



REPORT OF THE FIRST MEETING OF THE  
LEPROSY ELIMINATION ADVISORY GROUP (LEAG)

Geneva, 12 and 13 July 1995

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### **1. Opening of the meeting**

The meeting was opened on behalf of the Director-General by Dr R.H. Henderson, Assistant Director-General. In his opening speech, Dr Henderson re-affirmed WHO's commitment to achieving the objective of eliminating leprosy as a public health problem by the year 2000. He outlined the important achievements made so far, especially reaching a global MDT coverage of over 75% and with the possibility of raising this to 90% by the end of 1995.

Dr Henderson extended the gratitude of WHO to the Sasakawa Foundation for their contribution to making MDT available for all patients in the world. This, coupled with the political commitment so far achieved, makes it necessary for leprosy control programmes to try to achieve the maximum possible impact now. LEAG, whose membership is drawn from areas covering 80-90% of the global leprosy problem, has a crucial role to play in ensuring the achievement of the elimination target.

### **2. Scope and objectives of the LEAG**

Professor M.F. Lechat, Chairman of LEAG, made a quick review of the terms of reference of the group - finally summarizing them as the task of evaluating the past, moderating the present and preparing for the future. He also reviewed the events leading to the formation of LEAG as a replacement for the Leprosy Working Group, and challenged the members to devise strategies to stimulate interest in programmes for the elimination of leprosy in order to counteract any relaxation of efforts and loss of interest, even before the elimination goal is fully achieved.

Professor Lechat singled out the successful implementation of MDT as an important factor in justifying the setting of the elimination strategy. He thanked the Sasakawa Foundation for their commitment to finance the remaining MDT drug requirements.

### **3. Global plan of action for the elimination of leprosy - Progress and Achievements (1994-1995)**

Dr S.K. Noordeen, Director of WHO's Action Programme for the Elimination of Leprosy (LEP), made a brief outline of the programme structure as modified after the setting up of LEP in December 1994. It now consists of the following components apart from the office of the Director for overall management: (a) country support and special action projects (CSP); (b) monitoring and evaluation of elimination (MEE); (c) capacity building and health systems research (CBH). The main objective of the programme is to eliminate leprosy as a public health problem by the year 2000.

The current global burden of leprosy was summarized in the following indicators:

- estimated cases of leprosy, 1.8 million (decrease of 67% compared to 5.5 million in 1991)

- number of registered cases, 1.3 million, representing a global prevalence of registered cases of 2.3 per 10 000
- number of cases detected in 1994: 560 000, representing a case detection rate of 10 per 100 000 inhabitants
- disabled individuals, estimated to be between one and two million
- number of endemic countries, 72 (the top six of these contribute 84% of the global leprosy burden, while the top 19 contribute 92%).

The top six endemic countries are: India, Brazil, Bangladesh, Indonesia, Myanmar, and Nigeria.

The following are some of the indicators of the progress towards implementation of the programme:

- the number of people cured after MDT, 6.7 million
- people currently on MDT, 990 000
- current MDT coverage, 75% (was 50% at the end of 1993): members were cautioned about the interpretation of these data as the patients on MDT are only patients who have been registered and who have received MDT at least once.

It is intended that all countries reach close to 100% MDT coverage by the end of 1995; this is an important prerequisite for the achievement of the elimination target.

Dr Noordeen also discussed data showing the improved MDT coverage in the different WHO regions, with associated decrease in prevalence rates. The available data on disabilities suggest that widespread use of MDT has led to a significant decrease in the number of disabled patients. The difficulties being faced by the programme include:

1. dealing with the difficult-to-access areas and populations;
2. dealing with highly endemic areas - some with a heavy burden now and a high detection. It is still hard to extrapolate incidence from detection as it seems that only a small proportion of newly detected cases are truly incident cases;
3. difficulties in maintaining commitment, both political and professional, and the supply of resources;
4. maintaining sustainability and expertise.

#### **4. Introduction to the concept of campaigns for leprosy elimination**

In a presentation by Dr Noordeen it was observed that, in order to reach all the patients, a clear plan for each area is necessary, including an information campaign reaching a large part of the community, which would be followed by a rapid search, diagnosis and treatment. Developing such a plan would have to be preceded by an investigation into health service-related and patient-related factors which prevent patients from turning up for examination and treatment.

He challenged the LEAG to come up with some input towards further development and implementation of this concept.

