Global forum on the elimination of leprosy as a public health problem

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Executive summary

Leprosy, one of the most ancient, feared and disabling diseases of mankind, is on the verge of being defeated. The 1991 World Health Assembly resolution acted as a catalyst and today, 116 out of 122 endemic countries have eliminated leprosy as a public health problem.

To acknowledge unprecedented achievement against leprosy and to encourage the international community to continue its efforts, a Global leprosy forum took place on 26 May 2006 as a special section during the 59th World Health Assembly.

Since 1985, the global prevalence rate of leprosy has dropped by more than 90% and over 14.5 million patients have been cured of the disease through multidrug therapy. This success would have not been possible without a strong commitment of endemic countries supported by international community including the Nippon Foundation/Sasakawa Memorial Health Foundation, Novartis and the Novartis Foundation for Sustainable Development, bilateral organizations and national and international NGOs, notably the International Federation of Anti-leprosy associations (ILEP).

A striking feature of the leprosy elimination strategy has been twofold: improved access to diagnosis through integration of leprosy services into existing public health services and provision of effective drugs free of charge. Early detection has dramatically reduced the risk of deformities and disabilities among patients and ensured that leprosy sufferers can live normal lives with dignity.

Since 1995 WHO has provided free of charge treatment to all patients in the world thanks to significant contributions of the Nippon Foundation, Novartis and Novartis Foundation for Sustainable Development. High-level political support and social marketing campaigns to change the image of leprosy have also significantly contributed to the elimination of the disease.

Leprosy control has reached a critical state where number of patients has been dramatically reduced in recent decades but the disease still exists. As a matter of fact, in several areas and pockets within countries in Africa, Asia and Latin America, leprosy is a public health problem. Identifying the last patients at the local level is increasingly difficult thus free treatment would fail to reach them before deformities have been occurred. Therefore, greater attention should 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.

Global leprosy forum calls for stronger political commitment and further efforts to combat leprosy through a coordinated intersectoral approach, substantial funding and greater participation of NGOs and foundations.
Opening Speech

Dr M. Chan, Assistant Director-General

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

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 through the strong political commitment shown by the member countries themselves.

Since the adoption of the WHA resolution on the elimination of leprosy in 1991, 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 from 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 over the period 1995 to 2000. The other major partner of WHO 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, the remaining problem of leprosy is largely confined to 4 countries in Africa and one country each in Asia and Latin America. There are also major pockets of leprosy 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 calls for vigorous action to be taken so that leprosy elimination at global, national, and local levels is ensured. Besides this, there is an important need to sustain leprosy elimination everywhere, so that leprosy can become truly insignificant as a public health problem by the end of 2010. Therefore this is not a time to relax or be complacent, as the final phase of this fight against leprosy is as critical as the earlier phases.

By adopting a public health approach to leprosy, leprosy diagnosis and treatment have been brought closer to affected communities. Millions of patients have been protected from developing disabilities. Unfortunately, some patients have been disabled by leprosy due to the delay in starting treatment. We need to pay greater attention to their physical and socio-economic rehabilitation, and the human rights violations faced by some of them. This calls for a coordinated inter-sector approach, substantial funding and greater participation of NGOs and foundations. In this connection, the efforts made by the Nippon Foundation, through Mr. Yohei Sasakiw, the WHO Goodwill Ambassador for Leprosy Elimination, have been exemplary. The key to success in all these efforts will be a more intense participation of civil society and the leprosy affected persons themselves. 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, their easy reach, will we finally fulfil our commitment to Member States and help them free themselves from the devastating scourge and stigma of this disease.
**Dr. S.K. Noordeen**

This global forum is an important event to review the achievements made so far based on the WHA resolution 44.1 of 1991 on the elimination of leprosy as a public health problem. An earlier forum held in May 2001 reviewed progress during the first ten years. Now we are updating the progress in the following five years. All these achievements would not have been possible without the strong political commitment of the member states of WHO and the strong support provided by various partners including NGOs. With this brief introduction may I invite the speakers to make the key note address.

**WHO Goodwill Ambassador for Leprosy Elimination**

**Mr. Yohei Sasakawa**

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 DG Dr. Lee.

I spend roughly one third of the year travelling abroad mainly with the activities associated with the elimination of leprosy my destinations include both those countries that have reached the goal of elimination and those that have yet to achieve this goal.

There are three main purposes to make these trips to various countries. Firstly to talk with the politicians amongst 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 of 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 leprosy.

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 and have appeared in the last two years. This kind of coverage is very active when I go into the province 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 that leprosy is curable, that medication is available free of charge, and we are very grateful to Novartis for this, and third message 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 amongst 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 all the more it is important to enlighten these people.

