Report of the global forum on elimination of leprosy as a public health problem

Geneva, Switzerland
26 May 2006

World Health Organization

WHO/CDS/NTD/2006.4

Report of the global forum on elimination of leprosy as a public health problem

Geneva, Switzerland
26 May 2006

World Health Organization

© World Health Organization 2006

All rights reserved.

The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted lines on maps represent approximate border lines for which there may not yet be full agreement.

The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by the World Health Organization in preference to others of a similar nature that are not mentioned. Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.

All reasonable precautions have been taken by the World Health Organization to verify the information contained in this publication. However, the published material is being distributed without warranty of any kind, either express or implied. The responsibility for the interpretation and use of the material lies with the reader. In no event shall the World Health Organization be liable for damages arising from its use.

Contents

Executive summary ... **1**
Opening remarks ... **3**
Dr Margaret Chan, Assistant Director-General, WHO Communicable Diseases ... 3
Dr Shaik Kahder Noordeen, President, International Leprosy Association ... 4
WHO Goodwill Ambassador for Leprosy Elimination ... **5**
Mr Yohei Sasakawa, President, The Nippon Foundation ... 5
Review of countries achieving the elimination target ... **8**
Dr Ambumani Ramadoss, Minister of Health, India ... 8
Dr Filomeno Fortes, Director, Department of Endemic Diseases, Angola ... 9
Review of countries close to achieving the elimination target ... **11**
Mr Jarbas Barbosa, Secretary of Health, Brazil ... 11
Chief Medical Officer, United Republic of Tanzania ... 11
Review of countries sustaining the elimination target ... **13**
Professor Kyaw Myint, Minister of Health, Myanmar ... 13
International Federation of Anti-Leprosy Associations ... **16**
Mr Rigo Peeters, President ... 16
Public–private partnerships ... **18**
Professor Dr Klaus M. Leisinger, President and Chief Executive Officer, Novartis Foundation for Sustainable Development ... 18
Discussion ... **21**
Concluding remarks ... **23**
Dr Shaik Kahder Noordeen, President, International Leprosy Association ... 23

Annex 1. Agenda ... **25**

Annex 2. List of participants ... **26**

Executive summary

Leprosy, one of the most ancient, feared and disabling diseases of humankind, is on the verge of defeat. The 1991 World Health Assembly resolution[1] was a catalyst, and today 116 out of 122 endemic countries have eliminated leprosy as a public health problem.

To acknowledge this unprecedented achievement against leprosy and to encourage the international community to continue its efforts, a global leprosy forum took place in Geneva, Switzerland, on 26 May 2006 at a special session during the 59th World Health Assembly.

Since 1985, prevalence of leprosy has been reduced globally by more than 90% and over 14.5 million patients have been cured through multidrug therapy (MDT). This success has been made possible by the strong commitment of endemic countries supported by the international community, including the Nippon Foundation and the Sasakawa Memorial Health Foundation; Novartis and the Novartis Foundation for Sustainable Development; bilateral organizations; and national and international nongovernmental organizations (NGOs), notably the International Federation of Anti-Leprosy Associations (ILEP).

The strategy to eliminate leprosy is twofold: (i) improving access to diagnosis through integration of leprosy control services into existing public health services; and (ii) providing effective drugs free of charge. Early detection of cases has dramatically reduced the risk of deformities and disabilities among patients, ensuring that leprosy sufferers can lead normal lives with dignity.

Since 1995, the World Health Organization (WHO) has provided treatment free of charge to all leprosy patients worldwide thanks to generous contributions from the Nippon Foundation, Novartis and the Novartis Foundation for Sustainable Development. High-level political support and social marketing campaigns to change the image of leprosy have also significantly contributed to pushing the disease towards elimination.

Leprosy control has now reached a critical milestone: patient numbers have dramatically reduced in recent decades, although pockets of the disease remain in several countries of Africa, Asia and Latin America. Identifying the last patients at the local level is increasingly difficult, delaying their treatment before deformities occur. Greater attention should therefore also be paid to patients who face human rights violations and who require help for their physical and socioeconomic rehabilitation.

A good surveillance system is essential for sustainable leprosy control in countries which have eliminated leprosy as a public health problem.

---

[1] Resolution WHA44.9. *Elimination of leprosy as a public health problem.* Geneva, 44th World Health Assembly, May 1991 (available at http://www.paho.org/English/AD/DPC/CD/lep-wha-1991.htm; accessed October 2006).

The global leprosy forum calls for stronger political commitment and further efforts to combat the disease through a coordinated intersectoral approach, substantial increases in funding, and greater participation of NGOs and foundations.

Opening remarks

Dr Margaret Chan, Assistant Director-General, WHO Communicable Diseases

I would like to dedicate this forum to the memory of Dr Jong-wook Lee, who started his career at WHO by fighting this disease and continued throughout his career to demonstrate the highest personal and professional commitment to its elimination.

Leprosy, a disease which has devastated mankind from time immemorial, is no more a dreaded and intractable problem. This dramatic change in the leprosy situation in recent years has been made possible not only through generous donor support but also by the strong political commitment of Member countries themselves.

