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# A Life Fighting Leprosy

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A Collection of the Speeches and Writings of  
**Dr. Yo Yuasa**



Sasakawa Memorial Health Foundation



Dr. Yo Yuasa in 2001

*Y. Yuasa*

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# Foreword

Shigeaki Hinohara, MD

Honorary President, Sasakawa Memorial Health Foundation  
Honorary President, St. Luke's International Hospital

It is my great pleasure to see this collection of the speeches and writings of Dr. Yo Yuasa compiled and published as they reflect some three decades of intensive public health efforts by many individuals who have made it their mission to free humanity from the scourge of leprosy, or Hansen's disease. Without a doubt, Dr. Yuasa is one of these.

It is also a very timely undertaking, as the book attests that the reduced disease burden of leprosy we see today is due in no small measure to the work of these dedicated individuals. They personally felt the gravity of the suffering of the afflicted and took up the challenge to expand the reach of the cure, not for statistical success, but for the betterment of people's lives.

Our first encounter was at the 1<sup>st</sup> International Workshop on Leprosy Control in Asia held in Japan in December 1974, organized by the newly established Sasakawa Memorial Health Foundation (SMHF). Dr. Yuasa was one of the invitees from Nepal, where he was the medical superintendent of The Leprosy Mission's Anandaban Leprosy Hospital, and I was a board member of the foundation.

The three decades that followed saw unprecedented changes in the world of leprosy. The biblical image of the disease has been largely transformed by

modern medical advances, among them MDT, a combined chemotherapy regimen. Dr. Yuasa was at the forefront of this fight, carrying out our foundation's mission to free the world from leprosy by reaching out to those in need of cure. He successfully placed SMHF in alliance with an international agency, the governments of leprosy-endemic countries and non-governmental organizations in order to achieve the maximum benefit for people with leprosy. This book illustrates his faith in public health pathways and his enthusiasm for bringing an end to the millennia of suffering caused by this disease. He has gone about his work "Quietly, firmly, faithfully, brilliantly," in the words of a certificate of appreciation he received from American Leprosy Missions in 2005.

It is gratifying to see the continuation of global efforts to realize a world in which no one suffers from the unfortunate consequences of leprosy. At 103 years old and Dr. Yuasa's senior by 15 years, I do not believe it is realistic to think that either of us will witness that achievement in our lifetimes; we both have faith, however, that one day the world will succeed in making leprosy history.

June 2015

Shigeaki Hinohara, M.D.

A handwritten signature in black ink that reads "Shigeaki Hinohara, M.D." The signature is written in a cursive, flowing style.

# Global Strategy in Leprosy Control

Dr. Yo Yuasa

Executive and Medical Director  
Sasakawa Memorial Health Foundation

## I. Introduction

Good morning, ladies and gentlemen:

Before making my presentation this morning, I think I owe you a bit of an apology or an explanation, because the title is “Global Strategy in Leprosy Control.” I was just told by Dr. Teera that my talk is a kind of keynote speech, and that the discussion over the next three days will be partly based on what I say this morning. I really feel rather inadequate for the task of talking about the global strategy. You may have thought that I am going to announce some new policy or strategy formulated by the WHO or some other similarly authoritative body. In fact, what I am trying to do this morning—apart from

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National seminar on leprosy control, Bangkok, Thailand, August 1982

briefly introducing the new WHO-recommended treatment scheme—is just to present my own views on the things that are related to leprosy control, now and in the future, and I am hoping that some of the things I say this morning will be useful for your deliberations and discussions over the next three days.

My task is a bit difficult, too, because I understand that the audience this morning is somewhat of a mixed group. I am not addressing only leprosy specialists, and I am not addressing the medical profession as such. And so, necessarily, some of the things I say may not be quite relevant to some of the people in this group, but I hope, in general, that my presentation is useful in one way or another to most of you.

## II. What Is Leprosy?

Let us start by asking the question: “What is leprosy?” I must admit that sometimes I am quite amazed by the lack of understanding, even among members of the medical profession, of the true nature of leprosy. So please bear with me while I talk in general terms about leprosy, a subject that most of you should know quite well.

### 1. Leprosy—an infectious disease

Leprosy, of course, is accepted to be one of the oldest human diseases and we know from the ancient literature of China, India, Egypt and elsewhere that the people of these old civilizations knew about leprosy and had some understanding of it. Sometimes they even had some remedies for the disease. But at the same time, as you know, leprosy has been and still is one of the most misunderstood and feared diseases.

As you are well aware, leprosy became as much a social problem as

a medical one. I don't want to go too much into this aspect this morning, but basically I think this is due to the failure of the medical profession to deal adequately with leprosy as a medical problem and solve it effectively. Because of the failure of the medical profession to provide an effective cure for leprosy, the patients were left at the mercy of the natural process of the disease, resulting in severe deformities and disabilities. These, in turn, caused them to be separated from or rejected by their families and neighbors, which became a severe social problem.

The usual solution of society for dealing with such people in the past was just to discard them from their own community. However, I don't know that we can blame them too much for doing so, really, and in a way what they did was not entirely wrong because it was a form of enforced isolation of patients with an infectious disease.

This policy of segregation was adopted in modern society as well, with some medical justifications. It was vigorously enforced in Japan almost up to the end of World War II, although the public health merits of that policy are controversial even now. It was also strictly applied in countries such as Norway, although its implementation had many humane aspects. Until an effective cure for leprosy was found, physical isolation as against so-called "chemical" isolation was the only available method of preventing leprosy spreading in society, and that was in accordance with public health principles, i.e., trying to prevent the disease from spreading in the community and infecting healthy people.

Although people in the past did it for the wrong reasons, somehow they might have perceived unconsciously that leprosy was infectious and that the patient had to be removed. All those wrong notions about leprosy, such as it being a punishment by God and so on, are, I think, a kind of retrospective

justification for an act about which they must have had an uneasy conscience or a guilty feeling; and, of course, those people did not have medical knowledge to explain and justify the necessity of isolating leprosy patients.

So the first thing I want to mention about leprosy is that it is an infectious disease and not a hereditary one. Unfortunately, quite a number of people still believe that leprosy is inherited, even though this erroneous idea was publicly refuted at the 1<sup>st</sup> International Leprosy Congress held in 1897 in Berlin, approximately 90 years ago. The meeting was attended by Dr. Armauer Hansen, the Norwegian who discovered the causative organism of leprosy, called *Mycobacterium leprae*, in 1873.

Perhaps you will remember that *Mycobacterium tuberculosis*, the causative organism of TB, was found in 1882 by the renowned Dr. Koch, so the leprosy bacillus was perhaps one of the earliest pathogenic microorganisms in humans to be discovered. The Berlin Congress was also attended by some other well-known figures in medical history, such as Dr. Virchow, Dr. Nisser and Dr. Kaposi, and in that meeting they definitively confirmed that leprosy was an infectious disease. They also said that leprosy was transmitted only from infectious leprosy patients; thus, human beings were the only source of leprosy and there was no other reservoir of the infection.

The most interesting thing is that, nearly 90 years ago, they also mentioned that the nose or the nasal mucosa of patients would probably be the main source of the infective organism. Perhaps many of you were taught that leprosy is the result of a prolonged skin-to-skin contact. Even though we are now quite certain that the most likely main source of infection is discharge from the nose, we still have to retain the idea of skin-to-skin contact in some cases, and even the possibility of insects such as mosquitoes, acting as vectors.

Leprosy has been known, particularly by leprosy workers, as a rather

mildly infectious disease. This is based on the observation that very few people working in leprosy institutions, even after prolonged exposure, developed the infection. In the case of tuberculosis, people working in TB institutions are at a higher risk of infection than the general population and these workers indeed often contracted the disease. Other acute infectious diseases like smallpox and plague had very high infectivity. Hence, many people said that leprosy was not that infective because hardly anybody working in leprosy ever got the infection. Perhaps one of the best-known exceptions commonly cited is that of Father Damien, who worked among leprosy patients on the island of Molokai and himself died of leprosy. Recently, modern immunological studies have shown that leprosy is not a disease of low infectivity. In fact, it is fairly easy for leprosy bacilli to enter the human body, which is the definition of an infection. After prolonged exposure, something like 80% of the people working in leprosy institutions are said to get a number of leprosy bacilli into their body, meaning they are technically infected. But there is a great difference between getting infective organisms into one's body and actually developing a clinical disease. This gap is explained by the idea that each individual seems to have a different degree of inborn immunity against *M. leprae*. In fact, most people seem to be born with an adequate amount of natural protection, so that even if a large amount of leprosy bacilli enters their body, they will not develop clinical leprosy.

What really matters to us is the clinical disease and not the number of bacilli in the body, whatever the amount, and from that point of view leprosy is not very active as an infective disease. It can be expressed that leprosy bacilli have high infectivity but rather low pathogenicity.

The clinical manifestation of an infectious disease is the result of interactions between invading organisms and the host's immunity or defense mechanism,

and this immunity is in some way inherited. Quite often, therefore, if one family member has leprosy, there is a good chance that other family members develop the disease. It is not at all rare to have a mother or father and two or three of her/his children develop leprosy, which, superficially, gives an impression of leprosy being an inherited disease. Therefore, it is important to remember that leprosy is an infectious disease like tuberculosis.

Resistance against leprosy is common, however, and some authorities say up to 80% to 85% of people in the general population have strong enough natural resistance against the disease. What we usually tell people is that if they look back in their family history two or three generations, and if they cannot find any leprosy patient among their immediate ancestors, probably their family has strong enough natural resistance.

Leprosy was fairly common in most parts of the world and people were exposed to leprosy bacilli; people susceptible to leprosy must have developed the disease in those days. I am sure that most of you know this already, but this is the kind of thing that you must explain to people in general to make them understand the truth and overcome unfounded fears or discard unjustified prejudice.

## 2. Leprosy—a chronic disease

The next thing about leprosy is that it is a very chronic disease—indeed, perhaps the longest-persisting of known infectious diseases of man. TB is quite chronic, but leprosy—especially the lepromatous form—seems to go on forever. It has a long incubation period of something like five to seven years or more. Clinical diseases often progress slowly but steadily; with leprosy, it may take 15 to 20 years to turn into fully developed lepromatous leprosy.

Usually the acuteness and sub-acuteness of chronicity of an infectious

disease depend on the speed at which the causative organism multiplies. Because of the slow rate at which *M. leprae* multiplies, taking seven days or more against only a day or so for *M. tuberculosis* and only a few minutes for many others, progress of the clinical disease is equally slow. This, in turn, means that for the control of leprosy, unlike for smallpox or malaria or even TB, many years of patient care are usually required, even though, as I shall try to explain later, we are now trying to shorten the period of treatment as much as possible.

### 3. Leprosy—a disease of many appearances

The third characteristic of leprosy is that there are quite a number of different clinical manifestations of the disease, which makes it difficult to believe that they are all caused by the same organism. But, as far as we know, there is only one kind of leprosy bacillus in the world. We believe that what you see on a patient depends on the amount of immunity that patient possesses, and this is mainly determined by inheritance, as mentioned previously.

So, at one end of the so-called leprosy spectrum, where people have practically no resistance to leprosy bacilli, we have lepromatous leprosy. This shows a stereotypical picture of the disease with severe disfigurement of the face, such as collapsed nose, unclosed, blinded eyes, and so on, and severe disability due to nerve involvement resulting in deformity of the hands and feet. At the other end of the spectrum there is so-called tuberculoid leprosy, which we can call a self-healing type of leprosy because patients seem to have some natural immunity that leads to the eventual arrest of the disease by itself. Unlike the majority of people, they somehow cannot prevent the disease developing, but once the disease proceeds to a certain critical point, the natural immune mechanism that they have to some extent starts

functioning and limits the activities of the organisms to a very small area, and then destroys them.

Therefore, what you see in tuberculoid cases is one or a few very small, clearly demarcated skin patches with no sensation, and a possible loss of function of a single peripheral nerve. In lepromatous leprosy, on the other hand, the process is slow but eventually it involves the whole body surface as well as a number of major peripheral nerves. Therefore, in lepromatous leprosy, lesions are not only multiple but also symmetrical.

These tuberculoid and lepromatous types are called polar types, because they are situated at the opposite ends of the spectrum. Many leprosy patients belong to the group that is in between these polar types. They are called the borderline group, exhibiting characteristics that are a mixture of the polar types, and their disease is often rather unstable, tending to shift toward one polar type or the other due to many influences, such as pregnancy, vaccination or treatment itself.

#### **4. Leprosy—a disease of nerves**

Now it is most important to recognize leprosy as a disease of the nerves, because there is a big misunderstanding, even among the medical profession, that leprosy is primarily a disease of the skin. Leprosy is usually dealt with by the dermatology department of a medical school or hospital, which helps to enhance the impression of leprosy being a skin and not a nerve disease.

Leprosy certainly has skin manifestations, which are easier to see from outside. However, the main damage due to leprosy is in the nerves, and perhaps you will be surprised to hear that leprosy causes more disabilities involving nerve damage than any other single disease. Therefore, in leprosy control, prevention of nerve damage becomes very important, and if you

can succeed in it perhaps you can solve or even prevent a large part of the problems involved in rehabilitation.

### III. Treatment for Leprosy

So far we have discussed that leprosy is an infectious disease of a chronic nature with a variety of manifestations that sometimes causes serious damage to the nerves. One of the misconceptions people have about leprosy which we must change is that leprosy is an incurable disease. It certainly was in the past, at least as far as the lepromatous type was concerned, because there was no effective treatment at all.

At the Berlin Congress of 1897, it was said that since there was no effective cure, the only useful control measure was strict segregation. But an effective cure was discovered in 1941 by a physician called Dr. Guy Faget, working at the national leprosy hospital in Carville in the southern part of the United States. He discovered that a chemical compound called dapsone (DDS), originally produced as early as 1908 as a possible drug for tuberculosis but found to be too toxic, was remarkably effective against *M. leprae* at a dose safe to patients.

It is perhaps useful, at this point, to mention briefly the relationship between leprosy and tuberculosis. These diseases are both caused by mycobacteria; the organisms are remarkably similar in appearance and in many other characteristics, although there are some significant differences. One of the major differences is that TB mainly attacks the internal organs such as the lungs, intestines, kidneys and brain, and you cannot see these lesions from the outside. In marked contrast, leprosy bacilli attack the skin and peripheral nerves, so that the disease process is readily seen from the

outside. As the two organisms belong to the same group of mycobacteria, however, some of the drugs we used in leprosy control, such as streptomycin and rifampicin, originally came from TB control.

Since Dr. Faget's discovery in 1941 that dapsone can be used against leprosy, the disease became curable and we now have the means to control leprosy with a variety of drugs, such as dapsone, clofazimine, prothionamide, ethionamide, and rifampicin. We can also prevent all nerve damage, if we can treat patients at an early stage of the disease. Therefore, most of the deformities are now preventable. **“Leprosy is curable and deformity is preventable”** is the main message I want to impress upon each one of you this morning, even if you forget about everything else I have said so far.

However, we must now ask ourselves the next question: “Are we really curing the disease, and are we really preventing nerve damage?” Unfortunately, our answer today has to be a definite “no.”

Leprosy is curable, but many leprosy patients are not being cured. Most of the deformities are preventable, but many such deformities are not being prevented at the moment. The gap between what is possible and what is actually achieved is very great indeed in leprosy control work and we, who are involved in leprosy control, must take full responsibility for failing to do the job properly. It is our responsibility in the near future to narrow this gap and turn possibilities into realities for the benefit of leprosy patients, and for the benefit of society in general, by controlling this infectious disease.

#### IV. How Many Leprosy Patients?

Now let us consider what is happening in the world as far as leprosy is concerned. The first question to be asked is just how many cases have? It is

very difficult indeed to know exactly how many cases there are at present. Apart from an inadequate recording and reporting system concerning leprosy, one of the main reasons for the difficulty in estimating the number of cases, even in this country, is that leprosy has a very uneven distribution. You may find very high prevalence of leprosy in one village, say 10-15 cases per 1,000 people or sometimes even higher; yet a village only a few miles away in a similar locality may have no cases at all, and this makes an estimation on a nationwide scale very difficult indeed.

This is another feature of leprosy that is different from tuberculosis. The figures you can see in some publications usually state there are between 10 to 20 million leprosy cases in the world. In fact, the figure published by WHO is 10,595,000, which could be something of an underestimate, but is perhaps not too far off the truth. Twenty million is quite often used by voluntary agencies for fund-raising purposes and probably is a gross overestimate. WHO published the figure in 1979 based on data collected up to 1975, and this was based on reports submitted by individual governments

I don't know whether you think 10,595,000 is a big figure; it depends on how you look at it. If you think of diseases such as malaria, schistosomiasis and many other tropical infectious diseases, and many other health problems such as malnutrition or cancer, 10 million in this world is perhaps a small figure. You must remember, however, that leprosy is not only a chronic disease of many years' duration but is one of the major diseases of the peripheral nerves, resulting in deformities and disabilities that are permanent. So the neglect of 10 million leprosy patients today will result in large medical and social problems in the years to come.

Naturally, people like me who are involved in leprosy control activities regard 10 million as a quite staggering number and one that demands the

urgent attention of governments concerned. Of the 10 million estimated cases, it is unfortunate that only about one half have been diagnosed and registered so far. The WHO figure for 1979 is actually 3,599,949, based on reports from 154 countries. Since then, with the great efforts of countries such as India, more patients have been detected and registered recently, so that the figure now is probably nearer to 5 million. So what we are doing now is very little indeed and we still have a long way to go before we can make any claim to an effective control of leprosy.

