

FOR THE ELIMINATION OF LEPROSY

Leprosy is Curable.

Free Treatment is Available.

**Social Discrimination has
no Place.**

A MESSAGE FROM THE SPECIAL AMBASSADOR

My work in leprosy elimination has spanned more than 30 years. However, the roots of my work go even deeper than that, covering two full generations. My late father Ryoichi Sasakawa (1899- 1995), who founded The Nippon Foundation in 1962, deeply involved himself in the work of elimination. He had been immensely touched by the social effects of the disease since childhood, when he witnessed what happened to a beautiful young woman in his village who had contracted the disease. She was not allowed to marry the man she loved, was confined to her home and eventually was forced to leave. Seeing this made my father determine to eradicate leprosy from the surface of the Earth. I share in his determination and when I came to the foundation, we worked together. Since his passing, I have continued pushing toward the elimination of leprosy as my life's work. I have taken up his oath to rid the world of this ailment that has been around since the beginning of history.

Leprosy in fact has been a disease that makes human beings suffer for centuries. Since the dawn of recorded history, there have been numerous references to leprosy. Accounts of it can be found in the Old and New Testaments, the ancient documents of China and Indian classics from the sixth century B.C.

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Yohei Sasakawa
WHO Special Ambassador
President, The Nippon Foundation

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I am sure that there are some who do not understand what leprosy is. For much of history, it has been an incurable disease. It is an ailment that affects the skin and nerves of the people who suffer from it. If left untreated, it can lead to a certain amount of disfigurement, although deaths that occur directly from leprosy are rare in the extreme. As a result of this characteristic, through history, the leprosy-affected have suffered under a tremendous social stigma, often leading to banishment and disownment. This stigma has in turn made the disease one of the most feared in the history of humankind.

However, in 1981, the World Health Organization began to promote the use of a multidrug therapy, or MDT, as a complete cure. In 1985, there were 122 countries registered as being officially leprosy-endemic which, in medical terms, means that they had a prevalence of more than 1 case in 10,000. The effect of MDT has been simply stunning. Since 1985, the number of officially endemic countries has fallen dramatically, and the leprosy burden is now mostly concentrated in six nations. The number of patients has fallen from 5.3 million to fewer than 600,000.

These results were accomplished thanks to the dedicated efforts of WHO, governments and NGOs to truly use the discovery to bring about the greatest possible outcome. During the last 27 years The Nippon Foundation, of which I am the president, has provided the global elimination campaign with approximately \$200 million, working through WHO and the Sasakawa Memorial Health Foundation. As a part of this, we provided free MDT to any patient in the world from 1994 to 1999. Following that, Novartis took up the baton and is currently providing this service. I am convinced such continuous effort has brought about the drastic decrease in the number of leprosy patients around the world. Today, we stand at the point where this millennia-old disease can be eliminated; it is simply a matter of time.

However, it is said in Japan: "In a journey of 100 miles, the 99th mile is no better than half-way." The final mile is perhaps the most arduous.

WHO has given us a goal: elimination by the year 2005. For our final push toward this objective, in 1999 WHO organized the Global Alliance for the Elimination of Leprosy. This Global Alliance, which we often refer to as GAEL, is made up of the governments of endemic countries, The Nippon Foundation/Sasakawa Memorial Health Foundation, Novartis/Novartis Foundation for Sustainable Development, WHO, the World Bank, Danish International Development Assistance (DANIDA) and various NGOs. It is an alliance of diverse partners, working from diverse angles to achieve our clear numerical target: elimination in each and every country of the world by the year 2005.

At the first GAEL meeting, held in India in 2001, I was appointed to be the special ambassador. Since then, I have made elimination my highest priority and have worked in every endemic country in the world.

Through my work I have become convinced that we must focus on three important points if we are to achieve elimination. First, it is imperative that political leaders feel a strong commitment to the goal of elimination. Second, the support of the media is vital. And third, it is necessary to bring together a variety of different actors, such as WHO, the World Bank, national governments, international organizations and NGOs. The work of the Global Alliance is thus indispensable.