Since the adoption in 1991 of the World Health Assembly resolution on the elimination of leprosy, the prevalence of leprosy has fallen globally by over 90%, new case detection by about 50%, and the number of endemic countries by 120. This degree of achievement by countries, supported through WHO, would not have been possible without the generous support to the Organization of the Nippon Foundation, stretching back over a period of 30 years and including support to programme activities as well as the supply of MDT drugs, particularly during the period 1995–2000. WHO's other major partner in the free supply of high-quality MDT drugs since 2000 is Novartis, which has generously promised to continue such support until at least the end of 2010.

Currently, leprosy is largely confined to four countries in Africa and one country each in Asia and Latin America. There are also major pockets of the disease surviving within the larger endemic countries which have recently reached the leprosy elimination target at the national level. These remaining problem areas cannot be ignored, and vigorous action must be taken to ensure that leprosy is eliminated at global, national and local levels. Furthermore, there is an important need to sustain leprosy elimination globally, so that leprosy can become truly insignificant as a public health problem by the end of 2010.

This is not a time to relax or be complacent: the final phase of this fight against leprosy is as critical as the earlier phases.

By adopting a public health approach to leprosy, diagnosis and treatment of the disease have been brought closer to affected communities. Millions of patients have been protected from developing disabilities. Unfortunately, some patients have been disabled by leprosy because of delays in starting treatment. We need to pay greater attention to their physical and socioeconomic rehabilitation, and the human rights violations faced by some of them. This calls for a coordinated intersectoral approach, substantial funding and greater participation of NGOs and foundations. In this connection, the efforts made by the Nippon Foundation through Mr Yohei Sasakawa, the WHO Goodwill Ambassador for Leprosy Elimination, have been exemplary. The key to success in all these efforts will be the more intense participation of civil society and of those affected by leprosy. I sincerely hope that this area will receive increased attention in the future.

Let us pledge that we will continue to further strengthen our efforts to eliminate leprosy, until we finally fulfil our commitment to Member States and help them free themselves from the devastating scourge and stigma of this disease.

Dr Shaik Kahder Noordeen, President, International Leprosy Association

This global forum is an important event to review the achievements made so far based on World Health Assembly resolution 44.1 of 1991 on elimination of leprosy as a public health problem. An earlier forum held in May 2001 reviewed progress during the first 10 years. Now we are updating the progress made in the following five years. All these achievements would not have been possible without the strong political commitment of WHO Member States and the strong support provided by various partners, including NGOs.

With this brief introduction, may I invite the speaker to make the keynote address.

WHO Goodwill Ambassador for Leprosy Elimination

Mr Yohei Sasakawa, President, The Nippon Foundation

Thank you, Chair, for giving me the opportunity to speak. I would also like to extend my thanks to Dr Chan for making arrangements to make this forum possible, which, as you mentioned, was at the intention and wish of our late Director-General Dr Lee.

I spend roughly one third of the year travelling abroad, mainly for activities associated with the elimination of leprosy. My destinations include both those countries that have reached the elimination goal and those that have yet to achieve it. There are three main purposes for making these trips to various countries. Firstly, to talk with the politicians among whom the priority for the elimination of leprosy sometimes tends to be demoted to a lower rank. I want to make sure that they always keep the priority high for the fight against leprosy. So I talk with the politicians. Secondly, I make these trips to solicit cooperation from the mass media because they are an important partner in our struggle. And thirdly, I make these trips to encourage people working out there in the front line.

I just mentioned cooperation with the mass media. I feel that this is extremely important, and I am happy to say that over the past years the mass media has raised its awareness and interest in this issue of elimination of leprosy as well as the issues of stigma and discrimination associated with the disease.

When I visit these regions and countries, I sometimes appear on local TV programmes. These are the articles which have appeared in the print media in the past two years. This kind of coverage is very active when I go into the provinces, and I am very encouraged by the interest shown by the mass media.

We must remember that there are a lot of people who are illiterate. We must devise other ways and means to send out our message. I have three simple messages to convey: (i) that leprosy is curable; (ii) that medication is available free of charge, for which we are very grateful to Novartis; and (iii) that there is no place for discrimination. As we walk down the path towards eradication, these three simple messages must be spread throughout the world.

As I travel around the world, I am surprised to find out that among those who are supposedly highly educated people, there is still a high degree of ignorance. Many of them say, “This disease is hereditary, isn’t it?” Many say, “It’s a highly infectious disease.” There are still many people like that. That is the reality we are facing today. So it is all the more important to enlighten these people.

There is one very important point I would like to stress here: the use of the word “elimination”. Now, for me, elimination is a milestone towards a longer journey towards eradication. But I also know as a fact that some people active in the field fear that once elimination has been achieved, this movement will be completed. This is a misconception.

I will continue to visit various countries, especially those that have yet to achieve this goal, and throughout these trips I will emphasize that elimination is an important step towards eradication, the goal that has been decided upon by WHO some time ago.

Another point I need to stress here is that since the 1980s we have been able to cure more than 14 million people of leprosy. Have these people been socially reintegrated? Unfortunately, the answer is “no” to virtually almost all of these people; that is the way society is today. We need to realize that.

The medical aspect of this disease is obviously very important, and a lot of attention has been paid to that by various stakeholders, including WHO. However, we must realize that there are hundreds if not thousands of ailments in this world, but leprosy is the only one where even after one is cured, society does not accept you back into its system. There is still discrimination. There is a need to look at the social dimension of this disease – the stigma and discrimination that goes along with leprosy and has become an important issue to be addressed by WHO.