Perhaps I should give you some examples of what I have just said. India, as you know, has a population of nearly 600 million and an estimated 3.2 million cases of leprosy. In 1975, there were 1.5 million registered cases, although in recent years that number has greatly increased to nearly 2.6 million.

Next in terms of the total number of estimated cases is Burma. Burma has a population of only 31 million but an estimated 700,000 cases of leprosy, although less than 300,000 cases have been registered so far. Next comes Nigeria, with a population of 70 million and nearly 600,000 estimated cases, of which 312,000 have been registered.

What these countries have in common is that they belong to the so-called underdeveloped or even least developed countries, which are also called low-income countries. They have very limited financial resources and on average can usually afford no more than US\$5 per head per annum to deal with all their health problems. Having many other health problems, leprosy quite often comes very low down their list of priorities.

You can also think of the leprosy problem in terms of disabilities. Some people have estimated that 25% of the leprosy patients in the world have disabilities of one form or the other. Others have pointed out that a similar number, 25% of 10 million, are children aged 14 years old or younger who

still have a long time to live, hence there is an urgent need to arrest their diseases and prevent all deformities.

The next question to ask is whether leprosy is increasing in the world or not. I think we can fairly safely say that it is probably decreasing, even if very slowly. This idea is based on the fact that the estimated figure of leprosy cases has remained at around 10 million for the past 20 years or so, in spite of the fact that the world population has increased by nearly 1 billion, or an additional 25%. Of course, countries such as Thailand, Nigeria and some others with fairly effective leprosy control programs can produce some documentary evidence to show that both prevalence and incidence of leprosy are coming down.

Hence, even though we consider what we have been doing in leprosy control inadequate and not really meeting the needs, we still can take some consolation in realizing that perhaps what we have been doing was not totally wrong. Out of 10 million-plus estimated cases, roughly 6.5 million are in Asia, 3.5 million in Africa, with the rest in the Americas, Eastern Mediterranean countries such as Turkey, Syria and Egypt, and the countries in the Pacific region called Oceania.

Although many people tend to assume that leprosy has disappeared from Western countries, Europe still has something like 25,000 cases. The United States may have up to 3,000 cases of leprosy now—many of them coming from abroad, of course. I was in Hawaii recently and was surprised to learn that last year they had seven new cases among the native population in addition to a number of cases among immigrants. Leprosy, even though decreasing in general and having nearly disappeared in the developed or industrialized countries of the West, is not totally beyond their concerns.

## V. Failures of the Current Leprosy Control Schemes

I understand that your government is now discussing a new strategy of leprosy control, which is the reason for your presence at this meeting today. A similar reassessment and re-planning is going on in many other parts of the world. It is going on in WHO; it is going on in voluntary agencies like ILEP; and of course it is being discussed by the health authorities of the endemic countries. The reason for this must be the common realization of the failure or at least inadequacy of the current leprosy control methods.

### 1. Drug-resistant leprosy

We have not only failed to control the disease and cure the patients as some of our forerunners had hoped in the 1940s and 1950s, but we seem to be creating a new and more difficult problem of drug-resistant cases among the existing leprosy patients and, even worse, among the newly diagnosed cases in many parts of the world. Dapsone resistance is quite prevalent in many parts of the world and rifampicin resistance is already known. Before long, we may hear about clofazimine resistance. Resistance to prothionamide and ethionamide is expected to develop fairly readily, since they show cross resistance to thiacetazone, which has been widely used for TB control in many parts of the world.

Dapsone is a remarkably good drug in many ways against leprosy, and the major advantages of the drug for the governments concerned are that it is safe and is very cheap, costing only US\$2 to \$3 per patient per year. The organisms are very slow in developing resistance to dapsone so far.

Dapsone resistance was noted as early as in 1953, and it was fully

documented and discussed from 1964 onward. But it is really only now, in the last few years, that the people in leprosy work have taken this problem seriously and decided to do something about it. The magnitude of dapsone resistance varies from country to country, ranging from 2% to 3% per annum of total multibacilliary cases treated with dapsone therapy in a given country, but wherever dapsone monotherapy has been given, its resistance can now be found if sought. These are examples of so-called secondary resistance, but primary resistance, as a result of getting infected by patients with dapsone-resistant organisms, has been developing in most of these areas as well.

Dapsone has been used as monotherapy for the past 40 years or so, as the mainstay of leprosy control, as mentioned previously. A number of other drugs have been tried and added. The next drug that has a proven anti-leprotic activity is clofazimine, which was first introduced in the late 1950s. It has been used either as monotherapy or in combination with dapsone, but so far no proven case of clofazimine resistance has been reported, although most of the experts think it is only a matter of time.

The most potent anti-leprotic drug we have at present is rifampicin, which is also a powerful anti-TB drug. Its remarkable bactericidal effect against *M. leprae* is somewhat offset by its high cost, some serious side effects and by the apparent ease with which *M. leprae* becomes resistant to the drug. Secondary rifampicin resistance has been reported from a number of countries already, and in some cases has been seen to develop within a few months as against dapsone resistance, which on average seems to take five years or more.

## 2. Insufficient coverage of infective cases

As the main reason for the failure of leprosy control so far, inadequate drug treatment probably comes as number one. The second, but almost equally

important, reason for the failure is the inadequate coverage of leprosy cases in the world. In global terms, nearly 50% of the estimated cases are not yet discovered. Looking at individual countries, even a country like Thailand which has a relatively well-developed leprosy service both in terms of quality and quantity, still has a substantial number of leprosy cases yet to be reached by the health services.

Leprosy is an infectious disease, although not all patients are infectious. Therefore, to control the disease, as many infectious cases as possible must be detected and put under regular treatment. Today's coverage of 40% to 50% is a far cry from what is necessary, leaving a large source of infection untouched. In order to extend that coverage, more personnel are required, but it is hardly realistic or justifiable, in my opinion, to try to enlarge the vertical leprosy service, which in a majority of the endemic countries inevitably means sacrificing some other aspects of health services.

## VI. Global Strategy of Leprosy Control

### 1. Integration of leprosy services

Probably you have already detected what I am trying now to promote. The only approach that has a realistic possibility of eventual success, in trying to improve existing leprosy services in terms of coverage, is to integrate leprosy work into the general health service delivery system. And it is gratifying to note that many countries, including Thailand, have already accepted the total integration of leprosy services, along with all other vertical services, into the general health service scheme, including the primary health care system, at least in principle. Traditions die hard, and a traditional approach to leprosy problems by specialist groups, including those of voluntary agencies, still

has strong supporters for various reasons and motivations, some with good justification.

But leprosy, as one of the public health problems, definitely requires more integrated handling. This is not merely to increase the coverage by enlisting a larger number of people, but such an integrated approach is essential if the leprosy specialists want to practice what they preach, which is that leprosy is not a special disease apart from the rest but just like any other.

There is a cruel joke that goes: “In order to eradicate leprosy, leprologists must be eliminated first.” It reflects the unfortunate truth that it is often the leprosy specialists who insist on retaining traditional separate handling of the disease, thus contributing, although unintentionally, to maintaining the popular notion that leprosy patients are somewhat different from the rest of the people, which is the root of the common practice of segregation or ostracism of the unfortunate patients of this disease.

Perhaps most of you are aware that WHO is trying to strengthen all its activities under the battle cry of “Health for all by the year 2000.” I suppose there are many definitions of health, but under whatever definition it sounds like an idealistic goal. However, WHO is quite serious in promoting or implementing various programs for achieving that goal, both in coverage—that is, all the people on this Earth—and in timing, which is by the year 2000, only 18 short years from now.

If any health problem faces a danger of being left out of that program, it is most likely to be leprosy and we cannot and should not allow this to happen. “Health for all” surely must include health for leprosy patients, and it must mean, at the very least, provision of adequate diagnostic and treatment services to all the leprosy patients in the world.

Depending on the existing state of both the leprosy service and the general

health services, the approach to integration and the final shape of the leprosy component within the integrated health services are likely to be different from country to country. In spite of the 18-year time limit, the approach must be necessarily a gradual one. Even within the integrated services, it is more than likely that a core of leprosy specialists at different organizational levels will have to be retained for planning, supervision, monitoring and evaluation of leprosy activities, and these kinds of specialist groups are likely to be required for other components dealing with other serious endemic diseases as well.

If I understand correctly, you are here for the next three days, precisely for the purpose of discussing possible problems and constraints likely to be encountered in this country in the process of integrating leprosy into the general health services, and I shall be one of those who are keenly interested in the outcome of your deliberations.

## **2. New drug treatment schemes**

Another strategy of global importance is a new approach to the drug treatment of leprosy. In the absence of a protective vaccine, the only effective way to control the disease now in our possession is the judicious use of currently available anti-leprotic drugs in combination, on cases detected as early as possible. A special WHO meeting of leprosy experts was held in Geneva in October 1981 and the contents of the meeting together with the recommendations were made public in the booklet called "Chemotherapy of leprosy for control programmes," which is WHO Technical Report Series 675.

I trust you will be hearing about these recommendations later, but I want to point out to you, at this stage, two features which are almost revolutionary when judged from a traditional leprosy control point of view. The report advises to classify all cases of leprosy into two groups only: multibacillary and

paucibacillary. For each group, it recommends only one standard regimen of a limited period: a combination of rifampicin, clofazimine and dapsone for the minimum of two years for multibacillary, and a combination of rifampicin and dapsone for a mere six months for paucibacillary.

You will appreciate the revolutionary nature of these recommendations if you remember that up to now for lepromatous patients, who will be classified as multibacillary in the new scheme, virtually a lifelong treatment has been recommended. The new regimens stipulate a strict monthly supervision for the total period of the treatment, at which rifampicin will be ingested by the patient once a month in front of health services personnel to assure a proper intake of rifampicin. This once-a-month rifampicin should do the major portion of destructive activity against *M. leprae*, and the addition of dapsone and clofazimine is primarily to prevent emergence of rifampicin resistance, although these drugs are also effective anti-leprotics in their own right.

Both the simplification of the classification of the patients and the shortening and the simplification of treatment regimens should lead to more important changes for future leprosy control activities, which, thanks to the above-mentioned changes, are now made simple enough and more in line with the normal pattern of disease control work, thus contributing to easier integration. Of course, some problems such as the occurrence of lepra reaction or nerve damage, as well as non-medical problems of a social and psychological nature will always remain with leprosy work and need careful planning and adequate provision for proper handling. Nevertheless, the way for eventual integration is definitely made easier by the new recommendations of WHO.

In a way, it is much easier to plan for the new cases that will emerge from now on. For many governments, including that of this country, a big

headache probably is what to do with existing cases, especially those who already have some physical and psychological disabilities requiring special care for rehabilitation or permanent custodial care. I am afraid I have neither time nor expertise to go into this aspect of the problem this morning, but no doubt your discussions will touch on this too.

### 3. Research activities in leprosy

What I have mentioned so far does not require new tools, such as new drugs or a new vaccine, but only new thinking or a new approach using existing tools. There is no doubt, however, that development of such new tools, together with new discoveries or better understanding of the nature of the disease, of the hosts, and of various chemotherapeutic and immunological agents will greatly assist in our future effort to control and even to eradicate leprosy.

In the little time remaining, I shall try to mention very briefly some research activities that might assist or even alter our future strategies for global leprosy control.

Of course, research programs in leprosy are conducted in many of the leprosy-endemic countries. In Thailand, apart from those conducted by the leprosy division of the government in chemotherapy, epidemiology and a few other aspects, one outstanding example of such research is that carried out by the faculty members of the joint Chiang Mai /Illinois Leprosy Research Project in Chiang Mai. However, many of the more basic studies involve people from non-endemic industrialized countries.

WHO, under its TDR program (the Tropical Diseases Research and Training Programme), has two leprosy research groups, one called IMMLEP, or immunology of leprosy, and the other termed THELEP, or chemotherapy of leprosy. THELEP's activities contributed substantially toward the formulation

of the new WHO recommendations and the group will keep looking for more effective use of the existing drugs as well as searching for new and more potent drugs.

“Prevention is better than cure” for any disease and it seems particularly true for leprosy, since even after the clinical cure ex-patients could still be left with permanent physical or psychological damage. Search for a protective vaccine is therefore a number one priority in many research groups in leprosy, including IMMLEP.

Out of many efforts along this line perhaps I should mention only two. IMMLEP is concentrating on the use of heat-killed *M. leprae* as a possible vaccine, and they have just reached the stage at which they are ready to start human trials on the toxicity of the killed *M. leprae* derived from armadillos, but they are not yet ready to conduct an efficacy study of the vaccine on human subjects.

The second group is in Venezuela, under Dr. J. Convit, the former president of ILA and a well-known leprosy specialist. His vaccine is a mixture of killed *M. leprae* from armadillos and live BCG, and his approach was to start using the vaccine as a tool for immunotherapy for existing leprosy patients rather than as a protective vaccine for healthy persons not yet infected. The results his group have been obtaining in their immunotherapy so far are reported to be good, and that also suggests a possibility of using the same vaccine for prevention of the disease rather than for treatment only.

I have just mentioned *M. leprae* derived from the armadillo, an animal living in the Americas, and some of them, especially the nine-banded variety living in the southern parts of the United States, have been found to be susceptible to *M. leprae* infection. Probably most of you are aware that artificial or *in vitro* culture of *M. leprae* has not been achieved so far, and

the unavailability of a large amount of *M. leprae* has been one of the main bottlenecks in promoting research activities in leprosy.

In the late 1950s, C.C. Shepard discovered that the foot-pad of a certain strain of mice can provide a suitable environment for multiplication of *M. leprae in vivo*. Later, R.J. Rees improved the technique by immune suppression by means of thymectomy and X-ray irradiation of the mice, in turn leading to the successful utilization of nude or congenitally athymic mice. The amount of *M. leprae* that could be harvested using mice being too small, however, it has to await the discovery of mice that can provide a large enough quantity of *M. leprae* to make it possible to start the above-mentioned vaccine studies.

At the moment, all the armadillos used are caught in the wild, because attempts to artificially breed the animals have been unsuccessful. But for even greater amounts of contamination-free *M. leprae*, artificial breeding under laboratory conditions is a must. Recently it is reported that a certain kind of monkey is also susceptible to *M. leprae* infection. This looks promising, but an even more promising, although not yet fully attempted, method is one of the bio-engineering techniques by which appropriate antigens are selectively removed from *M. leprae* and grafted on to some easily-reproducible cells to act as a vaccine, even though the more traditional, but so far frustrating, effort at *in vitro* cultivation of *M. leprae* itself is still continuing.

There are many other important areas in leprosy in which serious research is being conducted, but I want to mention only one more—and not because some of you are already taking part in the study. It is an effort to develop a test by which an early and subclinical infection of leprosy can be identified. Some of you have been using either Abe's FLA-ABS test or ELISA in this country. There are others, such as M. Harboe's radioimmunoassay technique, and of course the lymphocyte transformation test. None of them have achieved high

enough sensitivity, specificity and reliability so far and all of them are too complicated to be used in the field on a wide scale. Therefore, development of a simpler skin test, something like the tuberculin test for TB, is desirable and there are a number of developments along these lines. However, there is no doubt that the availability of such a test is one of the prerequisites for field efficacy trials for a protective vaccine.

Ladies and gentlemen, I have attempted to cover some of the more important aspects of leprosy itself and the current and future methodologies of controlling the disease. It has been a rather superficial survey and not an examination in depth of any particular problem.

I trust all of you here this morning have some interest in and even a personal commitment to the control and eventual eradication of the disease, not only from this country but from all over the world. If my talk has provided some useful hints for your thinking and for your discussions over the next three days, I shall be honored and satisfied. Thank you.

# 2

## MDT for All

### Target-Oriented Leprosy Control Program in the 1990s

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#### I. Introduction

For over 40 years, leprosy workers have been saying that “leprosy is curable” and “deformities are preventable” without actually curing many patients or preventing deformities developing. These slogans have remained as mere dreams to most leprosy patients around the world. Now, with WHO-recommended MDT (multidrug therapy), we have a practical means to realize these slogans. It is therefore the duty of everyone involved in leprosy to make those slogans a reality for every leprosy patient now in existence and those who will come in the future. “MDT for all” must be our top priority.

So the issue before us should no longer be “*whether* to implement MDT”

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WHO meeting on “The Consultation on Technical and Operational Aspects of Leprosy,” Male, Maldives, June 1990

but “*how* to implement MDT.” In the last decade of the 20<sup>th</sup> century, with 10 years for us to reach our overall goal of “Health for all by the year 2000,” it must be regarded as a basic right of every leprosy patient to receive MDT. Therefore, not giving MDT must be considered “grave medical negligence,” a 100% failure of a leprosy program or of a national health service. Without MDT, there is no cure; with any sort of MDT, even a very poor one, there is a possibility of some cure. This means that almost any form of MDT is better than no MDT at all.

When planning an action, especially a new one such as the implementation of MDT, our natural instinct advocates caution, in order to avoid a possible failure, totally forgetting or ignoring an important fact that the true failure often is taking no action at all. Poorly executed MDT with 50% relapse will be commonly regarded as an unacceptable level of failure, especially from an administrative point of view. However, 50% failure at the same time means 50% success, and from the point of view of so many leprosy patients, that must be incomparably better than no MDT.