The following were highlighted for discussion from the two presentations by Dr Noordeen:

- (i) clear guidelines should be developed for estimating the number of people with disabilities; at the moment there is no accurate information on people with impairments or handicaps caused by having leprosy;
- (ii) ways should be sought of using the available data to decide on countries/areas where special assistance/collaboration in case-finding may be required;
- (iii) the relevance of leprosy information in Europe. It was noted that whereas there are pockets of leprosy in Europe, the numbers of cases are small and, as of now, there is no coordination of data collection;
- (iv) leprosy campaigns would probably lead to an increase in single lesion cases and the related problem of sensitivity of the diagnosis; this may have to be accepted as a consequence, especially in view of what can be learnt from the process;
- (v) If social factors, e.g. stigma, are involved in preventing patients from turning up, the campaigns may still serve to improve community awareness with the result that people will turn up for treatment in spite of the stigma;
- (vi) local NGOs and non-specific community groups should be involved in the campaigns, which should not be organized through vertical programmes.

#### **5. Review of Regional Leprosy Situations**

Summaries of the leprosy situation in five WHO Regions were presented, elaborating on the data shown in the WHO Weekly Epidemiological Record No. 25 and No. 26, 1995.

The African region contains nine out of the 19 most endemic countries. The elimination strategy, among other things, will include intensifying support for the highly endemic countries through meetings and offering assistance in developing national strategies and plans of action.

In the Americas, the prevalence rates have decreased from 4.5 per 10 000 in 1992 to 2.6 in 1994, and the MDT coverage has risen from 25% to 60% in the same period. The leprosy situation in the region is governed by the situation in Brazil, but that is counterbalanced by some countries with very low prevalence. A strategy, based largely on Brazil, aims at strengthening state programmes, promoting elimination activities, developing special approaches to urban areas and achieving (as an intermediate target) elimination in the high prevalence states by 1998.

In the Eastern Mediterranean Region, a significant reduction in prevalence was observed between 1989 and 1994. The greatest leprosy burden is in the Sudan. The important problems highlighted included that of defaulting "expatriate patients" with leprosy, and the case of one country not strictly using WHO-recommended MDT.

The South-East Asia Region carries about 66% of the global leprosy burden. Although there is a decrease in the total case load, the number of new cases remains stable. The countries have been grouped into 3 depending on the year for achievement of the elimination target: ie. 1994, 1997 or 2000. Important issues to be addressed at this stage include maintenance of political commitment, which is already good; acceleration of prevalence reduction; new case detection; and how to deal with low prevalence situations.

In the Western Pacific Region, almost all cases are treated with MDT. The overall prevalence rate in the region in 1994 was 0.25% per 10 000 inhabitants. The regional strategy for the elimination of leprosy is based on 5 main activities: (i) Extension of MDT to difficult-to-reach areas; (ii) Special Action Projects for countries/areas of high endemicity; (iii) improvement of managerial capabilities; (iv) monitoring and evaluation of the programme using a single regional information system; and (v) planning of a rehabilitation programme in countries where control of leprosy is well established.

## **6. Report of the WHO Study Group on Chemotherapy of Leprosy**

The study group last met in Geneva in November 1993. For his presentation, Dr R. Jacobson highlighted the important changes, clarifications and new recommendations formulated and included in the new report.

## **7. Progress on chemotherapy of leprosy**

In his presentation, Professor Grosset reported on relapse after long-term follow-up of multibacillary patients treated by the WHO-MDT regimen, and said that, in general, relapse rates were very low. In one study, relapse rates were higher in patients whose pre-treatment BI was over 4<sup>+</sup> and among those whose post-treatment BI was over 3<sup>+</sup>. All patients who relapsed had rifampicin-sensitive bacilli. He said it is advisable to keep to the present 24-months MDT regimen for multibacillary leprosy. The recent nude mice studies demonstrated that the nude mouse could be used as a model for chemotherapy of lepromatous leprosy, and showed that the bactericidal activities of combinations of new drugs as compared with those of WHO-MDT provided a firm basis to justify the present WHO-MDT as very effective treatment.

## 8. Presentations by International Nongovernmental Organizations

Dr Y. Yuasa gave a brief history of the International Leprosy Association (ILA) and its main functions, i.e. organizing the ILA Congresses and publication of the International Journal of Leprosy.