There is one very important point I would like to stress here the use of the word elimination of leprosy. Now for me elimination is a milestone towards a longer journey towards eradication. But I also now as a fact that some people active in the field fear that once or they understand / misconception once elimination has been achieved this movement will be completed. 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. Ever since the 1980s we have been able to cure more than 14 million people of leprosy. Have these people been socially integrated 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 obviously is 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 the society does not accept you back into its system. There is still discrimination. There is a need to look at this social dimension of this disease – the stigma and discrimination that goes along with this disease 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 am happy to do this. I recently read the new contract and saw that a condition has been included among my terms of reference and that included my continued activity in the fight in the social aspect the 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 Sub-commission has unanimously agreed to include this in their agendas and mandate and a draft resolution to that effect has been adopted.

So in my first contract as special WHO ambassador this mandate was not included. So my activities were personally motivated. With this new contract this will greatly help boost my activities with the hr commission so I am very grateful to WHO for adding that condition.

I am hopeful that in the not to distance future that 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 side and the social dimension of leprosy. This will give boost to further solution 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 long
Standing relations with NGOs which made it possible to come up with 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 have not been 100% ideal. It is my personal wish that working together with WHO and the relevant government and the NGOs these three parties must work together to achieved 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 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 on you.

Review of countries which have achieved elimination

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 of 75% of the world’s leprosy cases in 1991 to about 0.95 per 10’000 on 31st December 2005. The prevalence fell down further to 0.84 by 31st March this year.

We have focused on the changing the vertically run programme to one that is fully integrated into the primary health care system. In fact we had modified programme of leprosy elimination, MLEC, where we had house to house surveys where we brought it down to 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 and counselling leprosy patients, families and communities. The third area has been repeated mass information campaigns on curability of leprosy so as to promote self referral to centres as Mr. Sasakawa has said. The fourth area is the provision of free availability of drugs. The focus of IEC has been to reduce the stigma associated with the disease. Lastly we have stressed on 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 the WHO, the World Bank, ILEP Sasakawa and Nippon Foundation, Novartis and DANLEP. Mr. Sasakawa has a long bonding with India he is a particular entity on our country and I would like to thank him for what he has been doing in India and across the globe. Mr. Sasakawa is so famous in India that if he stands for elections I am sure he will win.
And 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 who has been fighting for this cause. And the late Director General Dr. Lee who has done work on leprosy elimination on India for 2 years and India and myself share close bonding 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. 7 states out of about 30 and 2 union territories are yet to achieve elimination. About 26 of them have achieved elimination. We intend to focus with the same commitment, resources and energy until leprosy has been eliminated from every state, every district, every sub-district in our country.

In the new phase of the national leprosy elimination we intend to focus on disability prevention and medical rehabilitation like 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.

Once we go back to my home country we are going to sit across the table and we are going to re-strategize our leprosy eradication priorities bringing in the NGOs, both the govt and non governmental, and private sector agencies and we are going for a national consultation. We are going to re-strategize like we did for elimination stage of the modified leprosy elimination strategy which had 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 very optimistic and we are going according to our programmes and schedules. Thank you very much.

Minister of Health Angola

For many years Angola was on the list of endemic countries of leprosy in the world. The disease caused physical incapacities, stigmatization and the 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 a public health problem i.e. less than 1 case per 10,000 inhabitants.

This commitment was taken in an unfavourable post war context dominated by the high level of poverty, illiteracy, weak health services coverage and demographic instability. At that time this endemic disease in our country was characterized by the following criteria: 5,245 registered patients; prevalence rate of 3.5 per 10,000 inhabitants; 13% of patients with grade 2 deformities; 12 % children; 70% MB. 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 that proved to be effective. At the end of the military conflict with the possibility 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 transforming leprosy units into primary health units.

At the recent international day of leprosy in 2006 Angola had the pleasure to announce reaching of the established elimination target. Angola now has prevalence of 0.9 cases per 10,000 inhabitants, no relapse and only 1,400 registered active cases.

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

**Secretary of Health, Brazil: Dr. Jarbas**

Very briefly, on behalf of our Ministry of Health I want to congratulate India and Angola because they reached the goal and reaffirm our commit that Brazil will reach the goal this year or in the next year. To be very honest in Brazil we wasted a lot of time with the leprosy programme. I believe the leprosy programme in Brazil was a neglected programme. Brazil has the tools and the infrastructure – so its not acceptable that we have not reached the prevalence 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 that we achieved in only three years show the impact of this priority. In 2005, Brazil reached the prevalence rate of 1.4 case per 10,000 inhabitants and 80 states reached goal of elimination. In 2006 we launched the new plan 2006-2010. In this plan we don’t accept a prevalence rate above 1 – we want to reach this goal not only at the national level but 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 only had 2000
clinics which provided leprosy diagnosis and treatment. Today, we have more than 5000. So I believe that in this year or the next one, 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 in every state and every municipality.