Let us remember that the essential part of MDT is nothing more than delivering certain drugs to the patients and helping them to ingest those drugs as prescribed. All the planning, training, supervising, monitoring, laboratory examinations, record keeping and reporting are, apart from being bureaucratic necessities, only to make sure that the essential actions of drug intake will take place in as many patients and as regularly as possible. In a meeting like ours today, we sometimes become more concerned with creating an ideal MDT implementation system, adding more and more requirements and refinements, calling for more resources and more time for preparations as well as implementation. We forget the sad reality that leprosy is not, and cannot be, a top priority in the long list of health problems in many leprosy-

endemic countries, and that resources available for MDT are therefore rather limited.

It is well for us to remember, when we are planning for MDT, what is expected of us by the leprosy patient somewhere in the world who is not yet receiving any treatment. All he is saying now, I am sure, is: "Give me drugs, and quickly." Our first job, therefore, is to start him on MDT and to give MDT to all the existing patients without any more delay. To do that, we must be flexible and do our utmost to fit our plan to the existing situation, rather than trying to change the current conditions to fit our ideal plan. The latter often is a near impossibility, or at least too time consuming to justify our neglecting the needs of existing leprosy patients, who are said to number up to 10 to 12 million globally.

Another basic consideration that must be behind our planning for MDT is the question of *equity*, which must form a firm basis for any policy of a government. When we talk of equality in relation to leprosy patients, we tend to assume that they are the victims of inequality, that they are getting less than others. Perhaps in an unconscious effort to overcome our guilty feelings, we sometimes tend to overcompensate by demanding much more care for leprosy patients, because of their disease, than people normally expect from health services.

It is hard to imagine any government of a developing nation providing regular rehabilitation programs for the victims of polio with physical disability or sufferers of onchocerciasis with blindness. Yet when we deal with leprosy, even in such a purely public health program as MDT implementation, someone always tries to bring in the question of rehabilitation as if its absence means that the MDT program itself is incomplete. Let us remember that even though equality means certainly not less than others, it also means no more

than others. Basic good intentions in trying to do the best for leprosy patients could, as a result, be the main cause of making leprosy patients different from the rest, thus resulting in discrimination and prejudice, creating the most difficult leprosy problems ourselves.

## II. General Considerations

### 1. The leprosy control program and MDT's place in it

In order to discuss “What is leprosy control?” it is necessary to agree on “What is leprosy?” For our discussion, it is probably sufficient to define “leprosy” as a disease having two quite distinctive natures, namely:

1. An *infectious disease*, thus a legitimate public health concern and amenable to regular control measures for any infectious disease, i.e., early case detection and effective chemotherapy of all the cases.
2. A *deformity- and disability-producing disease*, hence effective early chemotherapy could prevent most of these problems arising but not all. Besides, there are already several million leprosy sufferers in this category, with or without active disease.

From a public health point of view, leprosy control first of all means dealing with leprosy as an infectious disease, and therefore our primary aim should be to make all the clinically active patients non-infectious by chemotherapy. Ideally we should aim at the non-infectivity of all the patients, but this could be too expensive or technically too difficult to be feasible in many leprosy-endemic countries, which means that we must make allowance for some failures, the magnitude of which is related to the general state of available health services in a given country.

Whether handling leprosy as a deformity- and disability-producing

disease could come under the concern of public health is a debatable issue, closely linked to the degree of a country's social and economic development. Generally speaking, as far as leprosy-endemic countries belonging to the Third World are concerned, this aspect of leprosy is likely to be outside of the current responsibilities of public health authorities. If they have a separate agency to look after the physical and social welfare of their citizens, then leprosy sufferers with deformities and disabilities certainly should become its legitimate concern, but as far as the public health authorities are concerned, this aspect of leprosy, at present in any case, has in most probability to be outside of their responsibility.

I consider this distinction and its implications to be very important, because traditionally these two aspects of leprosy have never been consciously separated. Many existing leprosy control programs have tried and still try to address themselves to a mixture of these two, with the quite notable result of not doing an adequate job of either. In the days when the technology of controlling leprosy as an infectious disease was either lacking or inadequate, perhaps that kind of ineffectual dealing with both simultaneously was inevitable or at least understandable. But now, we do have a means to control leprosy infection quite effectively. Therefore it seems imperative that we concentrate our total effort on controlling leprosy as an infectious disease at this stage, since this task alone is likely to tax our global resources fully for quite some time, say the next five years if not ten years up to the year 2000.

From the foregoing, it should now be clear that the leprosy control program, as far as we are concerned, should be defined as a public health measure to tackle leprosy as an infectious disease. Thus, the implementation of WHO-recommended MDT, which has already proved itself to be effective in controlling *M. leprae* infection, is the main, if not the sole, activity of a leprosy

control program run by the public health authority of any leprosy-endemic country. I stress this last point, because the objectives of non-governmental agencies (NGOs), particularly of voluntary agencies, could be different. By the very nature of these organizations they are, unlike any government, not directly responsible or accountable for the public health aspects of leprosy work, nor for the welfare of the entire population of a country. However, it is strongly hoped that these NGOs see the importance and needs of a public health approach to leprosy and contribute substantially to strengthen and support the health authorities of leprosy-endemic countries in their effort to implement MDT, even if that means that the NGOs concerned must sacrifice some of their traditional care to their own patients.

## **2. Which MDT, and what is involved in its implementation?**

At this point, it is important that when we talk about MDT we should agree to mean the WHO-recommended MDT as spelt out in the WHO Technical Report Series 675, titled “Chemotherapy of leprosy for control programmes.”

However, there is one very important point that should be clarified before we proceed any further. It is the duration of the MB regimen, which, according to the WHO recommendation on page 23 of the above-mentioned publication in its section 3.1.3 “Duration of treatment”, is “...that the combined therapy be given for at least two years and be continued, whenever possible, up to smear negativity.” This statement is probably a correct one, as far as WHO is concerned especially in 1982 when it was made public. But the expression “whenever possible” is causing more confusion and resulting in a delay of MDT program expansion in the field, because the intended meaning of “whenever possible” is not defined. The clinicians who are responsible for the treatment of individual patients take this expression to mean that they must do

their utmost to have their MB patients treated until BI negativity, often citing ethical responsibility. What they fail to understand is that the MDT program is formulated for “Chemotherapy of leprosy for control programmes,” which in a majority of instances is synonymous with a public health program. It is meant to be advice to a planner or manager of an MDT program in the field, where, as the terminology implies, the first consideration is “the health of the public,” as against the concern of clinical medicine, which is the “illness of an individual patient.” Surely, there must be an ethical question from a public health point of view as against a clinical point of view.

As far as our meeting is concerned, in which MDT is discussed as a national health program within the global context, it should be quite clear to all of us that “whenever possible” should mean only one thing: that when all the existing clinically active leprosy patients are given the basic two-year MB treatment, then one should be allowed to consider a possibility of extending the treatment beyond this period, provided resources are available, which, in the case of most leprosy-endemic countries, is rather doubtful. It makes no sense at all if some patients are kept waiting to receive MDT, thus allowing their clinical condition to deteriorate and for them to keep infecting their contacts, while others who are already on MDT, thus no longer infective and in most instances becoming clinically inactive, are kept on MDT simply because their BI is still positive.

It is not easy to estimate the cost of MDT implementation. But from actual experience, US\$100 per case seems to be a fair estimate for many countries, which means if there are 10,000 cases in a given country, US\$1,000,000 is required to complete MDT implementation for all these patients, probably spread over three to five years of the program. This estimate assumes that PB/MB ratio is near 50/50, and this results in roughly 40% of the budget being

required for the purchase of MDT drugs. The remaining 60% is roughly divided equally between training and implementation, the significant portion of the latter for the monitoring of the program and whatever remedial action is needed. Purchase of equipment including transport facilities, production of work manuals, guidelines and other materials for the training of health workers and health education of the patients and the public are included. However, the significant exclusion from this costing is the regular salary of all the health workers involved in MDT, since it is assumed that these people are already in the field, and being paid regardless of whether they are involved in MDT or not.

It should not be forgotten that the above calculation is based on the implementation of basic MDT, which is a fixed-time treatment of 6 months for PB and 24 months for MB. Any extension of these periods could substantially increase the total cost. One should also remember that the above is for the implementation of MDT as such. The leprosy control program, even if we agree that MDT is its main component, is likely to involve some additional activities that will add up to more cost. From a global point of view, if we agree on “MDT for all by the year 2000” as our common goal, probably the total available resources will all be required for the implementation of basic MDT, with very little available for anything else. (US\$100 per case was the actual expenditure of the pilot study of MDT conducted in the Philippines covering somewhat over 2,500 cases in two provinces over three years; that country’s national leprosy control program currently under way to cover something like 40,000 cases over a five-year period also has a total budget of US\$4,000,000. Even though Vietnam has a totally different health structure as well as control methods, support given to them by one NGO is based on the same unit cost and the program seems to be progressing satisfactorily.)

In order to implement MDT properly, the following series of activities is involved:

1. Case finding (this will be discussed later)
2. Updating of existing registry of leprosy patients, by tracing individuals whose name is on the registry
3. Clinical and possibly bacteriological examination of each patient to determine current clinical status and to decide whether the patient requires MDT  
(As a result of 2 and 3 above, the actual number of patients requiring MDT may be as low as 50% of those on the original register.)
4. Give fixed-period basic MDT, with whatever support the service can give to the patient to assure regularity of the monthly clinic attendance and compliance of unsupervised daily drug taking
5. Dealing with any lepra reaction or drug side effects
6. Prevention of deformities by health education (HE), and teaching of self care of insensitive eyes, hands and feet, which should be a regular part of MDT implementation, even by general health services, although this aspect is very weak at the moment
7. Termination of MDT and release from treatment (RFT) after clinical and, if possible, bacteriological assessment (Any such examination during the course of MDT is most likely to be unwarranted.)
8. Some kind of post-MDT surveillance

One additional activity, which is normally considered essential, is a clinical survey (at least once but possibly annually) of the members of the household contacts of an MDT patient. True, the yield of new cases is not that high, but to protect the family members of known cases is usually accepted as an ethical duty regardless of the cost effectiveness.

Case finding is mentioned at the top of the list above, but it is most doubtful that any active case-finding effort, apart from the just mentioned “household contact survey,” is useful, especially at the start of the MDT program, which is designated as Stage I in the following discussions. A school survey or any other survey, including a so-called “chase survey,” if done for the purpose of finding leprosy alone, is most probably not cost effective. The only feasible case-finding method in every leprosy control program is so-called “*passive case finding*,” depending heavily on the public awareness of the disease itself and availability of its cure so that the patient himself or his family recognizes, or at least suspects, the symptoms or signs of the disease and comes forward voluntarily to be treated. It also depends on the alertness of health workers who have a chance to do a physical examination for whatever reason. If signs suggesting leprosy are found on an unsuspecting patient, immediate referral to the appropriate person is mandatory.

What else should be a part of basic MDT implementation? Probably very little, apart from general health education of the public on leprosy itself and on MDT to assist “passive case finding” just mentioned, and teaching of self care of insensitive eyes, hands and feet, in order to prevent either new deformities developing or existing ones getting worse. Active care of established deformities including treatment of tropic ulcers may or may not be considered as a part of care provided by existing health services, and even though that is a desirable service it cannot be considered as an integral part of basic MDT. Any further care, such as surgical intervention or physical and social rehabilitation, are certainly outside the scope of MDT, if not altogether outside of the public health concern.

### 3. What to do with other leprosy sufferers, who are not included in the MDT program?

The current WHO definition of a leprosy patient is “a person with active clinical leprosy requiring chemotherapy”. By this, any current or past leprosy sufferer who does not require MDT is no longer considered a case of leprosy and therefore not registered as such. If such a person requires some care, he will be categorized as an “ex-leprosy patient requiring care,” and is outside of our consideration for MDT. The previous discussion limited the scope of leprosy control to the implementation of MDT, excluding any care other than chemotherapy against *M. leprae*, with one or two minor additions.

It is most important not only to agree on this, but also for the health authorities to publicly acknowledge this fact. There is too much loose talk about “total care of leprosy patients,” which often is no more than lip service to the activities that most governments of leprosy-endemic countries are incapable of rendering. A much more constructive way is for the health authorities to acknowledge that “rehabilitation“ is an important aspect of the care of leprosy patients, but to admit that their resources will not permit them to tackle the problem themselves; and then to encourage participation of any interested parties, especially national and international NGOs, at the same time making sure that ex-leprosy patients are not excluded from any existing rehabilitation program for the physically handicapped if they need such help.

### 4. Who should implement MDT?

This is a crucial consideration and the success or otherwise of global MDT is likely to hinge on getting the right answer to this question. If we accept MDT as a public health program for control of an infectious disease, in order, first

of all, to protect the public from getting *M. leprae* infection, which only comes from clinically active cases of leprosy, then the following should be apparent:

1. The service that handles MDT must have wide enough coverage to reach every part of the country where a case of leprosy is found.
2. The service must be able to maintain regular and frequent contact with the patient, so that not only is the monthly clinic visit assured, but when necessary, it is possible to reach the patient as quickly as needed, for defaulter tracing, handling of lepra reaction or drug side effects, and for compliance check by pill count at unannounced home visits.

In addition to the above, for long-term care of patients over six months or two years, the existence of a rapport between the patient and health care provider becomes most useful. Such a rapport is more likely to be present if the health worker concerned is:

1. Living in the same area as the patient
2. Already providing care to the patient concerning non-leprosy health problems
3. Giving some health care to other members of the patient's family

The service which can meet the above-mentioned conditions in any country is, by definition as well as in reality, the general health services (GHS); a vertical leprosy service, however extensive or well developed, cannot meet all of these conditions anywhere in the world. Therefore, MDT implementation is best handled by GHS. There has been much talk of and several attempts, some serious and others not so serious, at integrating leprosy service into GHS. The results so far are not always encouraging.

What are the difficulties? The main problems are said to be:

1. GHS is already overloaded with many tasks and therefore the peripheral health workers have no time to do new extra work, such as MDT.

2. Leprosy control work is too complicated.
3. Health workers do not like to be involved in leprosy work, due to their fear of the disease.

Now it is useful to remember what is exactly involved in MDT implementation by a primary health worker (PHW) who actually treats the patient. The situation is different from country to country, but for the sake of our discussion we can think of a PHW as a person working, probably alone, at a village health station not far from her own home, meeting the basic health needs of the people in her catchment area with a population of 2,000 to 5,000. She is responsible for the basic communicable disease control (CDC) work in addition to maternal and child health (MCH), expanded program on immunization (EPI), nutrition and hygiene as well. For that work, she will be at the station two or three mornings a week, but otherwise she will be making regular rounds of homes in her area constantly. Probably once a week she will go to a main health center in a nearby town for reporting and recording of activities, receiving of supplies including medicine and getting any professional advice she needs. Supposing the prevalence rate of leprosy in her area is around 1/1000, she will have up to five MDT cases to start with. Is it going to be a big extra work? No, it is most unlikely.

Each MDT patient will come to the clinic once a month, half of them for 6 months only and the rest for up to 24 months. At the clinic, where she spends several mornings a week, it is likely to take no more than five minutes per case per month to ask a few simple questions about the health of the patient, give the monthly dose of drugs and watch the patient consume them, hand over other drugs for unsupervised daily taking at home, and make a simple record of the visit. If the patient does not come on time, she has to visit the patient at home, either to give drugs there or to tell the patient to come to

the clinic soon. She is normally expected to make at least one unannounced visit a month to the patient's home to do the pill count to check the patient's compliance.

How much time do these require? It is not easy to get a precise figure but one must remember that she can do all these works while she is at the clinic and when she is making the regular rounds in the village, thus no extra stay at the clinic nor extra trip from the clinic is likely to be required. In the Philippines, where the above-mentioned conditions generally prevail, it is estimated that no more than 1% to 2% of a PHW's working time per month is required for MDT as long as the caseload per PHW is no more than five.

And this is only two or three years after the start of MDT. Once known cases complete the treatment, a new case requiring MDT will appear only once in three or four year or even less because on average the incidence rate (IR) is only about one-tenth of the prevalence rate (PR).

In the Philippines, their work was made even simpler and less time-consuming by the utilization of monthly calendar blister packs of MDT drugs that were devised specifically for their program, but similar packs are now available commercially. This device prevents the chance of giving the wrong kind and amount of drugs, and there is no wasting of valuable time to count out the tablets from bottles, and the pill count during a home visit requires only a simple glance at the pack.

Other advantages of using the blister packs are no less significant and can be listed as follows:

1. Safeguards rifampicin against diversion or misuse, providing a better chance for the drug to reach the intended leprosy patient. (This aspect was considered so important that the use of blister packs was one of the conditions by which the Philippine government agreed to involve GHS,

which had never participated in leprosy work in the past, for MDT implementation.)

2. In addition to a simpler handing at the village health station by a busy PHW, inventory taking at every level from the ministry down to the field is made much simpler.
3. The missing of one or two component drugs of the MDT regimen, which often cause serious problems in the field, is avoided.
4. Safeguards drugs from damage due to adverse weather conditions or insects.
5. Facilitates the patient or his family to remember, not only daily drug taking, but also the date of the next monthly clinic.
6. Medication in that form looks more expensive, which often suggests more potency to both the health workers and the patients. This perception often leads them to take MDT much more seriously.