I am in the process of renewing my mandate in the fight against leprosy as WHO Goodwill Ambassador, and I am happy to do this. I recently read the new contract and saw that a condition has been included in my terms of reference: my continued activity in the fight in the social aspect of stigma and discrimination. I am very pleased that the condition has been imposed on me.

For three years now, I have brought this issue to the attention of the High Commission on Human Rights as a representative of the one NGO, and I am happy to say that the subcommission has unanimously agreed to include it in their agendas and mandate, and a draft resolution to that effect has been adopted.

In my first contract as special WHO ambassador, this mandate was not included; my activities were personally motivated. This new contract will greatly help boost my activities with the Human Rights Commission, so I am very grateful to WHO for adding that condition.

I am hopeful that in the not too distant future the resolution will be adopted at the next Human Rights Commission and that a set of guidelines will be given to each Member nation and that the government will take on that responsibility. When this happens, we will see an integrated approach covering the medical and social dimensions of leprosy. This will give a boost to further solutions, and we will see a new path opening in front of us.

Let me say that in this long journey in the fight against leprosy, I highly commend the role played by WHO and the members of Novartis who provide the medication, and the longstanding relations with NGOs that have made it possible to realize the achievements. Having said that, I must also be realistic and admit that there have been some cases where the relationship between NGOs and governments involved has not been 100% ideal. It is

my personal wish that, working together with WHO, the relevant government and NGOs, these three parties must collaborate to achieve the global elimination of leprosy, which is a milestone, and make it a success story in the history against the fight against this disease.

There is a Japanese saying that when you embark on a journey of a 100 miles, the midway in 99 miles. So the last mile, the final push, is the most difficult part. I am hoping that I can look forward to good relations with all of you for this final push of this last mile and that we can all display our solidarity in achieving that.

I am certain that the late Dr J.W. Lee is waiting for us to report to him and to describe the success story to him. It is a great source of happiness that I can continue to work with each of you.

Review of countries achieving the elimination target

Dr Ambumani Ramadoss, Minister of Health, India

It gives me great pleasure and satisfaction to report that India has met the challenge of its health policy 2002 and the World Health Assembly Resolution of 2001 to achieve the national elimination of leprosy, as targeted in December 2005. It has been a very long and hard road, from prevalence of 25.9, which comprised literally 75% of the world's leprosy cases in 1991, to about 0.95 per 10 000 on 31 December 2005. The prevalence fell further to 0.84 by 31 March this year.

We have focused on changing the vertically run programme to one that is fully integrated into the primary health-care system. In fact, under the modified leprosy elimination programme, we have carried out house-to-house surveys at the block level. The next aspect of our strategy has been the training and retraining of general health staff to increase their capacity to diagnose and treat the disease, and counselling of leprosy patients, families and communities. The third area has been repeated mass information campaigns (IEC) on curability of leprosy so as to promote self-referral to centres, as Mr Sasakawa has said. The fourth area is the provision of drugs free of charge. The focus of IEC has been to reduce the stigma associated with the disease. Lastly, we have emphasized strong logistics to ensure uniform and continued drug availability and a simplified information system to streamline data management. The strategy has allowed us to improve access to services throughout the country.

We have had strong partners in the fight against leprosy, and I would like to acknowledge the support received from WHO, the World Bank, the ILEP, Mr Sasakawa and the Nippon Foundation, Novartis and the DANIDA-assisted National Leprosy Eradication Programme. Mr Sasakawa is an important entity and presence both in India and across the globe, and I would like to thank him for what he has done in India and worldwide. Mr Sasakawa is so famous in India that if he stood for election I am sure he would win!

The Father of the Nation's long dream of doing away with leprosy is becoming a reality. We have achieved the first phase of elimination, and we will definitely achieve the stage of eradication. And, of course, Mother Teresa fought for this cause. And the late Director-General Dr Lee worked on leprosy elimination in India for two years. India and I share a close bond with Dr Lee and convey our appreciation for his efforts, which have no words for us.

We are extremely conscious of the fact that the elimination of leprosy as a public health problem is only an intermittent goal for India. Seven states out of about 30 and two union territories have yet to achieve elimination. About 26 of them have achieved elimination. We intend to work with the same commitment, resources and energy until leprosy has been eliminated from every state, every district and every sub-district in our country.

In the new phase of national leprosy elimination, we intend to focus on disability prevention and medical rehabilitation such as reconstructive surgery, focused intensive campaigns in rural areas, and diagnostic and treatment facilities particularly in urban slums. Even after elimination, by virtue of its huge population, India has the largest number of leprosy patients of any country in the world. But we are very confident that with a consistent and scientific programme, these numbers can – and will be – significantly reduced.

When we go back to my home country, we are going to sit across the table and re-strategize our leprosy eradication priorities, bringing in the NGOs, both governmental and nongovernmental, and private sector agencies, and hold a national consultation. We are going to re-strategize, as we did for the elimination stage of the modified leprosy elimination strategy, which worked wonders through household surveys.

We are trying to do that in the next phase of the programme, and I am very confident that India will achieve leprosy eradication in the next 10 to 15 years. I am highly optimistic, and we are working according to our programmes and schedules.

Thank you very much.