In my role as the special ambassador, I have attempted to achieve two fundamental aims. First, I have not only worked to obtain the firm commitment of the political leaders of endemic countries, but I have also urged them to grasp this window of opportunity and heighten the priority given to elimination within their governments. Second, I have been appealing to the media of the world to disseminate correct information on leprosy to the general public. It is particularly important for both of these groups to spread the following three messages: *Leprosy is curable; free treatment is available at all primary health centers; discrimination has no place in today's world.*

I have come to believe that it is necessary for us to reach people working for the public good, within and outside the field of leprosy. These people's support is very important, and they need to be in possession of all of the correct facts about the disease. If we can obtain the help of non-leprosy NGOs, we can then reach a much larger audience through them, turning our effort into a genuine social movement. We are at the point where we can motivate people in the community to take a vested interest in leprosy elimination. This newsletter is designed to achieve this kind of broad audience.

This publication is not the official newsletter of WHO or GAEL. Instead, it is something that I am producing in my capacity as special ambassador, with the support of The Nippon Foundation and the Sasakawa Memorial Health Foundation. It will include reports of my work as special ambassador, articles on GAEL activities, features on the elimination activities of endemic countries, the stories that individuals have to tell and more. Contributions are welcome. I hope that this newsletter will serve as a medium for information exchange among those working for leprosy elimination as well as those involved in non-leprosy related activities.

It is my sincerest hope that this exchange of information will become a major force, turning the leprosy elimination campaign into a global social movement. □



©Photo by Natsuko Tomioka

The opening ceremony of the 3rd GAEL Meeting.

GAEL MEETING

The Global Alliance for the Elimination of Leprosy

Third annual meeting, held in Myanmar, reaffirms collaboration among members.

From February 6 to 8, the Third Annual Meeting of the Global Alliance for the Elimination of Leprosy (GAEL) was held in Yangon, Myanmar. The meeting was organized by the World Health Organization, funded by The Nippon Foundation, and hosted by the Ministry of Health of the Government of the Union of Myanmar.

What is GAEL?

GAEL was created in November 1999 by WHO as a way to coordinate leprosy elimination efforts around the world, and thus achieve WHO's goal of eliminating the disease as a public health problem (reducing its incidence to less than one patient per 10,000 people in the population) in every country of the world by the year 2005. While elimination was achieved on a global scale in 2001, several countries remain that have yet to reach that goal. The alliance aims to bring together all of the key players in this fight, and thus comprises a rather lengthy list of very active and influential groups. Included are the governments of endemic countries, WHO, The Nippon Foundation/Sasakawa Memorial Health Foundation, Novartis/Novartis Foundation for

Sustainable Development, Danish International Development Assistance (DANIDA), the World Bank, Handicap International, and many national NGOs, such as Pastoral da Crianca and MORHAN, both of Brazil. Additionally, the positions of chair and vice chair rotate annually through the group; this time, the chairmanship was passed from Brazil to Myanmar, while the vice chairmanship went from Nepal to Mozambique. In this way, every country in the group receives a chance to lead and thus is encouraged to take an active role. By coordinating the efforts of all of these groups, WHO is confident that its 2005 goal will be attainable. Indeed, since the formation of the group, the number of endemic countries has fallen dramatically.

The first two meetings of GAEL were held in New Delhi, India and in Brasilia, Brazil. Since its start, the alliance's work and its success have renewed enthusiasm about leprosy elimination among politicians, policy-makers and program managers. Equally important it has stimulated media campaigns in endemic countries, which are helping to overcome the stigma traditionally associated with the disease. To make the efforts of the various groups as efficient as possible, WHO is providing technical and strategic leadership to the elimination

program, as well as operational guidance. The Nippon Foundation has pledged \$24 million to implement the group's Final Push. Novartis is providing free MDT for all patients (currently valued at \$30 million). DANIDA and the World Bank is supporting leprosy elimination efforts in India. With such strong support, WHO's goal is coming closer and closer to being realized.