There are some disadvantages to using blister packs, the most apparent one being the extra cost, but if compliance is improved by the packs, then the cost effectiveness must shift in favor of the pack. The bulk resulting from putting drugs into the calendar pack is another disadvantages cited usually in terms of storage as well as transportation. Returning to the question of the utilization of GHS for MDT implementation, there is an overwhelming advantage of using the blister packs over the loose drugs out of bottles, and often this could be used to persuade reluctant health authorities to accept MDT as a routine of GHS activities.

As to the idea of leprosy control being too complicated, publication of the WHO recommendation on MDT and its global acceptance has or should have changed the whole picture. Leprosy work in the past was indeed complicated in addition to taking too long. But MDT now being advocated is

not complicated at all. In fact, it is very simple both in concept and operation. There are only two classifications of patients and a standard regimen for each, regardless of whether the patient is new, old or relapsed.

This simplicity of MDT is definitely being undersold by many who, instead, try to put so many preconditions or requirements before starting MDT, such as the existence of reliable laboratory service, which tends to dissuade many potential users of MDT before even trying. As long as we clarify what is involved, and perhaps more importantly what is not involved, it is not that difficult for the health authority to see that MDT could indeed be undertaken by GHS.

It is most important, at this stage, to recognize that MDT can be and should be implemented by the “existing” GHS. Having so many constraints, it is almost useless to consider improving existing GHS for the sake of MDT implementation. If we accept the basic principle of equality for leprosy patients, as discussed previously, we should not expect MDT implementation to be any better or any worse than the level of health care existing GHS can provide, on a par with any other service they are providing to non-leprosy patients now. It may be very much less than what we hope to see, but accepting the idea that any MDT is better than no MDT, we must be prepared at least to start MDT at whatever level the existing GHS can provide, hoping at the same time that the situation will get better gradually as the level of GHS improves.

As to the reluctance of GHS staff to get involved in leprosy work for fear of the disease, it is probably more apparent than real. Of course, the stigma attached to leprosy is real and varies from country to country, and health workers’ attitudes are certainly influenced by the general belief prevalent in that community. However, because ignorance about the true nature of the disease is often the reason behind the fear, it is amenable to proper health

education to a degree. Furthermore, the existing reluctance on the part of the health workers to get involved in leprosy is often due to the total lack of training as well as the absence of the means to help the patient.

Many PHWs who are responsible for the health of the people in their area, which include leprosy patients and their families, in fact often take no action toward leprosy sufferers, not so much out of fear but more by their powerlessness due to the lack of training and provisions. At least in the Philippines, there was hardly any case of refusal by a health worker to do MDT, once a few days of training were given and an uninterrupted supply of drugs as well as technical support were assured. In fact, in my observation at least, many of these workers become so interested in MDT that I had some guilty feelings over the possibility of them neglecting their other more mundane duties. In any case, MDT implementation as such does not require a physical contact with the patient, and even those workers with intractable fear of the disease should be able to manage to do MDT work if adequate administrative pressure is applied.

## **5. What to do if there is a functioning vertical leprosy service?**

### **Should it be dissolved and absorbed into GHS?**

The answer to the above should be considered within a certain time frame and depends very much on the level of the existing general health services.

Implementation of MDT, in any form at present, is more important than doing it in a certain set formula, even if that is theoretically a better one, as far as our goal of Stage I is concerned, as will be discussed later. Under certain circumstances, especially if the level of existing GHS is much poorer than that of a vertical leprosy service, it might be permissible and certainly more logical to keep utilizing the existing functioning vertical leprosy services to initiate

MDT. If the total known caseload is not too great, and the existing leprosy service is reasonably efficient, then they may be able to finish Stage I by themselves within a few years, and if that is the case, it is obviously foolish not to employ them for the sake of the principle that MDT is better implemented by GHS.

However, such situations are not likely to be very common, and whatever exception we can find is likely to be a vertical service provided by a non-governmental organization and in that case their coverage in terms of both area and caseload are likely to be rather limited compared to the total needs within the country.

In the majority of the cases, the existing national vertical service is far from meeting the total needs. However, it is possible to think of a situation where the existing vertical service tries to provide as much MDT as possible within its means while GHS is being prepared to take over eventually for nationwide coverage.

But if the existing GHS is reasonably good, in terms of area coverage as well as level of functioning, it seems far better to start MDT with GHS while utilizing the personnel of the existing vertical leprosy service for the planning of the program as well as the training of GHS personnel on MDT, and once the implementation is started, use them as specialists stationed at various levels of health structure from the central ministry down to the second-level health station such as the main health centers, for supervision and monitoring of activities by GHS staff. Some lab technicians and senior paramedical workers of the leprosy service could actually take a supporting role to strengthen and improve the level of performance of MDT implementation through GHS.

It should be clearly understood and remembered that the total integration of the leprosy service, or any other vertical service, into GHS does not mean

disappearance of the specialists. Rather, it is a change in functions. Instead of doing the work by themselves, they are now taking a supporting role for GHS, which will do the work they have been doing.

As will be discussed in the next section, a fair number of leprosy specialists are required in any GHS, so that the prospect of present members of vertical leprosy service losing their job or being shifted to entirely different work is most unlikely, as long as the government intends to do a credible MDT implementation. As the total caseload diminishes, quite drastically in Stage II, they may have to undertake additional duties such as TB control work, but as long as leprosy remains the concern of the government, leprosy specialists are likely to be required at all levels.

What to do with localized MDT programs run by NGOs requires very careful handling. An absorption into the national program by GHS is probably the final goal, as far as MDT implementation is concerned. But we must remember that those patients under the care of NGOs are likely to have much higher expectations of service than any government can meet. It is probably better to leave such NGO programs for the time being but, where appropriate, request them to enlarge the area of coverage to have more cases on their MDT, by shifting their emphasis more to MDT and less to other care.

When Stage II is reached in that area, then GHS should take over the responsibility of MDT, but asking the NGOs, if they wish to remain there, to be responsible for care beyond MDT, which is unlikely to be taken up by most governments. Hastily taking over MDT patients under NGOs by a government service, either by GHS or even a vertical leprosy service, is likely to invite rather unfortunate consequences.

### III. MDT Implementation in Two Major Stages, I and II When, What, and How?

In every leprosy-endemic country, there is a large pool of leprosy patients who have developed the clinical disease sometime ago, but because of either the absence of treatment or ineffective treatment, still remain clinically active thus requiring MDT, and this fact is indicated by a relatively large PR compared to the IR.

It is not uncommon to find the PR (or more accurately case registration rate) being ten times higher than the IR (or in reality case detection rate), even though in some countries such as India, where MDT is widely implemented and those completing MDT are actively removed from the registry, this ratio is coming down to 5:1 or even smaller. When MDT is in full operation on a nationwide scale, PR/IR ratio should be near 2:1, and in terms of caseload it should be less than 20% of what it is now.

It is, therefore, proposed to consider a nationwide implementation of MDT in two stages. Stage I is to tackle this large backlog of patients in order to reduce the accumulated caseload and bring PR much closer to IR, say no higher than 3:1. Stage II then will take over and continue until the leprosy problem is firmly under control and eventually solved, or achieving the “elimination of leprosy” as a public health problem, if not altogether as a health problem.

## Stage I

### 1. General situation

Due to a large backlog of untreated or insufficiently treated patients, the ratio between PR and IR is greater than 3:1, often reaching 10:1 or even higher. In many countries, national mean PR is greater than 0.6/1000. Leprosy work is often done by a vertical leprosy service, managing to cover only a portion of existing patients effectively. There may be a number of expatriate voluntary agencies doing some leprosy work including MDT, but their activities are not fully coordinated with the national effort and their coverage is even more limited. On the other hand, their leprosy work is likely to involve much wider activities beyond MDT, including what is now officially termed as “care for the ex-leprosy patients”.

### 2. Objectives

The overriding importance of Stage I is to put all known active cases on MDT as quickly as possible. This is the basic principle of a public health approach to infectious disease control.

For this purpose the field must be prepared to do proper case holding, which aims at a high completion rate of MDT, in order to demonstrate both that “leprosy is curable by MDT” and that “existing health services can deliver the MDT” to earn the trust and confidence of the so-far rather skeptical patients and the public, and obtain their full cooperation.

Since the demonstration of “cure” is the main objective and since there are already a large number of known cases waiting for MDT, handling of which is likely to tax the existing resources, *case finding* should *not* be emphasized in Stage I. Also, restructuring of leprosy services, such as complete integration

into GHS, must be done carefully, sometimes postponing the process, if the existing vertical service can manage to do substantial MDT work for the known cases.

From the very start, careful long-range planning is necessary to cover both Stage I and Stage II implementation of MDT. Stage I needs much more flexibility and any structural change which is likely to be necessary in Stage II must be introduced rather carefully, always remembering that the MDT implementation itself in terms of the numbers of patients covered is much more important than establishment of a “proper” leprosy control structure as such. MDT Stage I is rather an expensive undertaking so that a substantial amount of financial support, mostly from international donor agencies, is likely to be required, which calls for effective coordination among all agencies concerned, including WHO in most instances, with the initiative coming from the health ministry of the country concerned.

To sum up, the main objective in Stage I is to give MDT to all the known active cases as soon as possible by establishing a reliable case-holding system. Case finding should not be emphasized at this stage and restructuring of leprosy services should be done only if that will strengthen MDT implementation. An effective coordination of all the agencies involved is mandatory since a large amount of external resources are likely to be required at this stage. Training also needs careful long-term planning because Stage I lasts only several years and when Stage II is reached, both the amount and the nature of leprosy work required is likely to change in step with a drastic reduction of the caseload.

### 3. Strategies

Because of the large scale of the undertakings in Stage I, it is best tackled as a special *national project* of three to five years' duration, with a specifically-established central (national) structure together with the national budget.

#### 3.1 Organization/Structure

##### Central (national/federal) level

a. National MDT Steering Committee (NSC)

Composed of a senior administrator, such as a vice minister, as the chairman and other senior officials, like directors-general of various divisions including the head of finance and personnel, as members. They will meet perhaps quarterly to oversee the progress of Stage I until it is completed.

b. National MDT Task Force (NTF)

The NTF functions as the effective arm of the NSC mentioned above. This group of a dozen or so members may be headed by the person to whom leprosy service belongs, such as the director-general of communicable disease control (DG/CDC). The majority of the other members should be composed of leprosy specialists in the ministry but a training and a health education expert should be included if available. The group's function is to draw up the plan for Stages I & II, then monitor and evaluate the activities starting from training and then implementation itself of Stage I. Each member, perhaps with the exception of the chairman if he is DG/CDC, must be able to go to the field frequently, say once a month for up to two weeks, for monitoring purposes and there should be a monthly NTF meeting for evaluation of MDT at the ministry with all members

attending; a quarterly report should be made to NSC. This kind of careful monitoring is so important that an adequate budgetary provision must be made for this activity.

One member of NTF should be in charge of the data collection and analysis of the MDT activities while another person must be specifically designated to be responsible for the logistics, which needs both constant monitoring and long-range planning, because drug supply from the manufacturer often takes six months or more to reach the peripheral health stations where they are actually needed.

The following two levels may not need a special structure, if MDT is to be handled by the existing vertical leprosy service.

#### Provincial (or state in case of a federal system) level

Often, health activities along with budget and personnel are controlled at this level, rather than directly from the national government. Therefore, even though Stage I is a national project, there must be a specially set up structure for MDT at this level, if it is handled by GHS. Provincial Task Force (PTF), composed of the provincial health officer (PHO) as the chairman, and one medical officer (MO) as the provincial MDT coordinator together with several others, probably public health nurses (PHNs) or senior paramedical workers (SPMWs). One of them must be specifically designated to look after logistics and another to look after data collection, although one person may be able to do the both. These people too must be quite mobile within the province for regular and frequent rounds of monitoring.

## Peripheral level

### a. Village health station/post/clinic

Actual implementation of MDT by giving drugs to the patient is best done at the most peripheral or primary health care level, say a village health station (VHS), of the area where both the patient and the multipurpose village health worker (VHW) reside and perhaps know each other. A monthly clinic is held at the VHS.

### b. Main health center

Often several VHSs are under the control of a main health center (MHC) in a nearby town with at least one MO, a few PHN or SPMW, possibly with a lab technician (LT). One of the PHNs or SPMWs should be designated as a MDT coordinator, responsible for both supervision and monitoring of VHW in the area, although the activities as the coordinator are likely to be done within her normal duties.

MOs at this level must be primarily responsible for the verification and clinical assessment of the known cases, diagnosis and classification of new patients, if any, and initiating and terminating MDT, giving outpatient care for lepra reactions and for drug side effects, or referring the case for inpatient care at the next higher level. The LT may be responsible for BI examination, even though it is probably better to restrict his task to taking the smears and fixing the slide only, leaving the job of staining and reading to the LT at the next higher level, who is likely to be based at a hospital. Clinical records of MDT patients are apt to be kept at the MHC.

### c. District hospital

In most countries, there is likely to be another level of health services structure, most probably based at a hospital. If so, at least one MO should receive special training on clinical leprosy so that proper inpatient care

can be given to a patient in case of a severe lepra reaction or drug side effects. That MO should also be competent in the diagnosis as well as the classification of leprosy, when a doubtful case is referred from MHC below. One competent LT at this level should be assigned for data collection and logistics as MDT coordinator, but this will depend on the general health structure and the caseload.

### 3.2 Financing and logistics

#### National budget

Since Stage I is a national project, it is essential that the Ministry of Health (MOH) should have an adequate fund to conduct all the activities of this stage, except the regular salaries of all the staff involved, which should come out of a normal budget, both national and provincial, unless some persons are specifically recruited from outside of MOH. Most MOH of leprosy-endemic countries are likely to require substantial support—partly in kind, such as drugs, equipment and printed material, and partly in cash—from outside to complete Stage I. (It is often necessary and/or prudent for NGOs that, in the event their contribution is very substantial, they insist on a counter budget from MOH for the project itself, excluding salaries, in order to make sure, both symbolically and in reality, that MDT is a national project of MOH and not of a funding agency. This arrangement is essential if Stage II is to succeed Stage I smoothly, because Stage II is meant to be a regular MOH program without large-scale external support, as far as MDT is concerned.)

The national budget should cover:

- a. Activities of NSC and NTF (planning and monitoring)
- b. May be required to cover the cost of PTF (monitoring)

- c. Activity cost of planning, training, implementation, monitoring, data collection evaluation, at various levels
- d. Purchase of drugs
- e. Acquisition of necessary equipment, including vehicles
- f. Production of material for training, health education, and working manuals

### Provincial budget

Apart from the cost of PTF, mostly for per diem allowances and the transport costs of its members, not much is required, since at this stage the drugs and other supplies are provided by MOH.

## 4. Key points in Stage I

1. Political commitment at the highest level of the national health authorities, reflected in:
  - a. Public announcement on MDT implementation as a national project
  - b. Establishment of special structures within MOH, such as NSC and NTF, with specific designations of personnel budget
  - c. Allocation of the national budget
  - d. Issuing of administrative order to all personnel in health services on MDT implementation
2. Detailed planning of Stage I with careful anticipation of the requirements of Stage II. The plan thus decided must be amenable to improvement by alterations if such become necessary as a result of monitoring by NTF.
3. Production and distribution of the plan of operation and a manual of operation in sufficient quantities to make them available to everyone directly involved in the field
4. Training—task-oriented to meet the need of assigned job performance.

Not much theoretical teaching is needed. Since a large number is likely to be involved, “self teaching material” should be utilized in full to cut down the time and expense required for teaching sessions. Ample provision should be made available for the expected amount of remedial or refresher training, because whatever the training given originally is bound to be inadequate for some of the people. If the training was found to be adequate for every participant, it probably indicates overtraining and wasting of time of some of the participants.

5. Establishment of a clear line of authority with strong central command and efficient local organization. At every level from MOH down to VHS, the person/persons responsible for MDT should be so designated and made known to everyone.
6. The primary objective of Stage I is the establishment of a reliable case-holding system to implement MDT to all the known cases and this should be demonstrated. Do not attempt any active case finding, except the household contact survey. Experience amply shows that if the fact that an effective treatment is being given at VHS becomes known, then most of those missed or so-called “hiding” nonregistered patients will come forward by themselves. It is a well-known fact that many leprosy patients present themselves to a clinic when some early symptoms, such as a skin patch or nerve disturbances, appear, but the true nature of the disease is missed by the health worker; subsequently, as the symptoms become more pronounced and the patients themselves become aware of the diagnosis, their mistrust of the health services stops them from coming forward. Intensive health education on MDT is no doubt useful, but only if the local health service can deliver a reliable MDT program.

## Stage II

### 1. General situation

Stage II starts when Stage I is completed, but without a break in between. Most of the backlog of clinically active cases should have received MDT during Stage I, so that the total caseload in most of the leprosy-endemic countries should have dropped to one-fifth or less of the original number. True IR may have started dropping somewhat by now, but even if it has not, the ratio of PR to IR should become 3:1 or perhaps less, because at this stage we should be dealing mostly with genuine new cases as well as a small number of relapsed cases.