Dr Filomeno Fortes, Director, Department of Endemic Diseases, Angola

For many years, Angola was on the list of leprosy-endemic countries in the world. The disease caused physical incapacities, stigmatization and consequent social discrimination. For that reason, in 2003, the Republic of Angola responded to the challenge by signing an international commitment to implement a three-year strategic plan to reach the target of elimination of leprosy as a public health problem, i.e. less than 1 case per 10 000 inhabitants.

This commitment was taken in an unfavourable postwar context dominated by high levels of poverty, illiteracy, weak health service coverage and demographic instability. At that time, this endemic disease in our country was characterized by the following criteria: 5245 registered patients; prevalence rate of 3.5 per 10 000 inhabitants; 13% of patients with grade 2 deformities; 12% children; 70% multibacillary. Based on statistics, strategic plans were developed by the Ministry of Health with valuable support from our national and international partners.

The plan took into account the following principles. There was strong political will concerning the problem. Angola had this experience in the fight against leprosy from the religious missions. The national plan was already implemented in the country and involved the distribution of MDT, which proved to be effective. At the end of the military conflict, it was possible to extend the diagnostic and treatment centres to all areas of the country. The Ministry of Health, with the support of WHO and partners, developed a strategic plan which focused on the elaboration and divulgation of guidelines and training

programmes, awareness campaigns, mobilization, creation of technical capacity among health personnel, reinforcement of stock of medicines, improvement of surveillance and monitoring, and transformation of leprosy units into primary health units.

At the recent international day of leprosy in 2006, Angola had the pleasure of announcing that the established elimination target had been reached. Angola now has a prevalence rate of 0.9 cases per 10 000 inhabitants, no relapses and only 1400 registered active cases.

Regardless of this encouraging result, we are conscious that the fight is not over. We still have some provinces which need to reduce prevalence, and patients with physical incapacities who require rehabilitation and social integration. The challenges for the next three years are to sustain the level of diagnosis and treatment, strengthen active case screening activities, enhance the system of registration and epidemiological surveillance, keep the population informed and mobilized, develop a project for physical rehabilitation, and improve partnerships, mainly to fight against stigma and discrimination.

Finally, Angola would like to express its deep gratitude and recognition to WHO, ILEP, Mr Sasakawa, Novartis and all other partners who directly or indirectly contributed to the successful outcome.

On behalf of the Ministry of Health, we would like to express our commitment to continue the fight against leprosy as one of the public health priorities until its complete eradication.

Thank you for this opportunity.

Review of countries close to achieving the elimination target

Mr Jarbas Barbosa, Secretary of Health, Brazil

Very briefly, on behalf of our Ministry of Health, I want to congratulate India and Angola on reaching the elimination goal and reaffirm our commitment that Brazil will reach it this year or next. To be very honest, we wasted a lot of time in Brazil with the leprosy programme. I believe the leprosy programme in Brazil was a neglected programme. Brazil has the tools and the infrastructure – so it is not acceptable that we have not reached the prevalence rate of less than 1 case per 10 000 inhabitants.

Since 2003, the programme has completely changed. Now, leprosy is a high-priority programme within the Ministry of Health and the results achieved in only three years show the impact of this priority. In 2005, Brazil reached the prevalence rate of 1.4 cases per 10 000 inhabitants, and 80 states reached the elimination goal. In 2006, we launched the new plan 2006–2010, in which we do not accept prevalence above 1 – we want to reach this goal not only at the national level but also in each state and each municipality. We are supporting states and municipalities to promote intense integration between leprosy and primary health care. For instance, in 1998, we had only 2000 clinics which provided leprosy diagnosis and treatment. Today, we have more than 5000. So I believe that this year or next, we will reach the goal. But this is not enough. We will go beyond this elimination goal – and we need to reach – and I believe it is possible for a country like Brazil to not only reach the goal at national level but also in every state and every municipality.

So I want to finish by reaffirming my commitment. President Lula da Silva himself is very committed to leprosy elimination and wants to congratulate again India and Angola. I know the effort they made to reach this goal – and I promise you that Brazil will join you very very soon.

Thank you.

Chief Medical Officer, United Republic of Tanzania

The United Republic of Tanzania has now reached a prevalence level of 1.2 cases per 10 000 inhabitants, thanks to its national TB and leprosy control programme. This is one of our priorities in the Ministry of Health, and those programmes work very well. In fact, I am told that it is one of the best programmes south of the Sahara. Let me thank and congratulate Mr Sasakawa for being our Ambassador again on this issue and for putting the banner of leprosy on the world map.

The challenge we have is to educate communities and health workers to enable early detection. Stigma exists not only among people in the communities. Health workers should not stigmatize leprosy patients; after all, these workers are the ones who should give the correct information and show an example to communities. You [Mr Sasakawa] stressed the problems of stigmatization and discrimination related to leprosy at societal level.

There is a need for rehabilitation of thinking in the attitudes of our health workers and communities to patients, and to give appropriate support. The medicines are now there, they are free, and we need to encourage communities not to stigmatize patients. From my side at the Ministry of Health, there is more than this. There is a need for rehabilitation of the complications for those who had leprosy and who came to treatment late. We need to identify them and rehabilitate them so that they take an active part in communities.

In our new vision, we are thinking that early detection and treatment are extremely important so that we do not witness the complications that we are seeing now. We aim at elimination; our current prevalence is 1.2 per 10 000. We thank you, as we said, for the lead you are giving and promise to work with you to reach the elimination target.