The Myanmar Meeting: Overview — Myanmar Achieves Elimination

The Third Annual Meeting began with an inaugural address by His Excellency General Khin Nyunt, Secretary-1 of the State Peace and Development Council, Government of the Union of Myanmar. In his speech, he astounded the assembly by announcing that Myanmar had just reached the elimination target in January 2003. Such a proclamation of success reassured the members that their efforts are indeed important and effective. The meeting thus continued in a very upbeat and proactive tone.

H. E. Professor Kyaw Myint, minister of health of



H.E. General Khin Nyunt announces leprosy elimination.

the government of the Union of Myanmar, then offered a warm welcome to the participants. Following this, in the introductory session, statements about the current global leprosy situation were delivered by Dr. Uton Muchtar Rafei, director of WHO Regional Office for South-East Asia, Dr. David Heymann, executive director for Communicable Diseases at the WHO and Yohei Sasakawa, president of The Nippon Foundation, who presented his report as a special ambassador.

In the following session, reports were given by WHO regional directors and other representatives from the Regional Offices for Africa, the Americas, the Eastern Mediterranean and the Western Pacific.

The ministers of health of GAEL member coun-

tries presented reports on the state of affairs in their respective countries, including major challenges and activities that are planned to further progress toward elimination. The countries that made presentations were Angola, Brazil, Central African Republic, Democratic Republic of Congo, Guinea, India, Indonesia, Madagascar, Mozambique, Myanmar, Nepal and Niger.

Both since the meeting was held in Myanmar, and due to the recent success of that country, there was a special session held, entitled, "Challenges and Achievements of the Myanmar Leprosy Elimination Programme: Experiences of Health Workers." The session was lead by Dr. Kyaw Nyunt Sein, deputy director, department of health, ministry of health. In this session, it was reaffirmed that the Yangon meeting was historic, due to the fact that the elimination target had been achieved in Myanmar. This achievement was all the more impressive for the fact that it was realized several months ahead of the official deadline.

Working Groups

The plenary sessions were important. However, one of GAEL's strengths is its ability to mobilize and coordinate health workers at various levels. As befits such a group, three working groups were organized that focused on the more concrete aspects of the elimination movement. These groups debated three different topics: Political Support for Integration, Paradoxical Detection Trends and Challenges for Elimination in the Remaining Countries. The lively discussions left participants feeling upbeat and inspired as they headed into the final stages of the fight to eliminate leprosy.

To conclude the meeting and lay the groundwork for future efforts, a document was drawn up, entitled "The Yangon Declaration." This paper set forth the tenets of the Third Meeting, chief among which were:

- an endorsement of the strategic plan, with emphasis on the fact that integration of treatment services and a change in leprosy's negative image are necessary;
- an acknowledgment that only 12 endemic countries remain and that special efforts should be made to help them reach the 2005 deadline;
- thanks to the special ambassador for his work; and
- an acknowledgement that services to women and many underprivileged groups remains insufficient.

A complete copy of this paper can be found at The Nippon Foundation's home page,
www.nippon-foundation.or.jp/eng/ □

Interview with Prof. Upendra Devkta, M.D., Health Minister, Nepal

The following conversation took place on February 7, during the Third GAEL Meeting in Yangon.

Special Ambassador Sasakawa: Your Excellency, please tell me about the current state of the leprosy elimination effort in Nepal.