So I want to finish by reaffirming my commitment. The president Lula da Silva himself is very committed to leprosy 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

Tanzania has now reached a point of 1.2 cases per 10,000 inhabitants is doing this by having a National TB and Leprosy Programme. This is one of our priorities in the Ministry of Health and doing fairly 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 in this issue and for putting the banner of leprosy on the world map.

The challenge we have is to educate the communities and health workers to enable the early detection. Stigma exists not only among people in the communities. Health workers should not stigmatize leprosy patients after all these health workers are the ones who should give the correct information and show an example to communities. You summarized the whole problem by the social dimension of leprosy.

There is need for rehabilitation of thinking and in the attitude of our health workers and communities to patients and give appropriate support. The medicines are now there, they are free, and we need to encourage communities not to stigmatize patients. From my side as the Ministry of Health, there is more than this. There is a need for rehabilitation of the complications for the ones who had and came to treat late. We need to identify them and rehabilitate them so they take active part in communities. In our new vision we are thinking that early detection and treat is extremely important so that we do not witness the complications that we are seeing now. We aim at elimination. Our current rate is 1.2 per 10,000 and 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

Minister of Health, Union of Myanmar

It is indeed a pleasure for me to speak at this forum. Myanmar, my country, used to be a country with heavy burden of leprosy. Leprosy had been a public health problem in Myanmar for many many years. And Anti-Leprosy Campaign was started in 1950/51 with the expertise and advice from the 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 the prevalence rate to 19.3 per
10,000; in 1997 registered cases were 13,357 with a prevalence rate of 2.9 per 10,000; in 2003 registered cases were 2,742 with a prevalence rate of 0.51 per 10,000 and in 2005 registered cases were down to 2,679 with a prevalence rate of 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 in 1995. To achieve the 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 workers staff
- Improved geographical coverage
- Established 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 under Ministry of Health and National Health Committee. The National Taskforce is a working group which 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 National Taskforce of Leprosy Elimination, officers from WHO and representatives of NGOs. Its main role was to review the work plan annually and provide the necessary support.

The main activities for achieving leprosy elimination were reviewed and identified:

- the job description of leprosy staff and basic health staff.
- Building partnerships and improving the capacity of health service providers and partners for example the Myanmar Maternal and Child Health, Myanmar Medical Association.
- Intensification of routine activities through proper planning
- Implementation, monitoring and evaluation.
- Conducting special activities like leprosy elimination campaigns, improving geographical coverage for leprosy elimination activities, improving awareness of general community as well as targeted groups after identifying needs'
- assessment
- health systems research and
- improving the programme based on the key recommendations were carried out.

Advocacy meetings at different level 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 participatory planning implementation monitoring supervision, evaluation of the activities were 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 of leprosy elimination activities Mr. Yohei Sasakawa and the remark is 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 has inspired me a lot at that time to try very hard at 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 can only be seen 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 has already achieved leprosy elimination at the national level by January 2003. The elimination status was declared at the third meeting of the Global Alliance for Elimination of Leprosy (GAEL) held in Yangon Myanmar February 6 2003 by Dr. David Heymann, then Executive Director of Communicable Diseases of WHO Headquarters at the same time the Yangon declaration was also formulated.

The achievements were due to the strong political commitment on the part of the government, technical support of WHO, free supply of MDT drugs from the Sasakawa Health Memorial Foundation and the Novartis Foundation. Close collaboration with international NGOs 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. After achieving elimination, appropriate activities were conducted to sustain leprosy continued. They include reducing the burden of leprosy and prevention of disabilities and rehabilitation of persons affected by leprosy.

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 American Leprosy Mission, Netherlands Leprosy Relief, Japan Inter-cooperation agency and the Leprosy Mission International, national NGOs from Myanmar, the Red Cross Society and persons affected by leprosy (PALS) and members from writers and journalist associations and members of the National Taskforce and officers from the department of health. The strategies laid down in the workshop were to continue the on-going activities in hardship areas, uncovered areas and areas with migratory populations.

To sustain the elimination status and to conduct prevention of disability and rehabilitation, the establishment of a surveillance system and referral centres for quality care of persons affected by leprosy and community involvement in community based rehabilitation were our main strategies. 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 health 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 with 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 (ILEP)

Mr Rigo Peeters, President, ILEP

ILEP is an International Federation of Anti-leprosy Associations. Its fourteen member associations support work in 84 countries where leprosy is endemic and spend over €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 with WHO's Global Leprosy Programme and 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 to further reduce the Leprosy Burden and Sustaining Leprosy Control.