Review of countries sustaining the elimination target

Professor Kyaw Myint, Minister of Health, Myanmar

It is indeed a pleasure for me to speak at this forum. Myanmar, my country, used to have a heavy burden of leprosy, where the disease had been a public health problem for many, many years. The Anti-Leprosy Campaign was started in 1950–1951, with expertise and advice from WHO. MDT was introduced in 1988, and the leprosy trend declined dramatically after the implementation of MDT. In 1987, before MDT, the total registered case-load was 204 822, with a prevalence rate of 53.4 per 10 000 inhabitants. In 1991, registered cases dropped to 79 973 (prevalence: 19.3). In 1997, registered cases were 13 357 (prevalence: 2.9). In 2003, registered cases were 2742 (prevalence: 0.51) and in 2005 registered cases were down to 2679 (prevalence: 0.8).

As you may recall, the 1991 World Health Assembly resolution to eliminate leprosy by the year 2000 gave substantial impetus to global leprosy control efforts as well as in Myanmar. The leprosy elimination programme included integrating MDT into primary health-care services starting from 1991 and completed in 1995. MDT services expanded and we were able to cover the whole country by 1995. To achieve leprosy elimination at the national level by the end of 2003, the following activities were implemented:

- IEC materials and materials for improving community awareness
- capacity building for health worker staff
- improvement in geographical coverage
- establishment of a surveillance system
- operational research on implementation strategies.

Activities for the elimination of leprosy were conducted under the guidance of the National Leprosy Elimination Steering Committee of the Ministry of Health and National Health Committee. The National Taskforce is a working group that was formed in 1999 with officials from the Ministry of Health and other related ministries and representatives of local NGOs and the private sector. The Leprosy Elimination Coordination Committee was formed in April 2000 and included the members of the National Taskforce on Leprosy Elimination, officers from WHO and representatives of NGOs. Its main role was to review the workplan annually and provide the necessary support.

The main activities for achieving leprosy elimination were reviewed and identified:
- describing the main duties of leprosy staff and basic health staff;
- building partnerships and improving the capacity of health service providers and partners, e.g. the Myanmar Maternal and Child Welfare Association, Myanmar Medical Association;
- intensifying routine activities through proper planning;
- implementing, monitoring and evaluating;

- conducting special activities such as leprosy elimination campaigns, improving geographical coverage for leprosy elimination activities, improving awareness of the general community as well as targeted groups after identifying needs' assessment;
- health systems research;
- improving the programme based on the key recommendations.

Advocacy meetings at different levels of administration were conducted. Commitment and support from local authorities and NGOs were key elements in this programme. For sustainability and surveillance, ownership was transferred to basic health staff. Training for management included how to plan and implement leprosy control programmes, how to monitor outcomes and how to supervise the team. An evaluation of activities was carried out to develop a strong partnership for facilitating the implementation of elimination strategies.

At this juncture, I would like to quote a very famous remark by the Goodwill Ambassador for Leprosy Elimination, Mr Yohei Sasakawa: "when you travel a long journey the last mile is the most difficult part of the journey". Mr Sasakawa's remark was so true and inspired me a lot at that time to try very hard in the early stages of the elimination programme.

We had to go out and reach patients in geographically hard-to-reach areas; patients who used to go out to the fields the whole day and could be seen only at night, and many, many other difficulties that we encountered. Fortunately, all these difficulties were borne with patience and tolerance by our basic health workers, particularly our midwives.

Myanmar had already achieved leprosy elimination at the national level by January 2003. Elimination status was declared at the third meeting of the Global Alliance for the Elimination of Leprosy held in Yangon, Myanmar, on 6–8 February 2003 by Dr David Heymann, then Executive Director of WHO Communicable Diseases; at the same time, the Yangon Declaration was formulated.

These achievements were a result of strong political commitment from the government, technical support from WHO, and MDT drugs supplied free of charge from the Sasakawa Memorial Health Foundation and the Novartis Foundation, as well as close collaboration with international and local NGOs and all partners, the active participation of the community, and a strong sense of devotion and dedication on the part of our basic health workers. Having achieved leprosy elimination, appropriate activities were continued to sustain elimination status. These included reducing the burden of leprosy and preventing disabilities, and the rehabilitation of leprosy patients.

A workshop on strategy for leprosy control beyond 2005 was conducted in Myanmar in June 2004. The workshop was attended by representatives of WHO, international NGO partners such as the American Leprosy Missions, Netherlands Leprosy Relief, Japan International Cooperation Agency and the Leprosy Mission International, national NGOs from Myanmar, the Red Cross Society, persons affected by leprosy (PALS), members of writerly and journalistic associations, national taskforce members and officers from the

Department of Health. The strategies laid down in the workshop were to continue the ongoing activities in hardship areas, uncovered areas and areas with migratory populations.

To sustain elimination status and conduct prevention of disability and rehabilitation activities, our main strategies were to establish a surveillance system and referral centres for high-quality care of PALS and involve communities in community-based rehabilitation. These activities were carried out with all our partners. Myanmar is continuing its effort to sustain the elimination of leprosy achieved in 2003, and is hoping to establish a network of care for those disabled by leprosy in order to minimize the social and economic consequences of the disease.