Upendra Devkta: First, I would like to commend those countries that have achieved, in a very short amount of time, the target set by the World Health Organization for the elimination of leprosy, for example, Myanmar. While we applaud that, I would like to say the leprosy elimination program in Nepal is also on the right track. We might not have been able to drastically reduce the curve, but there is steady progress in terms of case reduction. At the moment, we have somewhere around 3.4 per 10,000. We should be able to make the target on time. There have been both good points and a few shortcomings as well in our leprosy elimination program. The good points are that (A) we have a good network of institutions. Under the ministry there are about 30,000 staff members, so we don't need to recruit other people. The second point, (B), is integration. We have integrated our health-care system, so the same peripheral health worker who gives drugs for tuberculosis is going to give anti-leprosy drugs as well.

So we are integrated in terms of manpower and integrated in terms of programs. We don't have any of this "I'm a TB man, I don't give leprosy drugs," or "I'm a polio man, I don't give leprosy drugs." Our leprosy, polio and TB all are integrated at the delivery point. This is a good strategy to cure the disease, and we believe that is the way to go.

Otherwise, if we were not consolidated, you would have the kind of situation where the staff would eliminate a lot of the cases and then in the future forget how to take care of the few new cases that came in. You would be left with nobody who knew how to treat leprosy. But if you integrate the health services, then there will always be people who can treat it.

Now, the reason why the figures are still not as respectable as I would like — maybe I would have been happy if it had been 1.5 or 1.75, or something like that — the reason for that is that there is a lot of social stigma attached to this. And second, we have very difficult geographic terrain. Although institutions are there, people have to travel long distances to get to the health



Special Ambassador Yohei Sasakawa (right) with Nepal Health Minister Upendra Devkta.

©Photo by Natsuko Tomimaga

centers. I think that these are the two major problems. I don't think we have a problem with drug supply.

What we think we should be doing is, of course, continuing our current mass campaign to remove stigma. I think that we need to intensify our case-detection campaign, especially in heavily endemic areas. Finally, to enhance public awareness, we need to have more training for the people — especially journalists and other media people.

S: I understand that the logistics for the treatment of patients are successfully managed, but the problem is how to get patients to come for the treatment, come to the health center and take medication. One reason is the strong stigma. In West Bengal, India, I learned that there used to be a strong stigma but that now almost 90 percent of people come for treatment. What are needed are thorough publicity activities so that people become aware of availability of treatment. Those people who come late for treatment usually have deformities. We need to get them to come in sooner.

D: Publicity is already there, but again, we need to intensify. A lot of things have been achieved in a very short period of time. It is significant that the Nepalese prevalence rate has gone down from 70 to 3.4 in 15 years. That's not insignificant, but we still need to intensify our activities. What I have seen happen is that the leprosy patients have come to have absolute confidence. They are no longer stigmatized. In my own experience as a neurosurgeon, leprosy patients used to be very shy. This happens no more. They openly talk about the disease. Now they come forward. They say, "I am cured, I've taken treatment for this." Mass education takes time

but it really is a very significant and steady process. I think we should be able to accelerate it a bit. But I do know that we have a saying: “When the pot is boiling, you don’t need to heat it a lot.”

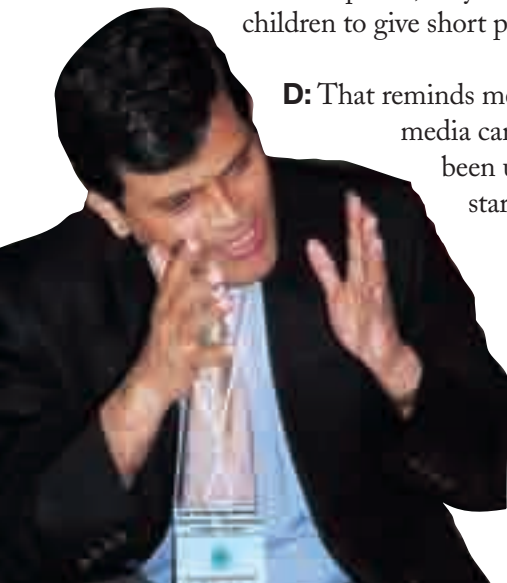
Our education program is very well planned and the mass media campaign is very regular. Every day, people see the television and come to the health centers, knowing that leprosy is curable. The message is very clear. The Nepalese believe that you are reborn 8.4 million times. In the past, they said that if you did something very sinful in a past life, you would be born with leprosy. But today, that is thought of as nothing but a story. This is a very positive change in terms of cultural education. We will, however, definitely intensify our efforts. We will do case detection campaigns targeted especially at bad areas, and our regular case detection programs need a bit of focus, but we should be able to handle that. I would like to invite you to see some of the areas where leprosy is still endemic. The deformity rate is gradually decreasing. Surgeons in leprosarria are highly qualified and even non-leprosy patients are seeking their treatment as well, as they do not mind entering those facilities. Leprosy patients don’t mind being called leprosy patients. So in other words, it is not a problem.