Mr T. Frist described the composition and functions of the International Federation of Anti-Leprosy Associations (ILEP). As of 31 December 1993, a total of 589 934 leprosy patients (35% of the global total of registered patients) were under chemotherapy in ILEP-supported projects. The Federation's impact on the leprosy burden has been to contribute to a reduction in the numbers of registered cases, and an increase in MDT coverage. ILEP's interim target and first priority is to provide MDT for all by the end of 1995 in all ILEP-supported projects apart from those adopted in the current year. Its other priorities include prevention of disabilities and rehabilitation.

Professor Lechat presented a brief description of the functions of the International Leprosy Union (ILU). This is a Federation of national NGOs whose performance is as of now constrained by limitation of funds. Although the ILU has recorded only limited achievements, it will be very instrumental in keeping up the momentum of elimination as an NGO group representing endemic countries.

Dr Yuasa outlined the functions of the Sasakawa Foundation (JSIF) and the Sasakawa Memorial Health Foundation (SMHF). The JSIF has made available to WHO US\$10 million for 1995 to support the procurement of MDT drugs. The SMHF does not run its own programmes but supports and strengthens national government efforts.

In a discussion related to these presentations, it was observed that there is now a need to coordinate further the efforts of all these organizations.

## 9. Introduction of "Guide to Eliminating Leprosy"

Members welcomed and endorsed WHO's Guide to Eliminating Leprosy as a Public Health Problem. The guide was presented by Dr M. Virmond as a "book of basic instructions" rather than a textbook. It was agreed that it will be used as a basis for writing manuals for national control programmes.

## 10. MDT drug distribution and management

Dr S. Lyons described what has been done by WHO in connection with procurement and distribution of MDT drugs since the Hanoi Conference of July 1994. He also listed the conditions to be met by all recipient countries. Between March and June 1995 the first shipments of drugs were sent to the most endemic countries.

Uniform reporting and monitoring procedures have been established which should be implemented by all concerned.

It is intended that special workshops will be held with the express purpose of capacity building in management of drug supplies.

It was emphasized that there was need to set up some degree of coordination between the WHO drug supply and that of others.

#### **11. "Post elimination" issues**

A discussion led by Dr Noordeen centred on what should be done after the year 2000, bearing in mind the need to plan ahead.

It was recommended that countries which have reached the elimination target at national level should look at elimination at the first sub-national level.

As numbers of leprosy patients become smaller, delays in diagnosis are to be expected; programmes should try to minimize them by truly integrating leprosy into the general health services.

Referral facilities/services will still be necessary but will move to a higher level of health service and become fewer because of the high cost of sustaining them. It will also be necessary to maintain expertise both through training and by gaining the interest of other medical professionals, e.g. dermatologists, in leprosy.

It was felt that, at present, efforts should be limited to reaching the elimination target. In any case there are as yet no tools for a leprosy eradication strategy. Consideration of post-elimination issues in countries should depend on the progress made towards elimination, and even so it should be handled cautiously to avoid confusion of priorities.

#### **12. Report on the first meeting of the Task Force on Monitoring and Evaluation of Elimination of Leprosy (MEE)**

The report was presented by the Chairman of MEE, Dr W. Cairns Smith. The group accepted the recommendations of the MEE as presented. It was agreed that, in some selected programmes, indicators additional to the six included in the recommendations could be looked at. These would include: incidence, disability, relapse, defaulting, child rate and socio-economic indicators. Whereas for global monitoring it would be adequate to report on the absolute number of cured patients, it was emphasized that at national level the indicator to use would be cure rates derived from cohort analysis. It was also agreed that MEE should keep an eye on the HIV/leprosy relationship, but not as a priority.

#### **13. Report on the first meeting of the Task Force on Capacity Building and Health Systems Research (CBH)**

The report was presented by the CBH Chairman, Dr P. Feenstra.

The LEAG accepted the recommendations of CBH as presented and incorporated the following views:

- (i) HSR should be linked much more with Programme Managers than with researchers;
- (ii) It should be used as an important component in capacity building, but only in so far as it relates to problem-solving at the local level;

- (iii) The Management Training Modules should continue to be used and should be expanded to incorporate an introductory module on HSR.

**14. Report on the First Meeting of the Steering Committee on Special Action Projects (SAPEL)**

The LEAG accepted the report as presented by the Chairman of SAPEL, Dr Yuasa.

The following points were clarified:

- (i) Whereas SAPEL is a WHO initiative, it is not an exclusively WHO activity;
- (ii) SAPEL should not be seen as a replacement for routine National Programme activities nor as an alternative source of funding for such activities.