In conclusion, I would like to acknowledge my personal gratitude to Mr Sasakawa, the President of the Nippon Foundation, who has inspired me with his devotion, goodwill and generosity, and also generally for his support in terms of vehicles, financial input and medicines. I would also like to express my thanks to the Novartis Foundation, which has generously provided us with MDT.

International Federation of Anti-Leprosy Associations

Mr Rigo Peeters, President

ILEP is the International Federation of Anti-leprosy Associations. Its 14 Member Associations support work in 84 countries where leprosy is endemic. ILEP spends more than €65 million annually on leprosy work, including almost €3 million on scientific support and research. We work in close partnership with national leprosy control programmes and the WHO Global Leprosy Programme and its regional offices. ILEP is proud of the major role it has played in the achievements of the Leprosy Elimination Programme and remains committed to supporting the new global strategy for further reducing the leprosy burden and sustaining leprosy control activities.

Activities, 2006–2010

ILEP is, of course, very pleased to have been instrumental in helping to bring about the commendable achievements in the elimination of leprosy as a public health problem in so many countries. Its mission, however, is to work for a world without leprosy, and to this end we recognize the importance of moving beyond the elimination goal.

The elimination strategy, while effective in reducing prevalence in the short term, was based on unsustainable vertical approaches to leprosy control. The “final push” strategy for leprosy ended last year, and after almost two years of development and consultation a new strategy was approved during 2005: the *Global strategy for further reducing the leprosy burden and sustaining leprosy control activities (plan period: 2006–2010).*[1] This strategy has been widely endorsed and acclaimed and is a vital element in WHO’s resolve to take leprosy control beyond elimination. The strategy builds on the achievements of the elimination strategy but is based on *sustainability, integration, quality assurance, equity and social justice.*

ILEP fully endorsed this global strategy in 2005 and is working to promote its effective implementation in all the countries in which its Member Associations operate. For ILEP, the strategy’s aim of further reducing the leprosy burden demands that four key elements be pursued:

- Essential leprosy services need to be sustained and diagnostic and treatment skills maintained.
- Emphasis must be put on the WHO Global Strategy indicators of new case detection and treatment completion.
- The setting of prevalence- or case detection-based operational targets for field workers should be avoided and emphasis instead given to achieving quality-assured targets which can reflect both the timeliness of detection (new cases with

---

[1] *Global strategy for further reducing the leprosy burden and sustaining leprosy control activities (plan period: 2006–2010).* Geneva, World Health Organization, 2005 (WHO/CDS/CPE/CEE/2005.53).

grade 2 disability) and the quality of patient management (treatment completion rates).
- Increased efforts are required to prevent disability, assist with rehabilitation and fight against stigma.

The whole leprosy community has been involved in the further development of this new strategy. A Global Leprosy Forum was held in April 2006 in Aberdeen, Scotland, to develop the operational guidelines to implement this new strategy. Leading leprosy experts, including members of the WHO Technical Advisory Group, the ILEP Technical Commission, 10 leprosy programme managers from the key leprosy-endemic countries, and an extensive WHO Secretariat presenting the WHO regions, participated in this forum.

Given the broad international consensus and endorsement achieved in adopting both the global strategy and its accompanying operational guidelines, ILEP finds it worrying that there may still be some who wish to continue to pursue target-oriented, non-sustainable sub-national elimination. The elimination strategy has been extremely successful, but its pursuit at sub-national level risks becoming counterproductive, pressurizing field-level health staff and distorting global reporting, making it impossible to interpret the current data.

Together with all the partners represented here today, ILEP celebrates the achievements of the elimination strategy. However, we must move forward with the new sustainable, integrated approach already endorsed by WHO. Anything other than complete support for the new WHO strategy by this forum will only serve to cause confusion in the leprosy world. In the interests of all those who will continue to be affected by leprosy, ILEP believes we must all reconfirm the political commitment and effective partnerships that are prerequisites for sustaining effective and quality-assured leprosy control.

Public–private partnerships

Professor Dr Klaus M. Leisinger, President and Chief Executive Officer, Novartis Foundation for Sustainable Development

I would first of all like to express my sincere condolences, and those of the Novartis Group, to WHO and to the family of Dr Jong-wook Lee. Dr Lee had been closely involved in the fight against leprosy from his earliest days with WHO. At the recent signing of the new WHO–Novartis Memorandum of Understanding for the MDT donation, he reiterated his continued support for leprosy elimination. We regret that he cannot be with us today to celebrate the elimination of leprosy from almost every country in the world.

When we collectively embarked on this journey towards leprosy elimination, there was a lot of scepticism about whether the goal was a realistic one – about whether we would ever make it. My comment four years ago, which is still valid today, was that asking if one can eliminate leprosy is like asking if there is life after death. We will not know until we get there. But we do know that the only way to cure leprosy and to reduce the disease burden is to detect all patients and to treat them with MDT. And this is the essence of the elimination strategy.

This approach has been a full success. It hinges on all stakeholders, i.e. WHO, national ministries of health, the NGOs dedicated to leprosy work, Novartis, and patients and communities working together. The country presentations provide clear evidence of this.

Leprosy elimination is indeed a major public health success story. About 20 years ago, fewer than 5% of patients were on treatment with MDT; today, every patient in the world is receiving MDT free of charge through the WHO–Novartis collaboration. Leprosy disease stands on the verge of being eliminated from every country in the world. This proves that with necessary political will on all sides, the right strategy and appropriate tools, one can move mountains.