S: Wonderful. Looking at the high endemic figures of the past, we can see that what you have accomplished is significant. But the final mile in a 100-mile journey is most difficult.

D: One thing I would like to add is that for the leprosy elimination campaign, we need to translate things into local languages. Messages are very effective in mass education if they are translated into local languages.

S: If we look at the Indian and Mozambique examples, they have the same kind of language issues. Even if you do campaigns through TV and newspapers, they may not effectively reach the local people as we want them to. In these places, they have been using school children to give short plays or sing songs.

D: That reminds me of our own mass media campaign. We have been using a very popular star to sing songs on TV.



S: That’s an excellent idea. Now, if I may change the topic, some people say that due to political turmoil in your country, it is difficult to make leprosy elimination activities effective. They say that we should wait until order is restored before really trying to work on the leprosy campaign there.

D: This is a very ignorant opinion. Today, 90 percent of health institutions are active. Even in the areas controlled by Maoist groups, health activities are continuing. Medical supplies are regularly provided in these areas. In the past, people were concerned that supplying these kind of medicines to the countryside would make the Maoists stronger. But when I became minister, I said that what rebels need are surgeons who can heal wounds, or fix broken bones. These services are today available only in the cities, which the Maoists do not control. Leprosy supplies are not going to make the Maoists any stronger and so why should we stop the supply lines? TB tablets or leprosy tablets or aspirin are not going to make the Maoists any stronger. Now the lines are open.

S: NGOs’ involvement is important and in Nepal we understand many NGOs are active. However, we have heard there was a certain period when NGOs were kicked out of the country. What do you think of the future of collaboration with NGOs?

D: We work with NGOs to intensify elimination activities. They can carry on as long as they like. But we have got our own mechanisms. I think that in the leprosy sector, we have achieved an excellent symbiosis. It has not been the policy of the government to kick out leprosy-related NGOs. They are not troublemakers. Of course, there are other NGOs creating a lot of trouble. Sometimes with them, we are not sure who is in the driver’s seat — them or the government. Again though, I have nothing but appreciation for what the leprosy NGOs have done.

S: In closing, what do you think of this GAEL meeting?

D: I think it is helpful. No doubt about it. Extremely helpful to come to a global consensus. One point that I would like to make is that while the sharing of success stories is good, it is sometimes more helpful to share failure stories. You sometimes learn more from the failures of others. In future meetings of GAEL, it will be good if we have a session in which we can listen to failure stories.

S: Good point. I’m sure we can all benefit from it. Thank you for talking with us. □

THE SPECIAL AMBASSADOR'S JOURNAL, 2002

Starting with this first newsletter, we will be presenting excerpts from the special ambassador's 2002 journal. As WHO special ambassador, Yohei Sasakawa spent a considerable amount of time in countries where leprosy is classed as endemic by the World Health Organization. In those countries, he met with political leaders to emphasize the importance of the elimination campaign, held press conferences to ensure that correct information about the disease reaches a wide segment of the population, and visited the frontlines: the health centers, hospitals and villages where the elimination movement is being pursued with vigor. When he went to countries where leprosy has already been eliminated, he visited villages and rehabilitation facilities to meet former patients and their caretakers.