**15. Supporting elimination at country level**

The presenter, Dr Feenstra, used the terms of reference of LEAG as a basis for leading a discussion on how LEAG could contribute to translating the elimination goal into realistic local targets and into feasible and practical plans of action.

Countries should be encouraged to develop national plans of action for elimination. In the larger countries such plans should be developed at sub-national level.

It is necessary to hold donor meetings; the meetings should be organized by national governments, and should give the donors sufficient preparation time. Such meetings could be held once a year for the larger countries and once every two years for the smaller ones. Apart from such meetings, programmes should seek other opportunities for coordination.

**16. Second International Conference on Elimination and Second LEAG Meeting**

The group recommended that the second International Conference on the Elimination of Leprosy be held before the end of 1996, as a follow-up to the 1994 meeting. India has informally offered to host the meeting in October 1996.

It was subsequently agreed that the next LEAG and Task Force meetings be held in India at the same time as the International Conference. SAPEL meetings will still be held in December 1995 and July 1996, as planned.

## CONCLUSIONS AND RECOMMENDATIONS

The Leprosy Elimination Advisory Group (LEAG) reviewed the progress being made towards the elimination of leprosy through the implementation of multidrug therapy (MDT) at the global and regional levels. The Group was encouraged by the steady improvement in the global leprosy situation. However, it expressed its concern with regard to the relatively slow progress in a few countries as it appeared from the reports submitted. While the elimination goal aims at a prevalence below 1 case per 10 000 population, countries should aim at reaching this target at national and sub-national levels.

Since late detection of cases remains a problem in a number of countries and MDT implementation appears to be slow in some places, the Group recommended developing in those places special reinforcing campaign approaches based on specifically targeted activities, which however would not be a substitute for current approaches through the general health services.

The LEAG considered that the task forces on Capacity Building and Health Systems Research (CBH) and on Monitoring and Evaluation of Elimination of Leprosy (MEE) and the steering committee on Special Action Projects (SAPEL) are appropriate for reviewing the situation and taking appropriate decisions.

The LEAG supported the further expansion and continuation of the management training modules, which have contributed greatly to improving leprosy services in many endemic countries. It recommended that leprosy be included in the curricula of medical schools and other schools for health professionals, especially through the development and provision of task-oriented learning materials appropriate for different levels. It also recommended that Health Systems Research (HSR) be used as an important component in capacity building, but from the lessons learnt it was clear that HSR should be oriented to problem-solving at the local level.

Essential Indicators for Monitoring and Evaluating elimination identified earlier are sufficiently reliable and should continue to be limited to six; it is important that they be analysed at sub-national level. The LEAG recommended that additional indicators, namely incidence, disability, relapse and defaulting, be monitored in selected projects.

SAPEL is a welcome innovative approach to addressing special situations and difficult-to-reach patients which cannot be quickly dealt with through the routine health services. It is recommended that this initiative should develop in close collaboration with all possible partners.

The LEAG welcomed and endorsed WHO's Guide to Eliminating Leprosy as a Public Health Problem as a timely publication, and strongly recommended its widespread distribution.

Early treatment with MDT is the most effective way of preventing disabilities. The WHO gradings of disability are useful for monitoring early detection, and there is a need for new approaches to assessing disabilities and handicaps due to leprosy. Simple and cost-effective action for the prevention of disability by patients, health staff and communities should be promoted and complemented.

Current research confirms the efficacy of WHO fixed-duration MDT. It is important to ensure adequate supply and distribution of the MDT drugs, which have been made possible through the generous support from the Sasakawa Foundation.

The LEAG emphasized that the present window of opportunity resulting from global political commitment, the provision of financial support for drugs and the scientific and technological breakthrough should not be lost. However, it should not be overlooked that elimination as a public health problem has not yet been achieved and further intensive efforts are needed. There is a risk of relaxing the required efforts, and steps must be taken to maintain the momentum at all levels, in close collaboration with different partners. The Group emphasized that, in the later phase of elimination, leprosy expertise must continue to be maintained at appropriate levels.

The group recommended that, in view of the important need for sharing experiences, reinforcing commitment, reviewing progress and maintaining momentum towards elimination, the next International Conference on the Elimination of Leprosy should be organized before the end of 1996 as a follow-up to the Hanoi Conference of 1994.

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