The leprosy drug donation programme is a practical expression of Novartis' values and our belief that a special effort needs to be made for diseases of poverty. The donation builds on the long tradition of Novartis and its Foundation in leprosy – dating back to the development of two of the three drugs used in MDT almost 40 years ago.

It is almost two decades since we at the Novartis Foundation started working to help bridge the gap between leprosy patients and their treatment. We have used a wide range of approaches, sometimes unconventional, to enhance the early detection and treatment of patients. For example, we pioneered the use of social marketing in combating this disease, to help change the image of leprosy from that of a fearful and incurable one to one of an easily curable disease. This went hand in hand with making leprosy treatment more accessible. Our approach of generating and meeting demand for leprosy services has become an integral part of the WHO leprosy elimination strategy.

We have also been involved with simplifying the provision of disability prevention and care in communities, a previously neglected area. Many of these approaches have now been incorporated in the disability care packages of governments and of NGOs.

We at Novartis and the Novartis Foundation remain fully committed to the elimination of leprosy as a public health problem. In November 2005, we signed a new Memorandum of Understanding to this end with the late Dr Jong-wook Lee. This ensures that all leprosy patients in the world will continue to have access to high-quality leprosy treatment, free of charge until the end of 2010.

The first phase of the MDT donation, from 2000–2005, has enabled the cure of more than 4 million patients and was worth US$ 40 million. The value of this second phase will range from US$ 14.5 million to US$ 24.5 million, depending on the number of cases detected over this period.

The commitment of the Novartis Group goes far beyond the monetary value of the donation. We have recently set up a state-of-the-art plant in India for MDT production. The plant has been successfully inspected and approved by the European health authorities, and the first shipments from this new plant will start from the third quarter of 2006.

We have come a very long way. Today, through early diagnosis and treatment with MDT, leprosy patients are far less likely to be disabled and to suffer the painful effects of social exclusion. They are treated alongside other patients in general health clinics around the world. The vast majority of them lead normal lives, while on treatment, and the disease then quite simply becomes a closed chapter in their lives.

We regard it as a privilege to contribute in the effort to realize the vision of a world without leprosy. This will require a continued, concerted effort by all parties to sustain the substantial gains made so far and to take leprosy elimination to the next step and focus on elimination at the sub-national level. We must retain a sense of urgency as we only have a small window of opportunity to do so in view of other pressing health demands.

Sometimes I worry that we have wasted a lot of time and energy in an academic discussion around "elimination". But let us not look back: diverting energy and time to such discussions would have a high price tag attached – one that is not paid by us but by the patients and the communities in which they live. Irrespective of whether one believes in elimination or not, or whether its focus is at the national or sub-national level, the strategy remains the same: namely, to provide patients and communities with easy and uninterrupted access to leprosy diagnosis and treatment.

We strongly believe that history does not just happen – it is made. By joining hands and focusing on further improving patients' access to leprosy services, particularly in the remaining endemic areas, we will consign the disease to history.

We look forward to a continued close collaboration with WHO, health ministries and other partners. For me personally, it has been a real privilege to have been involved in this exciting process as we stand on the brink of leprosy elimination – something one could never have imagined even 20 years ago!

Discussion

Leprosy control is reaching a critical state in international communities: while the global prevalence of leprosy has been continuously decreasing, new challenges and opportunities have emerged.

During the forum, the following key issues were identified and discussed:

Political commitment

As the number of leprosy patients is drastically reduced, political commitment may tend to shift to other diseases such as HIV/AIDS and tuberculosis. Countries should not shirk from addressing their attention to leprosy control and maintaining a high level of commitment until eradication.

Collaboration between countries

In leprosy control, every country faces the same challenges and difficulties and takes similar measures. It is therefore extremely useful to build close collaboration among countries at the field level where programme managers and health workers can share information, opinions and experiences.

Brazil has successfully integrated its leprosy control programme into the primary health-care system by learning from other countries such as Angola and India. While the nation procures free drugs from Novartis and WHO and provides technical guidance and assistance, municipalities have a primary responsibility to deliver treatments. The Brazilian case proves that it is important to exchange experiences and possible to develop a multilateral approach.

Stigma and discrimination

As a result of a very small number of new cases detected, leprosy patients ought to suffer social stigma now more than ever. Stigma is a society's reaction to a disease. Thanks to social marketing, the level of societal acceptance has improved significantly. However, a continuous global effort for anti-stigma is required. For total acceptance, the involvement of all four important parties – media, NGOs, foundations and governments – is essential.
Another issue is how to fight discrimination against leprosy patients and return them to societies. Lessons from India demonstrate that giving self confidence to people cured of leprosy (so called *logudutს*) is fundamental. They can go back to their community and say, "I had leprosy and I am cured".

Integration into the primary health-care system

Integrating health education, diagnosis and treatment of leprosy into the primary health-care system is a key success for elimination. A good surveillance and follow-up programme should also be integrated for sustainable control of the disease.

From elimination to eradication

Leprosy control is at a critical juncture: the disease has a very limited spread, and thus the level of international attention and political commitment tends to be lowering. However, the disease still exists and can resurge. The next step in leprosy control is to move towards eradication. Working together with governments and partners should make it possible to eradicate leprosy and consign the disease to history.