Unlike Stage I, case finding will be as important as case holding in Stage II, although this does not indicate employment of extensive active case finding. If a vertical service had much to do in Stage I, there is no longer any scope left for it as a separate service as far as MDT implementation is concerned, but if the government is willing to provide some care to the leprosy patients beyond MDT, then there could be room for a vertical leprosy service to stay on. Under most circumstances, such extra care in the leprosy-endemic countries in the Third World is best left in the hands of voluntary agencies, because it seems to be extremely difficult to justify the use of rather limited available public funds, which are most probably needed to deal with other pressing public health problems.

The MDT program now, in which case finding is as important as case holding, must be conducted by GHS for the reasons already discussed; if an efficient Stage II follows a successful Stage I, leprosy should no longer be a serious public health problem within 10 years or less from the start of MDT.

Stage II should be conducted as a routine program of MOH, without

special national budget and national structure, even though it might be a wise precaution for the national government to procure MDT drugs and distribute them to the provinces. This should act both as a reminder and as an incentive to the health authority of the provincial government to continue the MDT program under their own responsibility.

Only a very few countries have either reached or are approaching Stage II so far; therefore, there is not much point in discussing the matter too much in detail at present, and only some brief statements will be made in the following.

## 2. Objectives

By establishing efficient case finding as well as maintaining a reliable case-holding system through GHS, any new cases in any part of the country, together with cases of relapse, will be diagnosed without delay and put on effective MDT, which, with the addition of or substitution by more potent drugs, could well be shorter than what is now recommended as the minimum.

Our main objective in Stage II is to make leprosy no longer a major public health problem within five years or less of implementation, coming closer to an eventual elimination of the disease, with something like true IR of less than 1/1,000,000 per annum.

## 3. Strategies

Even in Stage II, where case finding is as important as case holding, there probably is very little scope for active case finding, except household contact surveys. Instead, it will heavily depend on efficient passive case finding based on three factors:

1. Knowledge of the signs and symptoms of leprosy, and what to do when the disease is suspected, by the general public. This will be done by

extensive and often repeated and sustained public health education using all available media and opportunities.

2. Keen awareness of the possibility of encountering a case of leprosy by every person involved in medical and health work, including doctors in private practices, PHN in schools or factories, etc. They should at least be able to suspect, if not actually to diagnose, leprosy and know where to refer such a case for proper handling.
3. Readiness by leprosy specialists to deal with the case, including initiation of MDT. This means that a certain number of leprosy specialists must be within the structure of GHS. Because the majority of peripheral workers are unlikely to face a case of leprosy to handle, there is not much point in giving specific training on MDT to everyone as a routine, but it should be given only when a VHW actually has a case, in the form of “on-the-job training.” However, all GHS personnel should be made to maintain a keen awareness of the possibility of leprosy in the community.

### 3.1 Structure/Organization

**Central (National)**—No longer any NSC or NTF

The head of the national leprosy service within CDC Division should take full responsibility to run Stage II, together with his staff in the ministry, through the regular administrative structure of GHS. A few leprosy specialists (MOs) may be designated as MDT advisers to assist the head of leprosy service.

It is important to continue reliable data collection from the field within the normal structure of data.

## 3.2 Financing

**National**—No longer is a special budget for MDT required, except:

- a. National government may keep purchasing MDT drugs and distribute them to provinces
- b. Special budget for monitoring of MDT and for an epidemiological survey, especially toward the end of Stage II
- c. Nationwide health education of the public and health workers is better done by MOH with its own national budget

**Provincial**—No special budget is required for MDT because any activities involved should form a legitimate part of routine work within GHS with regular operational budget.

## 4. Key points in Stage II

1. Even though MDT is no longer a special national program, “MDT for all” or even “elimination of leprosy” should be kept as a national goal and that should be made public frequently.
2. In conjunction with the above, a high level of health education must be maintained to keep both the public health and medical personnel aware of leprosy and how to deal with it.
3. Retain some competent leprosy specialists within GHS structure, so that their expertise will be available whenever needed.
4. Case finding, which is now as important as case holding, primarily depends on “passive case finding” or voluntary presentation by the patient as a result of the above-mentioned effective health education. Even though “active case finding” for leprosy alone should not be

encouraged, because of the poor cost effectiveness, any opportunities at clinics, hospitals, schools, factories, etc., should be utilized to look for possible signs of leprosy.

5. Since a major part of MDT is over by the end of Stage I, a possibility of further care of leprosy patients, especially those with physical disabilities, should be seriously considered, within the total context of the health care of the nation.

It is not recommended to utilize the public health budget of MOH for rehabilitation of leprosy patients, unless rehabilitation of the physically handicapped by any cause is already part of its work. However, it is definitely a responsibility of MOH to make sure that whatever rehabilitation program exists in the country should be made available to leprosy sufferers and, at the same time, to encourage NGOs, both national and international, to give assistance in this area, again making sure that it is not exclusively for leprosy. If there is a pre-existing specialized rehabilitation program for leprosy, it should be encouraged to open its doors to the needs of other non-leprosy sufferers.

## IV. Conclusion

1. In the last decade of the 20<sup>th</sup> century when we are all striving for the goal of “Health for all by the year 2000,” what is most important is to recognize and accept the basic principle that every leprosy patient, wherever he lives, has a right to expect MDT to be given. To give MDT the top priority, therefore even poorly implemented MDT, is better than no MDT.
2. “MDT for all,” therefore, should be a national goal of the health authority of every leprosy-endemic country. In order to make that goal attainable, the MDT program must be made simple so that any leprosy-endemic

country, with whatever the current state of health services, can adopt it.

3. The above goal may be reached in two stages. Stage I is to tackle all the accumulated known cases, concentrating on proper case holding. This should be a special national project with a national budget covering three to five years. Stage II is to establish and maintain an effective case-finding as well as case-holding system through general health services so as to cover all existing and newly emerging cases in any part of the country. This stage may also last up to five years, at the end of which leprosy should no longer be a public health problem.
4. Even though Stage I, by necessity, has to be a special project for leprosy only with a separate national budget, every effort must be made, especially in Stage II, to see that leprosy is no longer separated from other diseases, both in thought and practice, by health workers and hopefully also by the public.
5. It is necessary to recognize that even though MDT is capable of controlling leprosy as an infectious disease, it cannot fully control leprosy as a deformity- and disability-producing disease. This aspect of leprosy, at present, is likely to be outside of the concern of public health authorities of leprosy-endemic countries. As a result, this provides large scope for interested NGOs to make a useful contribution in this area.

We should not rest until the day when every leprosy patient all over the world can say that “leprosy is curable” and “deformities are preventable,” not as a dream but as a reality based on their own personal experience.

# 3

## Making a Man Whole

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### 1. Why MDT now?

Just as the Ten Commandments are considered to be the basis of Western civilization, the so-called Hippocratic Oath is considered by many to be the starting point of Western medicine. Its basic injunction is “Do no harm.” The medical profession, whatever it does, should never make the situation worse than before its interventions.

Since Dr. Faget’s epoch-making discovery of Promin as a truly effective chemotherapeutic agent against leprosy in the early 1940s, sulphones, especially in the form of dapsone, made a great contribution in controlling leprosy, and made slogans like “Leprosy is curable” and “Deformities are

preventable” realities or, more accurately, realistic possibilities—although unfortunately, for a long time, not for a great many leprosy patients in the world who have been denied access to this cure.

The signs of trouble were apparent by the early 1960s, however. The slow-acting and relatively weak bactericidal effects of dapsone, due especially to the long period of intake, often lasting a lifetime, and the very small doses prescribed in the late 1950s and 1960s in reaction to the earlier damage resulting from very large doses, led to the emergence of dapsone resistance—first secondary, but then primary—in many parts of the world and the situation became steadily worse.

Even though several other effective chemotherapeutic agents, notably clofazimine and later rifampicin, as well as less effective thiacetazone, thiambutosine and various other sulphones were added to the arsenal of the anti-leprosy campaign, dapsone monotherapy remained as the standard treatment for leprosy up to the early 1980s. By then, some people, including those in WHO, considered that perhaps dapsone monotherapy was doing more harm than good by spreading dapsone-resistant *M. leprae* worldwide, even though its use was undoubtedly successful as shown in the case of leprosy control in China. Some instances of rifampicin resistance were also reported by then, as expected from the earlier examples of tuberculosis treatments, although fortunately no confirmed case of clofazimine resistance was recorded.

In October 1981, a study group was called by WHO to examine the problem, and its recommendations were published in the spring of 1982 as a booklet titled “Chemotherapy of leprosy for control programmes” (WHO Technical Report Series 675). What the study group recommended was multidrug therapy, one regimen containing dapsone, clofazimine and

rifampicin for a minimum of 24 months for the group of patients of MB (multibacillary) type, and another regimen of rifampicin and dapsone only for 6 months for PB (paucibacillary) patients. It was exactly 10 years ago that this study group took place.

In spite of initial doubts even among those in the study group, and many objections, often good intentioned but misguided, from eminent leprologists and leprosy workers, MDT took root firmly and made usually cautious WHO to propose “Elimination of leprosy as a public health problem by the year 2000” as a global goal. This proposal was adopted by the World Health Assembly in May this year in Geneva, but I am happy to mention that a leprosy workshop organized by the Western Pacific Regional Office of WHO in Manila had made exactly the same proposal in November 1989, almost two years ahead of the Geneva resolution.

Therefore, the reason “Why MDT now?” is, first of all, to prevent drug resistance emerging in leprosy treatment—although a search for better chemotherapy in terms of more effective bactericidal results, a quicker disappearance of infectivity, shorter overall treatment, better prevention of deformity and a smaller relapse rate, were also intended. All of these expectations are being fulfilled so far, although the period of observation is too short for the notoriously chronic disease that is leprosy—especially in terms of the eventual cumulative relapse rate and more difficult-to-measure effect on prevention of deformities, which is almost as important as curing leprosy as an infectious disease, and thus as a public health problem.

In 1981, those of us involved in the study group were convinced that MDT had to be better than dapsone monotherapy, but I very much doubt that anyone in the group dared to predict, at that time, the possible elimination of the disease within this century by this new treatment regimen.

## 2. Significance of MDT

WHO-recommended MDT (WHO/MDT), as a globally applicable field control measure against leprosy, is undoubtedly, as originally intended, a remarkably effective, safe and cost-effective way of treating active cases of leprosy; and, in the last 10 years, it has become gradually accepted and reached the current status of almost universal adoption by the national leprosy control programs of endemic countries. Although there is an unending search for better regimens in terms of even shorter duration and less side effects, the current regimens are so effective as to make it realistic to plan for the elimination of leprosy within this century, a mere eight years from now and an amazingly short period, at least to those old hands of leprosy work familiar with the excruciatingly slow progress of leprosy activities up to now.

I trust that the technical details of WHO/MDT as well as its merits, as an effective chemotherapeutic tool against leprosy, are familiar to this audience. Therefore, using the relatively brief period given to me this morning, I propose to discuss the merits of current MDT, as I see them, beyond its effectiveness in chemotherapy. These other areas are perhaps not so apparent, but for me they are much more significant in the long run for the future of leprosy control and the welfare of leprosy patients and thus worth examining in this meeting, where the implementation of MDT as such is no longer of primary importance, but the way we proceed post MDT is a much more significant and relevant issue.

## 2.1 MDT as an effective tool for the integration of leprosy work into general health services

WHO-recommended MDT, although not emphasized in the “Chemotherapy of leprosy” booklet and afterward disregarded by many, is probably a most effective tool in making the work of leprosy control, or at least the chemotherapy part of it, acceptable to the personnel of the general health services (GHS) in the course of their routine activities.

Various regimens used before WHO/MDT to meet the needs of several classifications of patients—Madrid, Ridley-Jopling or Indian—plus patients who have relapsed with or without drug resistance, resulted in a bewildering variety of regimens containing dapsone and other agents. In terms of indication, dosage, frequency of administration and duration of treatment, they were simply too complicated to be handled by busy multipurpose field workers of GHS.

Traditional care of leprosy patients, of course, went beyond chemotherapy, and often that care, other than drug-giving, took up most of the time of leprosy workers, although strictly from the medical point of view, the effectiveness of that care is somewhat questionable. Altogether, care of leprosy patients is not suitable to be handled by existing GHS, and various attempts to integrate leprosy work have usually failed or at least been severely criticized by leprosy workers and perhaps by patients as a lowering of the standard.

However, the greatest failure of leprosy service up to now, as a vertical service of whatever size, has been its inadequate contact with known and unknown patients, both in terms of nationwide coverage and in frequency. With fixed clinics, the frequency of contact was severely restricted. A patient who failed to attend the clinic on a fixed day or who developed lepra reactions

or drug toxicity often had no immediate access to medical help.

Now, GHS has an advantage over vertical services exactly on these points. Of course, some countries have only a basic GHS. But within any given country, GHS as a rule has a wider coverage and more intimate contacts with the population.

The elimination of leprosy as a public health problem definitely calls for the involvement of GHS with MDT now as well as in the future, when both prevalence and incidence become very low but there are still patients scattered nationwide. As the examples of many countries in this region such as the Philippines show, current WHO/MDT can be fully and effectively implemented by existing GHS provided that the necessary training as well as supervision are given utilizing most effectively the personnel of the existing leprosy vertical service.

It is extremely important to make sure that not too much is asked from GHS. As long as it is limited to MDT implementation proper—that is, a monthly clinic and possibly a compliance check between the clinics, retrieval of defaulters, surveys of the patient's household contacts, and hopefully health education including deformity prevention—then most of the existing GHS are likely to be able to cope with MDT adequately. Once expectations go beyond these limits, and GHS personnel are asked to look after existing tropic ulcers of the foot, etc., then the authorities in charge of GHS are more likely to refuse involvement in leprosy work on account of the shortage of both time and material in their hands, and they are usually right.

What is intended by MDT is to control leprosy as an infectious disease. Although an early effective chemotherapy is the single most useful preventive measure for leprosy as a deformity-producing disease, it has little effect on existing nerve damage or resulting physical injuries and disabilities.

There is an unfortunate opposition to the utilization of GHS for implementation of MDT, on the ground that the additional care beyond MDT is being neglected. What many people with such a view commonly fail to see is that the so-called proper care of patients was almost never provided by a vertical service to all the existing patients, both registered and not yet registered, and was enjoyed only by a limited number of patients in any given country.

In a sense, it is a choice between quality and quantity. But as long as our primary consideration, at present, is a public health control of leprosy as an infectious disease, quantity in terms of covering as many patients as possible at a given time must be the most important factor in deciding the program.

By the way, this argument is equally valid in discussing the relative merits of deciding the duration of MB treatment, which is either 24 months or until BI (bacteriological index) negativity. Although MDT has a superior bactericidal effect, bacterial clearance as indicated by the fall in the BI in skin smears is practically identical to that of dapsone monotherapy. This by itself should be a good enough reason not to rely on BI values to judge the effectiveness of chemotherapy and determine its end point; however, an absence of any reliable alternative indicator seems to make some people still depend on this particular method. In that case, the best argument to employ seems to be “MDT for 24 months until every existing case is covered.” What anyone wishes to do after reaching that point depends on his priorities, although extending MDT until BI negativity probably has a much lower priority than more effective case finding or deformity prevention.

As a public health measure, WHO/MDT is never intended as a 100% cure, even if that is possible at all. But what some people usually fail to see is that even a 10% relapse by utilizing fixed-duration MDT for MB—which,

by the way, is most likely if currently available data are any indication—still means 90% success, which is certainly acceptable as a public health measure. Extending MDT beyond that period means overtreatment for 90% of the patients, which will have all-important consequences and involve serious ethical questions far beyond mere wastage of scarce resources, which by itself is a serious point.

One of the important merits of WHO/MDT, therefore, is its basic simplicity and short fixed duration. This makes it eminently suitable for implementation by almost any existing GHS and thus will make the hitherto often discussed, but seldom successful integration of leprosy work possible—provided, of course, unreasonable demands are not added on. This is probably the only way to ensure that some effective leprosy work continues beyond the year 2000, when the disease is “eliminated as a public health problem” but still remains as a serious problem to some.

### **3. What else can we expect from MDT?**

The merit of WHO/MDT as a suitable starting point for an eventual full integration of leprosy work into GHS was just mentioned. After all, what leprosy patients can expect from GHS is entirely dependent on the efficiency and general performance level of existing GHS.

Whatever care GHS can provide to leprosy patients, the very fact that GHS, rather than a specialized vertical leprosy service, can look after leprosy patients has very much more significance beyond theoretical benefit for better MDT implementation. At the start, it may be more symbolical than real in a significant way; nevertheless, it should mean that leprosy is no longer a disease apart and, by inference, that leprosy patients are no different from the

rest of mankind. The fundamental difficulty in tackling the leprosy problem, in almost any culture and religion, is the age-old popular notion that leprosy patients are a race apart, untouchable under Hindu law and the same in many other countries, although seldom so clearly stated.

To go into the origin of such a notion is beyond the scope of this paper, but the universal existence of such a notion, even in non-leprosy-endemic countries, is proven by the fact that leprosy is often one of the most effective fund-raising causes. The large amounts collected for leprosy undoubtedly helped to start effective care of leprosy patients in many parts of the world, long before most health authorities in leprosy-endemic countries took up some of the responsibilities for the care of leprosy patients.

But with modern effective treatment, especially WHO/MDT, the care of patients, at least the chemotherapy part, should be fully in the hands of the health authorities of the country as a regular part of their health care responsibilities to their own citizens; it should not be left in the hands of non-governmental organizations, both national and international. If their resources are inadequate, the government should seek whatever support they require, but still do the job by themselves.

