This can be done at a reasonable cost.
- An ILA web-site will be developed, which will have an area free to the public and a members-only area, which could include many different features, including the ILA Forum and other discussion groups. Email newsletters, or perhaps locally printed material, containing material from the restricted part of the web-site could be produced for members without access to the web-site. It is assumed that electronic access will continue to increase rapidly in all parts of the world, making this provision less and less necessary.
- The Editor will have overall responsibility for the Journal and the web-site, with an Editorial Board.

#### B) Proposed changes

In order to effectuate these and other changes, the following amendments of the ILA Constitution and Bylaws are required:

#### Constitution

1. Article 2: 'objects' to be changed into 'objectives'. '... concerned with leprosy.' to be replaced by '... concerned with all aspects of leprosy.'

2. Article 4b: Add: '... Europe, 3, subject to a reasonable distribution of disciplines.'

3. Article 4d: Delete: '(of five years each)'.

#### **Bylaws**

1. Article 1b: Replace 'be sent' by 'have access to'.

2. Article 1c: Replace 'he shall receive a copy of each issue so withheld, provided that copies are available' by 'access to all issues and other privileges of membership shall be restored'.

C) Steps to be taken in order to have the proposed changes implemented

1. The proposals have been discussed by the Council Members, and are now being submitted for final approval to the General Assembly of Members during the 16th ILC in Brazil.

2. The appointment of the Editor will be immediately after the final approval by the General Meeting of Members at the 16th ILC in Brazil, August 2002.

3. The new editor and the business office of the IJL will then develop a business plan (including proposals for the development of a web-site) to be submitted to the Council by October 1st, 2002.

4. Any necessary revisions to the business plan can be made, but the final plans should be approved by November 1st, 2002, so that implementation can begin on January 1st, 2003. 5. Actively campaign for new members during the ILA congress in Brazil.

6. Nomination for Councilors

The Council agreed on the following nomination:

Africa: Y. Aziz, A. Guedenon, O. Ogbeiwi.

Americas: N.T. Foss, J. Justice, A. Law, G.O. Penna.

Asia: W. van Brakel, P.K. Gopal, M.T. Htoon, R. Hussain, I. Nath.

*Europe:* B. Ji, J. W. König, J. Terencio de las Aguas.

7. Venue next Congress

India has shown interest to host the next meeting, but this has not yet been fixed.

8. There being no other business, the President closed the meeting.

Respectfully submitted,

—P. Feenstra

Secretary