Concluding remarks

Dr Shaik Kahder Noordeen, President, International Leprosy Association

In the main building, near the library, there is a big poster entitled "Hidden successes and emerging opportunities". Although the poster refers to a group of neglected tropical diseases, it is most appropriate for leprosy. Hidden successes: because we do not realize the enormous achievements we have made in leprosy. Often, it is taken for granted that leprosy came to this stage on its own and not by the concerted efforts of people in countries, partners, governments and everywhere. Emerging opportunities: the discussion today brought out the emerging opportunity and that a large number of participants say, "Why don't we move from elimination to eradication even if we have to quarrel with some epidemiologists on the meanings?" When leprosy elimination as a public health problem was proposed at the Assembly of 1991, it was not the epidemiological nit-picking that was important but rather a consensus that there is a way to build political commitment. The elimination resolution did that irrespective of interpretation.

We had an excellent review of the leprosy situation in the world and in specific countries. The achievements as detailed by them are enormous, but the extent of achievements varies from country to country. Some are lagging behind but catching up.

World Health Assembly resolution 44.1 adopted in May 1991 on the elimination of leprosy as a public health problem was an historic one in the fight against leprosy, an age-old disease; the deadline set was 2000. Even though the deadline slipped in a small number of countries, progress was phenomenal.

Among the presentations, I would like to mention the fervent plea of Yohei Sasakawa, the Goodwill Ambassador, who insisted on continuing the fight beyond elimination and not as an end-point. He started the ball rolling. Let us dream of eradication at a future date. His role as Goodwill Ambassador has been pivotal in keeping political commitment in several endemic countries which he has visited, some multiple times. In the history of the fight against leprosy, his name will forever be remembered. His emphasis on empowerment of leprosy-affected people and protecting the human rights of such people through fighting stigma has been most valuable.

We heard from the ministers of health of Angola and India on the achievements in leprosy elimination; these two countries reached the goal at the end 2005. We heard from the ministries of health of Brazil and the United Republic of Tanzania on the great progress being made to eliminate the disease, with the strong hope that elimination at the national level will be reached sometime soon. The Minister of Health of Myanmar presented important efforts that are being made to sustain leprosy elimination and further reduce the disease burden. ILEP emphasized the need for further strengthening commitment towards anti-leprosy work, sustaining activities to further reduce the disease burden and ensuring quality of services. Professor Leisinger highlighted the importance of drug security and the role of his foundation and company to ensure that this essential

element of a free drug supply is not jeopardized and that leprosy elimination is sustained and the disease burden further reduced.

In conclusion, I would like to highlight five points:

1. All countries endemic for leprosy strongly commit to the goal of elimination and would like to progress further to elimination at the local level. There is also a strong urge to move towards leprosy eradication. This means that the commitment towards leprosy control will continue and hopefully will prevent complacency setting in because of the success achieved so far.

2. Countries are increasing focus on rehabilitation of leprosy-affected people and fighting the social problems of stigma and discrimination.

3. The human rights issues of leprosy-affected people have been coming to great importance recently thanks to the Goodwill Ambassador, and this issue needs to be addressed more rigorously than hitherto.

4. Positive elements of leprosy work and free drug supply need to be protected in the future as much as possible

5. Lastly, the best tribute we can pay to Dr J.W. Lee, the late Director-General, is to realize his dream of seeing a world free of leprosy and of leprosy-related problems. The word leprosy elimination was coined by Dr Lee long before the World Health Assembly. This gives us the opportunity to remember him.

Annex 1 Agenda

Friday, 26 May 2006

12:00–14:00

Opening speech
Dr Margaret Chan, Acting Director-General

Keynote speech

Dr Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination

Review of countries achieving elimination

Dr A. Ramadoss, Minister of Health, India
Dr F. Fortes, Director, Department of Endemic Diseases, Angola

Review of countries close to achieving the elimination target

Mr J. Barbosa, Secretary of Health, Brazil
Chief Medical Officer, United Republic of Tanzania

Review of countries sustaining the elimination target

Professor K. Myint, Minister of Health, Myanmar

International Federation of Anti-Leprosy Associations

Mr R. Peeters, President

Public–private partnerships

Professor Dr K.M. Leisinger, President and Chief Executive Officer, Novartis Foundation for Sustainable Development

Open discussion

Closing remarks

Dr S.K. Noordeen

Annex 2 List of participants

Invited speakers

Mr Jarbas Barbosa
Secretary of Health
Brazil

Dr Filomeno Fortes
Director
Department of Endemic Diseases
Angola

Professor Dr Klaus M. Leisinger
President and Chief Executive Officer
Novartis Foundation for Sustainable Development
WRO-1002.11.59
4002 Basel
Switzerland

Professor Kyaw Myint
Minister of Health
Myanmar

Dr Shaik Kahder Noordeen

Dr Ambumani Ramadoss
Minister of Health
India

Mr Rigo Peeters
President
International Federation of Anti-Leprosy Associations
234 Blythe Road
London W14 0HJ
England

Mr Yohei Sasakawa
President
The Nippon Foundation

*Minister of Health
United Republic of Tanzania

---

* Invited but unable to attend

WHO Secretariat

Dr Margaret Chan, Assistant Director-General, Communicable Diseases
Dr Lorenzo Savioli, Director, Department of Control of Neglected Tropical Diseases
Dr Denis Daumerie, Project Manager, Department of Control of Neglected Tropical Diseases