This also calls for a changed approach on the part of NGOs, who previously often took over the responsibility of patients' care from the government, doing so with or without the official consent of the government, which often seemed more than happy to relinquish such burdens in the face of a multitude of other health problems. The main trouble with this situation was that such non-governmental agencies never felt responsible for caring for all the existing leprosy patients in a given country. They usually decided on the number of patients to be cared for, in relation both to the amount of resources in their hands and the kind of care they thought they should give. This usually

resulted in a small fraction of total patients getting a level of care that only a non-governmental agency could give.

With acceptance, in principle at least, of the “global leprosy elimination goal” by all leprosy-endemic countries as members of the World Health Assembly, implementation of MDT is now a responsibility of the government of every leprosy-endemic country, using whatever resources they have at hand. This is likely to result in leprosy patients in a given country getting as good or as poor a service as the level of existing health services—in other words, the same level of health care as anyone else in the country is getting. Equity, a fundamental precept for any governmental actions, is more likely to apply to leprosy patients under these circumstances now than ever before.

We should take full advantage of this situation and make sure that, in the eyes of government health authorities, leprosy patients are entitled to the same level of care being provided to other people. Equality means no less than others, but also no more than others. We must be careful not to demand more care for leprosy patients than for others, however much we may feel these patients need it, based on our past experience with NGOs or vertical services.

This brings me to the last point of my presentation, which is how we should deal with the problem of rehabilitation of leprosy patients, or rather ex-patients, many of them with disabilities due to deformities. This aspect of leprosy care has been, and still is, a strong point in leprosy activities by NGOs. How should we proceed?

This topic is obviously outside of MDT, which is the subject I am given to discuss. But, as I hope you have realized by now, I consider WHO/MDT to be potentially an excellent tool to achieve equality of leprosy patients, thus abolishing the popularly-held notion that leprosy patients are somehow apart from the rest of a country’s citizens. To ensure that this kind of equality is

achieved and maintained, there should be no plan to establish a rehabilitation program exclusively for leprosy patients. Any new scheme for a rehabilitation program should encompass physically and socially handicapped people, including leprosy patients.

Of course, the special interests that many people have in the leprosy program as a worthwhile act of charity mean that rehabilitation programs for leprosy patients are often at an advanced stage compared to similar schemes for non-leprosy patients. If that is the case, then just as reconstructive surgery in leprosy paved the way for the development of similar techniques for non-leprosy cases, and just as some immunological research in leprosy assumed a pioneering role in research for other immunodeficiency diseases, so the rehabilitation program in leprosy could be a pathfinder for such programs for non-leprosy patients.

Only when leprosy work becomes beneficial to others are we likely to achieve the true acceptance of leprosy and leprosy patients and their medical problems by the medical profession and also by society as a whole. Surely, our final goal must be not mere healing of leprosy the disease, but restoration of leprosy patients as whole persons in the community. I submit that the most significant merit of WHO/MDT lies in the possibility of opening the door to this ultimate goal.

# 4

## Inaugural Address as Incoming ILA President

Dr. Yo Yuasa

Executive and Medical Director  
Sasakawa Memorial Health Foundation

Dr. Meyers, dear colleagues, ladies and gentlemen:

We have just completed all programs of this 14<sup>th</sup> International Leprosy Congress save one, which is this address from me as the new ninth president of the International Leprosy Association (ILA), an association with a proud history of over 60 years. By the way, the International Leprosy Congress predates the founding of the International Leprosy Association by more than 30 years. The first congress was in Berlin in 1897 and two more, one in Bergen and another in Strasbourg, took place before 1931, when the association was born in Manila, the Philippines.

The great strides made in the science of leprosy, in immunology, microbiology, epidemiology or any other areas within a broad spectrum of

leprosy as a disease, are, in large measure, by the members of our association. Multidrug therapy (MDT), which has made such a significant reduction in the global caseload possible, could not have been conceived without much effort by many of the colleagues within our association, specializing in chemotherapy, pharmacology or animal experiments, working closely in various capacities with the World Health Organization (WHO).

There is no doubt at all that a large number from among the members of our association have made key contributions to making the global picture of leprosy so different today, which is something that could not have been hoped for, let alone expected, only 10 or 20 years ago. I trust that they will keep making their invaluable contributions even more in the years to come.

However, when we think of contributions made by the association as a whole, the picture is not so clear. Apart from publishing a highly respected scientific journal, the *International Journal of Leprosy and Other Mycobacterial Diseases*, and organizing every five years a popular—judging from the large number of non-ILA members attending—congress, I am hard pressed to come up with any specific contribution that could be attributed to the effort of our association.

It seems that as long as the association meets the needs, whatever they are, of its individual members, this association is likely to survive. However, I for one am rather uncomfortable in accepting such a situation. If I am to be a part of this association, I want it to be a proactive and a purposeful one, so that I can be proud of my membership. This happens only if each member is willing to think and act to make the association a truly useful one for the future of leprosy, and to make it a meaningful partner to WHO, ILEP (International Federation of Anti-leprosy Associations), ILU (International Leprosy Union) and others, together with the governments of leprosy-endemic countries for

the benefit of their leprosy patients. In this, I am recalling one of the more memorable speeches by John F. Kennedy, in which he asked U.S. citizens not to think of what the country can do for them, but rather think what they can do for the nation.

I trust that we all agree that we are in the midst of a very significant, one might call historic, movement, which WHO calls “Elimination of leprosy as a public health problem by the year 2000” by globally implementing what ILEP calls “MDT for all by the year 2000.”

Is the association for it, or against it? There seems to be no ‘voice’—at least, not an audible one. One cannot judge the attitude of the association toward the “elimination program,” either from the contents of the *Journal* or from the program of this congress. The simple truth is that there probably is none—no majority feeling, let alone a consensus. ILA is, in a sense, a very conspicuous silent bystander to the momentous movement that is taking place all around us, and this current situation of our association is, to me, a great shame.

Some people say that ILA is an association of scientists, which, almost by definition, makes it neutral and non-proactive. The current composition of its members, at least partly, justifies that notion. However, neither the composition of the association in the past, say in the 1950s and 1960s, nor the current constitution, indicate that it has to be an association of scientists only. My own understanding is that it is supposed to be an association of professionals working in leprosy. Therefore, the membership must be open both to the medically qualified and to so-called “non-medicals.” Their lines of work could be in basic or applied sciences, clinical medicine or public health control of the disease, or care of the patients or ex-patients, physically, socially or spiritually within a broad frame work of rehabilitation. Why do I want such an association, and on what issues should it be proactive?

There has been a great deal of discussion, both public and private, on the WHO-initiated “elimination program.” But to my great concern and dismay, although not altogether unexpected, support for that program is not that unanimous, to put it rather mildly. I accept that any program of this magnitude could not be without some controversial points. Disagreement over terminologies used or questioning on the validity of target settings are understandable, and even healthy. What I am unhappy about is the rather negative tone of some questions or comments, although some of them, no doubt, were meant to be light-hearted ones. As aptly cautioned by our distinguished keynote speaker, we should try to avoid, by all means, repeating the kind of euphoria of the early dapsone days, and try to resist making over-optimistic predictions.

However, the “elimination program” basically is no more or no less than putting as many patients as possible and as quickly as possible under MDT. Thus, it should merit all the support we can give and nothing should discourage the expansion of that program until all the existing clinically active patients are given MDT. That should be the bottom line or starting point for the planning of any other activities, however worthy or important by themselves.

I shall avoid, in this presentation, getting any further into controversies surrounding the “elimination program,” because to express my personal view on this issue is not relevant and is not my intention. What I am trying or hoping to do is to make ILA a group of professional individuals who will openly and freely express their views and opinions, in an effort to find collectively the best available solutions for the problems we face in leprosy work now and in the future—and the “elimination program” should come at the top of possible subjects for such discussions.

WHO, supported by 183 countries and territories and working primarily to meet their needs, and ILEP members, depending on their public fundraising and thus being answerable to those donors, both have definite limitations in what they can say and in what and how they can act. ILA, on the other hand, being composed of professionals who join the association individually of their own free will, has no such limitations. The members can think, discuss or argue freely, and can express individual or collective views on the issues of common concern without external or internal restrictions.

The enormity of leprosy activities currently undertaken is such that it calls for a full mobilization of every available resource. In my view, ILA as a group could be one of the more important such resources of technical expertise and, using its unique freedom, could even become a beacon or pathfinder to show where leprosy work should be heading and how.

I mentioned already that I want our association to do more than publish the *Journal* and organize congresses, although they are undoubtedly very important contributions now and in the future. The ILA constitution lists five objectives, two of which are related to the *Journal* and the congresses. The other three are “to encourage collaboration between persons of all nationalities concerned in leprosy work,” “to help in any practicable manner the anti-leprosy campaign throughout the world” and “to cooperate with any other institution or organization concerned with leprosy.” Very broad objectives indeed(!), and I believe they call for a much more proactive association than exists now.

How do I intend to bring about these necessary changes? First of all, I would like to enlarge the membership by inviting many more field workers in leprosy-endemic countries actually involved in giving care to leprosy patients, in whatever capacity. I would also like to see many more so-called

“non-medicals” (in the absence of a better term) who will have a significant role to play beyond MDT, an aspect that is becoming increasingly important and urgent as the “elimination program” advances. This will not be easy to achieve. The current membership fee is too high for many of these people, and the *Journal* with its current contents may not provide the kind of information they seek. It is up to the new council, which is going to have its first session immediately after this meeting, to explore various possibilities to overcome these difficulties, provided, of course, that they agree with my basic notion about the association.

The second point is, with or without an enlargement of our membership and compositional changes of our association, I would like to stimulate much more open discussion on the current, ongoing programs, and on the future course of leprosy work, perhaps using our *Journal* as an open forum. I would like to encourage anyone and everyone interested in leprosy to express their opinions on what and how leprosy work should be done, without restriction, provided they are constructive.

I must emphasize, at this point, that in order to maintain the professional integrity and high standards of our association, built up over the years by our current and former scientific colleagues, we must keep a significant portion of our membership for scientists and research workers. Their role within our association will become even more crucial in the future as nonscientific colleagues are being added. However, in order to widen our professional sphere of interests and expertise, enlargement of our membership, in more diversified areas, is mandatory so as to be able to meet new and wider challenges of current and future leprosy work.

Finally, let me talk of a dream. Thirty years ago last Saturday, there was a historic civil rights march in Washington, D.C., and in front of the Lincoln

Memorial, Martin Luther King made that soul-shaking speech, in which he said, “I have a dream.” Nice literary style apart, I wondered why? Why did he not say, “I have a plan” or “I have a hope”? I think a plan belongs to a realm of probability. A hope one can talk of within a possibility. But if one wishes to talk about something that looks so preposterous, so fantastic, so far away from the present reality, then one can talk only in terms of a dream.

I am convinced that, in spite of various positions taken toward the “elimination program” by our colleagues, all of us involved in leprosy work have a common final goal, which is an eventual total eradication of leprosy from the face of this Earth, which, for me, should be a realistic hope. But to expect that to happen, as I do, in or around the year 2050 is perhaps too preposterous for many. Therefore, heeding wise counsel given, I will talk about it as a dream—my dream on this occasion. But it is well to remember that sometimes a dream can propel men to great achievement. Columbus found a new continent and men reached the Moon by dreaming. Today, 30 years later, Martin Luther King’s dream is still far from realization, but remarkable changes have already taken place in the United States in terms of human rights and racial equality. If Reverend King were still alive today, perhaps he could start his talk by saying, “I have a great hope.”

Compared to his dream, I am convinced that mine is much nearer to a hope. I cannot conceive of any great opposition to my dream from any quarter, unlike his. We have many useful technologies already in our hands, and the resources required are potentially available. All that is really needed is our own determination and our own effort to make that dream into a hope and then into a plan. If we do not succeed, we have no one to blame but ourselves.

Eradication of leprosy, when it finally comes, will not only be a medical triumph, as in the case of smallpox or polio eradication, but could be

considered more as a profound human victory, because by eradicating leprosy we will be removing forever the most widely known throughout the world and the most long-lasting, over several millennia, misery and accompanying injustice ever known to man. In that sense, realization of my dream, or rather our common dream, could have equal significance in the history of mankind to the realization of the dream of Martin Luther King.

Well, I cannot promise any great results, but you have my pledge to do my best with the help of my fellow officers, Dr. P. Feenstra, Dr. F. Ross, Dr. R. Hastings and the councillors over the next five years, in order to make our dream nearer to becoming a hope and then into a plan. I humbly beseech your understanding and support.

Thank you all for this opportunity you have given me and thank you for your kind audience.

I now declare the end of the 14<sup>th</sup> International Leprosy Congress. Safe journey home. We shall meet again in Beijing in 1998.

# 5

## How Can We Accelerate Progress toward Elimination of Leprosy?

Dr. Yo Yuasa

Executive and Medical Director  
Sasakawa Memorial Health Foundation

### 1. Introduction

The title given to me obviously presupposes that some acceleration is necessary in the execution of the ongoing global program for the “Elimination of leprosy as a public health problem by the year 2000.” The first question is, “Why the need for acceleration?”

According to the most up-to-date figures given by WHO, 6.5 million leprosy patients have been cured by multidrug therapy (MDT) so far. This is within the 12-year period since WHO’s recommendation on MDT was published in the spring of 1982, although the majority of those cures were effected recently. WHO at the same time estimates that 5 to 6 million more

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ca. the latter part of 1994

patients have to be cured by MDT before the year 2000 in order to achieve the goal of the “elimination” program.

Since MDT implementation quite understandably and logically has been started in more readily accessible areas in the field and with more easily manageable patients in the majority of leprosy-endemic countries, future MDT programs are likely to be in more difficult geographic areas and with more difficult patients to deal with for a variety of reasons.

Thus, using the figures provided by WHO, it is possible to say that in 12 years we have so far completed only 50% of the MDT implementation target, in easy areas, which leaves us with an equal number of more difficult cases to deal with in half the time, that is, in the six years remaining up to the year 2000—hence the need to accelerate MDT implementation now as much as possible.

At this point, I would like to make a basic and a very important observation regarding MDT. Very simply put, MDT implementation in its most basic form, which is to give the necessary drugs to patients and help them to ingest those drugs as prescribed, is admittedly only one of many things we can do, and often feel we should do, for leprosy patients. In many leprosy-endemic countries, however, such basic MDT is probably one of the very few interventions, if not the only one, on which it is possible to justify allocation of the precious few resources available to public health authorities, in the face of ever-increasing demands made by other urgent health problems, including TB, malaria and AIDS, in addition to more basic demands for nutrition, sanitation, immunization, etc.

We are attending a meeting on leprosy and thus it is quite natural to talk almost exclusively about this disease. But I feel strongly that if the conclusions of this meeting are to be accepted not only in principle but actually implemented

in leprosy-endemic countries, we must be constantly aware that leprosy is only one of many urgent and serious health problems and we must be able to defend whatever decisions we make here in the face of all the questions and even criticisms from our colleagues whose main interest is health problems other than leprosy. This is basically an ethical question, although that aspect of public health is not yet clearly established, unfortunately.

Now, back to my task at hand. Just before the first International Conference on Elimination of Leprosy held in Hanoi, I had a chance to visit Dr. Noordeen's office and noticed three words scribbled on the board beside his desk. They were "Fast," "Flexible" and "Focused," and he said to me that he believes these are the three key operative words that could help us to succeed in our task up to the year 2000. I could not have agreed more. Therefore, I would like to proceed with my presentation under these three headings. In conjunction with these three Fs, I would like to add three Es, common but important key words for running any program: "Effective," "Efficient" and "Economical": effective in terms of producing expected results, efficient in terms of manpower requirement and economical in terms of cost-benefit considerations.

## 2. "Focused" actions

Let us start with "Focused" and see what it means. To me, it means that we concentrate only on those things that we can justify to our colleagues who are fighting to get a larger share of allocation for their own cause from the same and much too small resources available. This means that what we do, at least in the field, must be of proven effectiveness with predicable results, in addition to being efficient and economical. As to the last of the three, of course, leprosy is exceptionally fortunate in having quite a large

amount of extra governmental financial resources, thanks to the hard work of international non-governmental agencies such as the members of ILEP (International Federation of Anti-Leprosy Associations). The magnitude of their support for leprosy is the envy of our colleagues in other health sectors, as clearly demonstrated in a recently published booklet by the TB unit of WHO. However, additional financial support cannot solve the problem of limited human resources, which often is the real bottleneck of expanding any program. Additional finances may enable some manpower to be shifted to leprosy, but in those instances it is almost always at the expense of some other health programs. Can we justify that? I am not always so sure.

I believe we are on very firm ground to justify MDT implementation, because we are quite sure of its positive and meaningful outcome. In other words, MDT is a proven effective, efficient and economical methodology already in our hands with predictable results. That now begs the question, “Do we have any other similarly proven effective, efficient and economical tools in our hands to deal with any other leprosy-related problems?” Unfortunately, the answer probably is negative. That means we can and we should go ahead with MDT implementation without hesitation, regardless of the presence and situation of other health problems. However, if one wishes to add any other activities for the presumed benefits of leprosy patients, then such undertakings must be able to justify their use of resources, both financial and especially human, in the face of demands from other urgent health problems.