In 2002, he traveled to such countries as Brazil, Malaysia, Mozambique, Papua New Guinea, the Philippines and India. This issue's entry covers a trip to Brazil, where the second meeting of GAEL was held.

January 2002, Brazil Meeting with President Henrique Cardoso — “NGO Involvement is Crucial”



Yohei Sasakawa (left) with President Cardoso of Brazil

My first leprosy-related activity of the year 2002 took place in Brazil when I participated in the Second GAEL Meeting, held in Brasilia from January 29 to 31. Taking advantage of this opportunity, I met with then President Fernando Henrique Cardoso on January 30 and asked his excellency to give leprosy elimination a high priority among the country's many public-health issues. President Cardoso expressed his willingness and a strong commitment to promote leprosy elimination as an important part of his government's agenda. He evaluated the concept of GAEL highly, placing

crucial importance on the collaboration between different stakeholders, such as those in GAEL, in the fight for public health. He particularly pointed out the important role NGOs play, citing the successes of such groups on the issue of HIV/AIDS in Brazil. I left feeling that the health of Brazil was in exceedingly capable hands.

Elimination in Rural Amazon Villages: The Important Role of Local Medical Staff



With the family of a patient in Amazon

I also had an opportunity to visit the Amazon State capital of Manaus and the nearby city of Manacapuru, both of which have a high incidence of leprosy. The Health Bureau of Manaus kindly arranged for us to visit clinics and nearby villages where leprosy patients live. We traveled with local paramedics to small villages on the banks of the Amazon River, where we visited the homes of people undergoing treatment. I was very impressed with these paramedics' dedication to detection, medical care, record keeping and skilled operational management. I was deeply touched by the warm care given by family members. Contrary to what has often been the case in the past, in that region the patients are not abandoned but protected and cared for by loved ones. This degree of warmth would not have been possible without a successful campaign of information dissemination.

I returned to Japan with two firm beliefs: that the dedication of these field workers, working silently but efficiently on the periphery, is vital if we are to achieve elimination, and that strong and loving families are essential to social rehabilitation. □

(to be continued)

Editor's Note

With this publication, we are aiming to reach not only specialists in the field of leprosy elimination, but a much wider group of people who might not have given much thought to the leprosy elimination campaign before. It is our hope that, if we can obtain the understanding of the general public, we will truly be able to achieve the 2005 elimination goal. Your support is invaluable.

As you may already know, this issue's focus was on the 2003 GAEL meeting in Yangon, Myanmar. Since that country achieved elimination this past January, next time, we plan to do a special feature on Myanmar and its elimination campaign.

We will publish this newsletter at least six times a year. From next issue, we hope to begin publishing not only hard, factual articles about organizations and movements within the field, but also print more human stories about people working in the field, people who have been affected by leprosy, people who have made a difference in the lives of those around them. For this, we would like to appeal to our readers to offer your advice, comments and whatever stories you have to contribute. In this way, together we will make this newsletter a deeply meaningful tool, delivering messages that need to be heard, to people around the world.

Walk together with us over the course of this final mile of our 100-mile journey. We look forward to hearing from you and working with you.

Tatsuya Tanami,
Editor in Chief



MDT Blister Packs

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Publisher

Yohei Sasakawa

Editor in Chief

Tatsuya Tanami

Proofing Editor

James Huffman

Contributing Staff

Mihaela Serbulea, Akiko Nozawa

Editorial Office

WHO Special Ambassador's Newsletter

5th Floor, Nippon Foundation Building

1-2-2 Akasaka, Minato-ku, Tokyo 107-8404, Japan

Telephone: +81-3-6229-5601 Fax: +81-3-6229-5602

Email: smhf_an@tnfb.jp

With support from: The Sasakawa Memorial Health Foundation
The Nippon Foundation

www.nippon-foundation.or.jp/eng/

Contributions or comments should be addressed to the Editorial Office as listed above

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