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. ILEP's mission however, is to work for a world without leprosy and to this end we recognise the importance of moving beyond the elimination goal.

The elimination strategy, while effective in reducing the 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: 'Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities - 2006 - 2010'. 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 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 targets which can reflect both the timeliness of detection (new cases with grade two 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, UK 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, ten leprosy programme managers from the key leprosy endemic countries, and an extensive WHO Secretariat presenting the WHO regions, participated in this Forum. The Operational Guidelines have been finalised and endorsed by the WHO Technical Advisory Group and by the ILEP Technical Commission and are due to be published by WER shortly.

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 levels risks becoming counter productive, pressurising field level health staff and distorting the 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 which are prerequisites for sustaining effective and quality assured leprosy control.

Public/Private Partnerships

Professor Klaus M. Leisinger, 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 has 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 Multiple Drug Therapy 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's 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. the World Health Organization, the national Ministries of Health, the NGOs dedicated to leprosy work, Novartis, 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 less than 5% of patients were on treatment with MDT; today every patient in the world is receiving free MDT, 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’s 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 40 million US dollars. The value of this second phase will range from 14.5 million dollars and 24.5 million dollars 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’ve 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 a 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 is paid for by the patients and the communities they live in. 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!

**Discussions**

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

During the forum several key issues are identified and discussed as follows:

**Political commitment**

As the number of leprosy patients is drastically reduced political commitment may tend to shift to an increasing number of other diseases such as HIV/AIDS and TB. Countries should not shirk from addressing their attention to leprosy control and maintain 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. Therefore, it is extremely useful to build a 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 primary health care system by learning from other countries such as India and Angola. 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**

Due to 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. Thank to social marketing the level of societal acceptance has a significant improvement. However, a continuous global effort for anti-stigma is required. For the total acceptance, the involvement of all four important parties, namely, media, NGOs', foundation and government, 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 loguduts) is fundamental. They can go back to their community and say “I had leprosy and I am cured”.

**Integrate in the primary health care system**

To integrate 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 a sustainable control of the disease.

**From elimination to eradication**

Leprosy is faced with a critical state in which the disease is in a very limited spread thus the level of international attention and political commitment tends to be lowering. However, the disease still exists and can be resurged. The next step of leprosy control should move towards eradication. Working together with the governments and partners it would be possible to eradicate leprosy.

**Concluding comments**

**Dr. S.K. Noordeen**

In the main building near the library there is a big poster entitled “Hidden successes and emerging opportunities”. Although the poster refers to group of Neglected Tropical Diseases it is most appropriate for leprosy. Hidden successes because we don’t realize the enormous achievements we have made in leprosy. Often its taken for granted that leprosy came to this stage on its own and not by concerted effort by 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 is there 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 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.

The World Health Assembly Resolution 44.1 adopted in May 1991 on the elimination of leprosy as a public health problem was a historic one in fight against leprosy and age old
disease, the deadline set was 2000. Even though deadline slipped in a small number of countries the 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 end point. He started ball rolling - let us dream of eradication at a future date. His role as Goodwill Ambassador has been pivotal keeping political commitment in several endemic countries which he has visited, some multiple times. In the history of the fight against leprosy and accomplishments, his name will forever be remembered. His emphasis on empowerment of leprosy affected persons and protecting human rights of such persons through fighting stigma has been most valuable.

We heard from Ministry of Health Angola India on the achievements of leprosy elimination and these two countries reached the goal at the end 2005. We heard Ministry of Health Brazil, the United Republic of Tanzania on the great progress being made to elimination with strong hope will reach elimination at the national level sometimes soon. The Ministry of Health Myanmar presented important efforts that are being made to sustain leprosy elimination and further reduce the disease burden. ILEP brought out the need for further strengthening commit towards anti-leprosy work, sustain activities to further reduce disease burden and ensure 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 free drug supply so that leprosy elimination and sustaining and further reducing burden does not suffer.

In conclusion I would like to highlight 5 points:

1. All leprosy endemic countries strongly commit to goal of leprosy elimination and would like to progress further to leprosy elimination at the local level. There is also a strong urge to move towards leprosy eradication. This means that the commitment towards leprosy will continue and hopefully will prevent complacency setting in because of the success achieved so far.
2. The countries are increasing focus on rehabilitation of leprosy affected persons and fight the social problems of stigma and discrimination
3. The human rights issues of leprosy affected persons is coming to great importance recently thanks to goodwill ambassador and this needs to be addressed more rigorously than done hitherto.
4. Positive elements of leprosy work and free drug supply needs to be protected in the future as much as possible
5. Lastly the best tribute we can pay to J.W. Lee, the late Director General is to realize his dream on seeing a world free from leprosy and also leprosy related problems. The word leprosy elimination was coined by him long before the World Health Assembly.