This focusing only on essential and justifiable tasks is important not only for now to achieve the “elimination goal” within the allotted time, but it is even more crucial in ensuring the acceptance of leprosy control activity into basic health services, which is the only way to see that the necessary medical care for leprosy patients is provided beyond the year 2000.

In translating the above into actual planning, the key point here is that nothing, however worthy on its own merit, should prevent or deter the current MDT implementation and its future expansion.

### 3. “Flexible” actions

The second operative word of Dr. Noordeen is “Flexible.” The concept of flexibility in terms of solving our urgent task at hand is much easier to grasp than the idea of being focused. When WHO’s recommendations on MDT were published nearly 12 years ago, people understandably and rightly took the recommended regimens as golden rules and tried to apply them as strictly as possible. Many people added a number of prerequisites that further increased obstacles for the hoped-for rapid expansion of MDT implementation. Sensing the need to speed up MDT implementation in as wide a field as possible, and backed up by positive results far beyond what was expected originally by the members of the Chemotherapy Study Group of 1981, a series of recommendations, mostly relaxing or removing prerequisites but also allowing some operational changes under certain justifiable conditions, have been introduced by WHO and ILEP. Thus, “Flexibility” has already appeared in implementation of MDT. The second Chemotherapy Study Group, which met in October last year, made some of these changes official.

The adoption of Resolution No. 44.9 by the World Health Assembly in May 1991 gave the whole matter of MDT implementation a much-needed boost in elevating its status in the public eye, strengthening political commitment of governments concerned and highlighting the sense of urgency that was somewhat lacking up to that point.

As MDT implementation in practically every leprosy-endemic country

passes the 50% mark, all those program planners and managers of MDT must be aware of the existence of groups of leprosy patients who are hard or impossible to treat with the standard WHO-recommended MDT. It could be due to geographical location, seasonal climatic conditions, occupational or lifestyle variations or even the epidemiological situation in some cases, in addition to more common personality problems of some individual patients. Some political upheavals unfortunately so prevalent in many parts of the world nowadays further add to these difficulties. Ten or even 15% of the expected 5 to 6 million cases who need MDT may belong to this category, and all of them call for some alternative approaches to MDT implementation.

At this juncture, it is most important to reaffirm the very basic concept that should be common to us all, that every single leprosy patient deserves an effective treatment for cure as a basic human right, and that it is our solemn duty at least to try to fulfill their expectations. It is true that a cure from a disease, especially a chronic one like leprosy, could only result from collaborative joint efforts of both patients and health workers, but it is our duty, at least, to bring the necessary drugs to the patients without which they have no chance of cure.

It is thus not difficult to accept the notion that “Flexibility” is the key to success in achieving the “elimination” goal by providing “MDT for all,” an adopted common goal of ILEP members whatever the situation. However, to arrive at the right solution for this flexibility question is not that easy. Among the three Es, sacrificing of “Effectiveness” is not an option here, except in very limited cases where the personality of the patient is so unmanageable that achievement of “non-infectiousness” could be the only realistic hope without cure of the patient. This means that “Flexibility” applies only in terms of “Efficiency” and “Economy.”

In order to safeguard the effectiveness of regimens, it is most unlikely that the notion of supervised ingestion of at least some key components, such as rifampicin or ofloxacin, will be dropped altogether. The question then is: “Who is the one to supervise, and how often, where ‘Flexibility’ is called for?” It is not my duty to list up several alternatives now. That will be dealt with later by a more specialized group under WHO’s auspices. But in order to come up with various flexible alternative MDTs, it is necessary first to identify and categorize those patients who require different regimens. Actual implementation must be undertaken by each country for its own needs, but perhaps this meeting can come up with a number of universally applicable groups of patients and suggest some useful mode of MDT.

Up to now, I have been addressing only the question of MDT delivery. However, effective case finding is an essential component of the elimination program, and “Flexibility” in this aspect is also mandatory. No doubt this question also will be dealt with in a group discussion later in this meeting.

“Flexibility” both in planning and implementation calls for a substantial amount of ingenuity, unconventional thinking, and above all the courage to move away from accepted and well-tried routine. How flexible we are, at this point, could well decide whether we will succeed in reaching our goal.

#### **4. “Fast” actions**

Let us come to the third and last of the key words, which is “Fast,” the closest word to the title of my presentation. “Fast” could mean haste, but in the present context at least, I choose “Fast” to mean “no delay,” first of all, and then “accelerated.”

There is a traditional view and resulting attitude that leprosy is a slow-

growing chronic disease, thus a sense of urgency is not necessary and is often lacking among those involved in leprosy control. Leprosy has many misunderstood notions and is associated with misguided attitudes, and this idea of “no urgency” is perhaps the most serious one. A single day’s delay in instituting an effective chemotherapy to an infective patient could mean a few more innocent healthy persons getting infected. A week’s delay in giving proper treatment may well mean that the patient in question could pass a point of no return in terms of nerve damage, thus condemning him to end up with physical deformities and disabilities and with well-known social and psychological implications—not only for the patient himself but for his family members as well. Therefore, there is really no justification at all for delaying necessary actions for leprosy, including expansion of MDT to difficult areas. Please remember, all the non-medical implications of leprosy are due to the failure of medical and health services to deal adequately with leprosy as an infectious disease up to now.

In almost any leprosy-endemic country, not a small proportion of those who need MDT up to the year 2000 belong not to the new or incident cases but to what are called backlog cases. These are people who have developed the disease more than a year ago but have been left either unregistered—thus constituting what is termed estimated cases—or registered, but for some reason still waiting to be put on to MDT regimens. Any delay in initiating MDT for these latter cases is inexcusable, and those unregistered cases must be detected as soon as possible.

Thus registering and treating those difficult-to-reach cases that have usually been deferred up until now for some justifiable reasons can no longer be left untouched. The actions called for are to define the nature and magnitude of these difficult-to-reach cases as precisely as possible in each

leprosy-endemic country. At the same time, the WHO committee of experts in leprosy must come up with alternative regimens to fit several possible scenarios in terms of frequency and dosage of drug administration and the total duration of the treatment. In some instances, the new regimens are likely to include those new drugs like ofloxacin, minocycline and clarithromycin.

The above-mentioned two exercises, one national and the other international, should commence immediately, followed by detailed planning of actual implementation of MDT with one of the new regimens for a particular target group. In this process, a slow and cautious beginning is not necessarily a virtue. A quick but tentative start with readiness to modify as required could well be a much more fruitful approach.

As I mentioned earlier, “Effectiveness” in terms of curing the patient should not be compromised, but as far as “Efficiency” and “Economy” are concerned we may have to make quite substantial allowances different from the implementation of standard MDT in the field normally. The operations are likely to be much more manpower intensive and costly, judged in terms of the resources required per cure of individual patient. The valuable contribution of international agencies, acting as donors in support of the national effort, has been mentioned already, and indeed without their valuable contribution, achieving the elimination goal by the year 2000 is inconceivable.

The only justification for adopting such non-efficient and non-economical MDT operations for some specialized cases now is that the elimination program has a relatively short time frame. More importantly, we are confident that come the end of this program by the year 2000 the whole picture of leprosy is going to be substantially different and no longer a public health pressure on government. But that calls for “Fast” actions as well as “Flexible” and “Focused” actions, as I have been trying to explain.

## 5. Conclusion

I am fully confident that anyone, whatever their current position may be, if interested in leprosy at all, will not see the achievement of the elimination goal by the year 2000 as the end of leprosy problems. It will be a very significant step, no doubt, as without reaching it there is really no hope of going further. Once that point is reached, the nature of leprosy work is likely to change significantly. Leprosy workers then can give full attention to the needs of individual leprosy patients beyond chemotherapy, as well as tackling the problem of rehabilitation of those cured but disabled patients that are estimated to number anywhere between 2 million and 6 million globally, depending on the source. It is also quite clear to most of us that the bulk of the above-mentioned tasks have to be carried out by NGOs, both international and national, for which purpose, after all, most of them were originally established.

Now let me put in a nutshell what I was trying to say. The “eradication of leprosy” is potentially possible, not only as an infectious disease of significant magnitude but also as a source of profound misery and shameful injustice throughout the world for thousands of years. But it must be preceded by the “Elimination of leprosy as a public health problem,” which can be achieved only by being “Focused” on the essentials—primarily on the implementation of MDT—by adopting a “Flexible” attitude as well as by acting “Fast”—and by always judging our actions on whether they are “Effective,” “Efficient” and “Economical.”

## 6

# 'Elimination of Leprosy' and Sasakawa Memorial Health Foundation

Dr. Yo Yuasa

Executive and Medical Director  
Sasakawa Memorial Health Foundation

Mr. Ryoichi Sasakawa is considered by many to be a man of vision with his personal creed, "The world is one family; all humankind are brothers and sisters." However, his publicly expressed desire to eradicate leprosy, when he established Sasakawa Memorial Health Foundation in 1974 to support leprosy programs around the world, was, in reality, no more than a mere dream or the wishful thinking of a well-meaning amateur well versed in the actual status of leprosy control activities at that time. Although both rifampicin and clofazimine as well as some other anti-leprotics were already available, dapsone monotherapy was still the regimen of choice globally, in spite of accumulating evidence of its ineffectiveness as a control tool in the field and of mounting danger of the emergence of drug-resistant *M. leprae*.

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WHO Western Pacific Regional Meeting on Leprosy, ca. the latter half of 1994

WHO, as well as scores of other interested agencies, including our foundation, sensing the potential total collapse of an already far-from-successful control effort, began to seek new and hopefully more effective leprosy treatment schemes. One of the most useful fruits of these efforts was the now-famous MDT (multidrug therapy) recommended by the Chemotherapy Study Group of WHO, which met in October 1981.

MDT was adopted by the study group, not so much with a great confidence in or an earnest expectation of its effectiveness in controlling the disease, but more in desperation to prevent the global spread of drug resistance. There were many skeptics and even open opponents, and the spread of MDT was painfully slow, at least for those enthusiastic supporters like me.

By the late 1980s, however, its implementation became fairly global. Data accumulating from various parts of the world and under different field conditions clearly demonstrated that MDT is not only very effective in preventing the spread of drug resistance, as it was meant to do, but that even in its basic time-limited forms (only 6 months for paucibacillary cases and 24 months for multibacillary cases) it is also effective in actually curing patients, much more so than anyone in the study group dared to hope originally. Another proof of its effectiveness is the amazingly low rate of relapses observed so far.

This more-than-expected success of MDT in curing the disease, thus reducing the prevalence rate, was such that some of us began to think of a global campaign for tackling the disease with a view to its effective control, if not yet total eradication, which was and still is Mr. Ryoichi Sasakawa's dream.

In June 1989, at the WHO Regional Workshop on Leprosy Control in Manila, those in charge of leprosy control in the member countries of the Western Pacific accepted the working plan with a goal of "Elimination of

leprosy as a major public health problem by the year 2000.” The choice of a suitable term for the program was not easy, but after some research, we decided on “elimination,” borrowing it from the booklet published by the U.S. Public Health Service on their program for the “elimination” of tuberculosis in the United States.

Admittedly, the leprosy problem was not so large in the Western Pacific region, with only a handful of larger countries having a prevalence rate of much higher than 1/10,000 even then. It was apparently a politically shrewd move, however, because it gave the leprosy control program in every leprosy-endemic country a clearly defined and achievable target, the successful attainment of which any health authority, each facing so many ever-increasing public health problems, could be proud. Thus, political commitment, which is key to the success of any national program, became evident in every leprosy-endemic country in the region. Following this, with further evidence of the successful outcome of MDT, which clearly demonstrated its robustness as a useful tool in the field, the Leprosy Unit of WHO decided to propose a global campaign for the “Elimination of leprosy as a public health problem by the year 2000” and this was adopted by the 44<sup>th</sup> World Health Assembly in May 1991.

Our co-founder and the first chairman of the board, Professor Morizo Ishidate, is considered to be one of the foremost experts in the chemotherapy of tuberculosis, cancer and leprosy in Japan, and our foundation has been interested from the very beginning in scientific approaches to leprosy-related problems, particularly the chemotherapy aspect of field control. Thus, our first international workshop was on the chemotherapy of leprosy, held in Manila in January 1977 to search for possible alternatives to dapsone monotherapy. Joint Chemotherapy Trials soon followed, involving experts

in South Korea, the Philippines, Thailand and Japan. Although our efforts were modest compared to high-powered groups such as THELEP/TDR (the Working Group on the Therapy of Leprosy of the Tropical Diseases Research and Training Programme) and some others, they lasted up to 1985 and no doubt have made some significant contributions to making these countries both sensitized and technically ready to accept MDT when it was officially recommended by WHO in the spring of 1982.

As the executive and medical director, I have been in a position to plan leprosy programs of the foundation for nearly 20 years. As the organizer of the Joint Chemotherapy Trials from 1978, and as one of the members of the Chemotherapy Study Group of 1981, I was committed to MDT from its inception, especially sensing its suitability to be handled by general health workers in the field, under totally integrated services that assure wider field coverage. Consequently, our foundation also has been solidly behind MDT's wider implementation, supporting and collaborating with the health authorities of more than a dozen leprosy-endemic countries, mostly in Asia but in Africa and Latin America as well. Our support consisted mainly of the supply of drugs to meet their national requirements, together with some transport facilities and medical equipment. Where appropriate, we have also provided fellowships or funds to cover their local costs for training, planning, implementation, monitoring and evaluation of nationwide implementation of MDT.

A close working relationship with WHO has been one of our key modes of operation from the beginning. With the Sasakawa Foundation (the Japan Shipbuilding Industry Foundation, or JSIF)'s two-pronged approach to leprosy problems, one through the Leprosy Unit of WHO and the other through our foundation—each in a sense competing for an annual program fund for leprosy

from the same source—our foundation has been trying to complement and/or supplement the work of WHO whenever feasible and needed; I am happy to acknowledge that similar cooperation has been received from WHO. This kind of close working relationship seems even more imperative from now on up to the year 2000, in view of the new announcement from the Sasakawa Foundation (JSIF) of a US\$50 million contribution over the next five years in support of the “elimination” program, primarily in the form of drug supply.

Our foundation is also a member of ILEP (International Federation of Anti-Leprosy Associations). As such, we are closely coordinating our activities with some of our fellow members—Americans, Belgians, Britons, Canadians, Danes, Dutchmen, Frenchmen, Germans, Italians, Swiss and others in a number of leprosy-endemic countries. These collaborations too are bound to be strengthened as we approach more difficult parts, both geographically and technically, of global MDT implementation under the common ILEP banner of “MDT for all by the year 2000,” which is almost mandatory if we are to achieve the “elimination of leprosy by the year 2000.”

This WHO-lead global campaign with a targeted prevalence rate of less than 1/10,000, at least at the national level in every leprosy-endemic country, is certainly not an end of leprosy work. To make Mr. Ryoichi Sasakawa's dream come true requires much further effort. Nevertheless, reaching the “elimination” target by the year 2000 will not only be a remarkable achievement by itself for which everyone involved can take pride, but even more significantly it is an essential step for the eventual total solution of leprosy problems. It should be clearly understood that without reaching this step there is no hope of providing the necessary care and support—physical, mental and socio-economic—to every individual suffering from leprosy as patients or ex-patients and as their relatives, which has been the intention,

if not always fully put into practice, of many leprosy NGOs. Thus, whatever their particular line of interest or approach, all those who are concerned with the welfare of leprosy patients as well as with leprosy control should now make their best effort for the success of the "elimination" campaign.

Notwithstanding what I have said above, we are already at a stage, in my view at least, where we should begin discussing various approaches and plan for necessary actions beyond "elimination." Mankind has suffered from leprosy over several millennia without any effective means to fight it. A cure from the disease for individual patients became a reality only 50-odd years ago. Effective control of the disease by MDT was made possible only 12 years ago. But now, almost to our own surprise, we do have necessary tools in our hands, and are likely to have more of them soon to achieve our final goal. Whether we reach that goal and how soon rests squarely on the shoulders of those of us currently involved in leprosy work in whatever capacity or position.

Many people ask, "Why leprosy?" There are a number of problems that rank higher on almost anyone's list of public health priorities. There are diseases that afflict very many more people, such as malaria or hepatitis. There are much more lethal disease, such as AIDS or even TB; so why leprosy? It is because leprosy is definitely one of the very few diseases of public health concern that is controllable with currently available and affordable tools. Our effort now almost certainly will make the disease no longer a major public health problem, and for good. The amount of resources required, if applied anywhere else would be unlikely to make much impact. Perhaps more importantly, unlike the eradication of smallpox, which was undoubtedly one of the triumphs of medical history, effective control of leprosy, even if not total eradication, is likely to remove one of the most significant sources of

misery and human injustice, perhaps the longest-lasting and most widespread scourge ever known to man. Victory over leprosy is far more than a medical victory. It could indeed be an epoch-making event in human history. It is Mr. Ryoichi Sasakawa's dream. It is also the earnest wish of all those involved in leprosy, patients and workers alike. And it should be the hope and expectation of everyone on Earth!

N.B. The accompanying green pamphlet titled "MDT for All: Target-Oriented Leprosy Control Programme in 1990s" is an old paper I wrote in early 1990, and first presented at a WHO meeting held in the Maldives in June that year (see Chapter 2). Some data quoted there, such as the figure of 10 to 12 million cases in the world, are totally outdated now, but otherwise the contents in general are hopefully still relevant. It was my personal view of how MDT should be considered and implemented, and our foundation's support to the national leprosy control programs of various leprosy-endemic countries has been influenced by the views expressed in it.

The "elimination" program with MDT as its main tool is often criticized for things that were never the program's original intention. For instance, it is faulted for the fact that in spite of a rapid fall in prevalence rate there is only a slight fall in incidence rate; but the latter was never an expressed goal of MDT per se or the "elimination" program. Many people also criticize MDT for not going beyond "mere" chemotherapy and for not yet reaching all the existing active cases in the world.

This booklet, hopefully, will explain what the top priority is now, which in my view at least is to expand basic MDT globally as quickly as possible. Anything and everything else, almost by necessity, has to wait until "MDT for all" is achieved. We live not in an ideal world with unlimited resources to do

all we want. Our task is not to dream of everything we wish to come true, but to make difficult and even painful choices according to our priorities, and do what we can do as best as possible. In leprosy, I am convinced that MDT is what we should be doing now.

# 7

## SAPEL: Why, What and How

Dr. Yo Yuasa

Executive and Medical Director, Sasakawa Memorial Health Foundation  
Chairman, Steering Committee, Special Action Projects  
for the Elimination of Leprosy, WHO

### 1. Why was SAPEL created?

As you yourselves are witnessing, with global implementation of WHO-recommended multidrug therapy (MDT), the leprosy scene has gone through a remarkable transformation over the last 10 years or so. No longer is the fight against leprosy the hopeless unending struggle it was up to the early 1980s, when widespread resistance to dapsone and then rifampicin seemed to make our efforts at controlling the disease even less rewarding.

WHO-recommended MDT, announced in April 1982, reversed this trend almost overnight, although most of us have been rather slow to grasp this reality and its true significance. Originally adopted primarily to prevent

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Meeting of national program managers and leprosy workers, ca. the first half of 1996

further spread of drug resistance, MDT has turned out to be a godsend tool for leprosy control in the field by being remarkably effective, first of all, in arresting and curing the disease. In addition, by virtue of its simplicity, cost effectiveness, robustness in field use and its fixed and relatively short duration, it made it possible for the first time for the general health services to handle at least the chemotherapy part of leprosy control as part of their routine activities. This meant there could be universal coverage of patients, wherever they were, in most countries, thus overcoming the critical and universal shortcomings of any vertical service—namely, the almost inevitable restriction on the extent of geographical coverage and the rather limited opportunity for contacts with patients over a period of time.

I am sure that most of you here are witness to this development, which prompted the 44<sup>th</sup> World Health Assembly in 1991 to unanimously adopt the WHO-proposed resolution calling for the “Elimination of leprosy as a public health problem by the year 2000.” We are slightly over the halfway mark toward achieving that goal, in terms of the time frame, and perhaps nearly at the two-thirds point in terms of covering the total caseload in order to bring down national prevalence to less than 1/10,000 population in every leprosy-endemic country.

Can we be sure of attaining our goal in time? The correct answer, unfortunately, is “no.” In terms of the number of the patients to be put under MDT, we have much less than halfway to go. But in terms of the difficulties in reaching these patients, we are just starting to experience them. WHO estimates that currently slightly less than 1 million existing cases have yet to be detected and/or put on MDT. These may well constitute up to 20% or 25% of the cases we must put on MDT up to the year 2000.

Somehow, even MDT implemented by the general health services staff,

which in theory at least should mean universal coverage, failed to reach them and thus we categorize these patients as “hard to reach” or “difficult to access,” whatever the reasons. To address this particular problem, Special Action Projects for the Elimination of Leprosy, or SAPEL, was conceived as the outcome of the first International Conference on Elimination of Leprosy in Hanoi in 1994.

## 2. What is SAPEL?

As I have stated, SAPEL stands for Special Action Projects for the Elimination of Leprosy.

The words “Special” and “Action” are critical. At the Hanoi Conference, I was asked to discuss the way to accelerate the elimination program and I emphasized the need to take “Fast,” “Flexible” and “Focused” actions. SAPEL, in fact, is an example of a program embodying these basic approaches.

It is strictly a “special” program to meet unique situations/needs. In no way is it intended to replace or compete with regular MDT implementation, if the latter is at all possible, however difficult it may be. Regular MDT implementation presupposes an existing functioning health services infrastructure that can detect cases and deliver MDT regularly over a prescribed period of time to all the cases in their catchment area.

Unfortunately, in almost every country, there are a not-insignificant number of leprosy patients for whom such health services infrastructure does not exist, either physically or functionally. Physical absence stems from the fact that these patients are living in remote and/or thinly-populated locations—on a small island, deep in the jungle, high up in the mountains, or in the middle of a desert—so that stationary health services are not provided,

being totally non cost-effective to the public health authorities. Functional absence may be caused by seasonal climatic conditions, or some fighting or political upheavals, which result in a temporary absence of regular health services, or by patients being refugees or belonging to ethnic minorities that are normally excluded from existing government services of any kind, or because their way of life or their occupation forces them to be constantly on the move so that no regular health services can handle them over a period of time. Sometimes, a section of the urban population, especially those in slum areas, can be categorized as a “hard to reach” group functionally.

SAPEL is meant to deliver MDT to these “difficult to reach” patients, which obviously calls for considerable “flexibility,” a quality neither needed nor desirable for regular implementation of MDT. The kind of “flexibility” needed for SAPEL is mainly operational, in terms of case finding, drug delivery and regular supervision of monthly dose intake. If monthly supervision is difficult, it may be done once in two or three months. If regular health workers are either not available physically or functionally—due to language differences, for instance—then non-health workers belonging to that group of “hard to reach” people must be used as substitutes after appropriate training or instruction. On rare occasions, technical flexibility, which is basically the use of a regimen other than the standard MDT, may have to be utilized.

The second key word about SAPEL is “Action.” SAPEL projects are meant to act fast without undue delay for planning or preparation. It is to solve the existing problem here and now, and not sometime in the future, even if longer preparation could possibly produce a better solution. The time frame is a critical factor for a SAPEL project.

As to the need to be “Focused,” SAPEL is strictly concerned with implementation of basic MDT, which is to deliver MDT drugs regularly to the

patients, and nothing else, even though things like prevention of deformity (POD) should be a regular part of MDT implementation under normal conditions.

### 3. How does SAPEL function?

Under the newly created Leprosy Elimination Advisory Group (LEAG) after the Hanoi Conference, three functioning subgroups were also created. One is a task force on “Capacity Building and Health System Research” (CBH). The second is a task force on “Monitoring and Evaluation” (MEE). The third is the steering committee of SAPEL.

The SAPEL steering committee consists of seven members chosen for their expertise on technical and/or operational problems on MDT implementation, as well as three co-opted members, the chairpersons of the LEAG, MEE and CBH. It is responsible for screening applications for SAPEL projects submitted by the national leprosy control program managers of the endemic countries. The steering committee itself does not initiate a process of formulating a SAPEL project at present and thus it is not as proactive as the two other subgroups; however, individual members of the steering committee, in addition to the more usual prompting by leprosy officers of WHO headquarters or regional offices, may suggest to some national managers that they submit such a project. The steering committee meets twice a year, normally in July in conjunction with the LEAG meeting and once in December. It scrutinizes the objective, methodology, feasibility and budget of the proposal, and either accepts it as it stands or with some modifications, or rejects the proposal but usually recommending that another proposal be submitted instead. Outright rejection is rare, because the steering committee considers it its duty to

encourage program managers to think innovatively about how to face the many problems that undoubtedly exist in MDT implementation, especially the problem of hard-to-reach patients, rather than neglecting them altogether for the reason that it is too difficult or too costly.

Each project should be a fairly compact one, limiting the number of the patients to be covered and the duration of the project. The typical project may cover several hundred to a few thousand cases and the usual duration is 12 to 24 months, although there could be exceptions. The budget should be in the range of US\$10,000 to \$30,000, although again there may be rare exceptions. Up to December 1995, there have been three steering committee meetings, and out of 41 projects submitted for screening, 28 were accepted, a few with some modifications and these projects are currently being implemented. The majority of those not accepted were returned to those who submitted the proposal, with an explanatory note from the SAPEL secretariat on why they were not accepted and how they should formulate new alternative proposals. The current members of the steering committee are appointed for a two-year period; therefore, they will have two more meetings, in July and December of this year.

What is important for the national program managers to realize is that each project is covering only a fraction of the existing problems in each endemic country. The total number of patients getting direct benefit from SAPEL projects, even if SAPEL is available up to the year 2000, must be around 50,000 at most, which is nowhere near the total of “difficult to reach” patients that, as mentioned before, could number near 1 million.

From that point of view, SAPEL projects are a kind of pilot project and, if successful, are to be followed up with similar projects in a similar situation within the country. The advantage of a SAPEL project is that it is sponsored by

WHO, which takes technical responsibility for the plan. Therefore, whatever innovations or flexibility involved that depart from the usual standardized MDT implementation practices, such variations are in fact sanctioned by WHO, making them different from any other modifications by individual program managers in different parts of the world that could be haphazard and unwise, leading to confusion. When a project is approved by the steering committee, the WHO secretariat takes the responsibility for funding, either by finding a suitable sponsor or by financing it out of its own funds.

SAPEL projects are definitely not experiments, nor are they research undertakings as such, even though careful recording and regular reporting to the steering committee are mandatory. Perhaps SAPEL projects could be considered as very specific forms of health system research, although that term itself is often subject to misunderstanding. The key concept here must be a quick problem-solving effort for existing difficulties in MDT implementation.

SAPEL also should not be considered as an exclusive program of WHO. Any interested NGOs are welcome to participate, in funding individual projects first of all, but also in the original project formulation or actual implementation. In the future, once some SAPEL projects prove to be effective, similar projects may be undertaken by the health authorities themselves alone or in collaboration with NGOs, without the involvement of the SAPEL steering committee for screening. The function of SAPEL projects in that sense is that of a role model.

## 4. What SAPEL could be, and what I think it ought to be

What I have been talking about so far is, more or less, an official version of SAPEL. Neither Dr. Noordeen and Dr. Pannikar of WHO nor fellow members of the SAPEL steering committee are likely to disagree violently with what I have said, even if they may wish that I could have presented SAPEL in a better light. What I am going to express from now on is purely my own view, hoping that it may be of some use to your own thinking for the future course of leprosy control.

I have said at the start of my presentation that SAPEL was created to accelerate MDT implementation in order to make sure that the “elimination” goal is attained in time. From that point of view, it is one of the instruments of the elimination program and thus a public health measure. What I am trying to do now is to point out that SAPEL is in fact based on an altogether different health service principle—that treatment of the individual patient is of utmost importance—and thus SAPEL goes far beyond a public health goal.

I do not agree with the idea that public health measures are only concerned with numbers and not individual patients, who in fact make up those numbers. Nevertheless, it must be admitted that most public health measures are primarily concerned with, and their success or failure judged by, quantitative figures, such as the prevalence or incidence rate and its percentage-wise reduction.

SAPEL does not talk about numbers, and although not stated publicly, it is, in my view at least, based on the idea that every leprosy patient deserves to receive MDT wherever they are. That concept is better expressed in the International Federation of Anti-Leprosy Association (ILEP)’s adopted target

of “MDT for all by the year 2000.” I have been deeply involved in MDT ever since the time of the Chemotherapy Study Group of 1981, and as early as 1985/86, I started talking publicly of “MDT for all” as a practical realization, in terms of leprosy work, of the “health for all” concept, which I personally and the Sasakawa Memorial Health Foundation (SMHF) I represent accepted and adopted from the beginning, and still do.

That concept of “health for all,” now wrongly considered as unrealistic and therefore not worth bothering with, is in fact a noble concept worth being supported by every health worker as an ultimate goal, but one that WHO seems to have mishandled rather badly. Instead of being made an expression of a basic principle or a dream, if you like, on which to build practical programs with more modest but achievable targets, it was considered by many, admittedly mostly uninformed outsiders, to be an actual goal to be achieved, and that misunderstanding was reinforced by the inclusion of the expression “by the year 2000.”

Great human achievements sometimes come out of a fantastic dream. To fly like a bird was a dream harbored for centuries by many people, but now we can fly faster and higher than any bird. To explore far off heavenly bodies was considered a pure fantasy until very recently, but we can now send a probe packed with sophisticated instruments to Mars or Jupiter, in addition to putting human beings on the Moon or keeping them in space. Realizing these dreams is made possible by developing suitable technologies, but it is often the persistence of dreamers that sustains these development efforts.

True, some dreams are hard to realize. A world without war, dreamt of by the founders of the United Nations, is still far away after 50 years. Racial equality dreamt of by Martin Luther King is yet to be achieved in the United States, after over a quarter of a century of trying. These are not a matter of

developing new technologies but rather a matter of changing human nature. How about “health for all,” surely a dream worth dreaming? It certainly depends on developing some new technologies, better cures and perhaps more importantly better preventions, for instance. But probably it also involves some changes in human nature—how one considers oneself and how one treats one’s fellow human beings.

“Health for all,” however it is defined, is impossible to achieve at present, hence it is more of a dream than an actual goal. But at least in terms of smallpox, the dream was realized by totally eradicating the disease. Can we do the same for leprosy? Some say yes and others are skeptical, probably with good reason. But I am for the goal of eradication. To do that we must first eliminate leprosy as a public health problem, as we are trying to do now, and then eliminate it as a disease of individuals. This should make it possible to eliminate every social problem related to the disease at the same time, but that is less a matter of new technology and more of a change in human nature.

We already have tools, however, not only to make leprosy no longer a public health problem, but also to eliminate it as a disease of individuals. Therefore, it surely must be a worthwhile undertaking and indeed a duty for those involved in leprosy control to pursue that goal. SAPEL projects, which basically are trying to fit MDT to the needs of individual patients, at least in terms of accessibility, and not the other way around, may teach us a way to proceed beyond the year 2000, although SAPEL as such is likely to end at that point.

It is perhaps unwise at this stage to talk about leprosy work in the years beyond 2000, at least publicly, but in a meeting like this of leprosy workers I trust it is not too early to start thinking about it. There is a fear among some leaders of MDT that to talk about leprosy beyond the current elimination

program is counterproductive, because that may lead to a weakening of the firm resolution now shown by health authorities that is essential in order to reach the elimination goal as it stands now. There is no question that eliminating leprosy as a public health problem will indeed be a great achievement and one for which no apology is necessary.

It is also important for us, however, to clearly understand what attaining the current elimination goal means. It is only a milestone, however significant it may be; it is definitely not our final goal. At the same time, we should remember that unless we first reach that milestone, we cannot go any further. Therefore, we must put our best efforts at present into reaching the elimination goal, but be prepared to carry on beyond that milestone when the time comes. SAPEL is a means to reach that milestone, but it could also teach us the importance of caring for each individual and show us a way forward until our final goal is reached.

# 8

## A Celebration of 30 Years of ILEP

Dr. Yo Yuasa

President  
International Leprosy Association

The Princess of Wales, Ma'am, Madam Mayor, Your Excellencies, Ladies and Gentlemen:

It is a great honor as current president of the International Leprosy Association to make a statement on the occasion of the 30<sup>th</sup> anniversary of ILEP.

Throughout history and in every society, leprosy has exposed some of the least admirable aspects of human nature: our innate cruelty, our insensitivity, and our selfishness in the face of deep suffering by fellow human beings.

Yet leprosy has also shown how kind, how sympathetic, how self sacrificing men and women can be. Father Damien of Molokai remains, a hundred years on, a popular example of such humanity.

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30<sup>th</sup> anniversary of ILEP (International Federation of Anti-Leprosy Associations), London, UK, 9 December 1996

The member-associations of ILEP, established in different countries and at different times, share that deep concern for the welfare of people suffering from leprosy.

It is most fitting, Ma'am, that you should grace this occasion with your presence. We remember how you ignored hysterical media advice not to touch "Lepers." We are most grateful for your evident and continuing public commitment.

With the global success of multidrug therapy (MDT), the caseload of leprosy patients is coming down rapidly. Today it is hardly a tenth of what it was only 10 years ago; a great achievement for which no apology is needed.

But this success story tells only one half, some say the less important half, of the continuing struggle against leprosy. We must prepare ourselves for an era in which the care of individuals who have been affected by the disease will be the main focus.

The key players in such future activity are likely to be ILEP and ILA, together with other interested groups, especially ILU and that rapidly developing organization, IDEA, whose president, Dr. Gopal, has just spoken.

ILA over 64 years and ILEP over 30 years have made a considerable contribution. We should be proud of what we have done to achieve the current leprosy situation. What was useful in the past, however, is no guarantee for future success.

Thus, although the centennial International Leprosy Congress in Beijing in 1998 will commemorate the first 100 years of modern leprosy control activities, its main focus will be on the future—with the theme "Working toward a world without leprosy." There will be critical examination, not only of what is needed to achieve that goal, but of how and by whom.

One of the most important keys to success in the future will be strong

leadership able to take responsibility for a more wide-ranging program than that of the WHO over the past two decades. In my personal view, ILEP is the most likely candidate. I hope it will have the vision to take on and adapt itself to that role.

On behalf of the members of ILA, I wish to express to ILEP our sincere congratulations for your past achievements and our best wishes for your future as we work in partnership toward a world without leprosy.

Thank you.

# Synthesis of Promin in Japan and Global Elimination of Hansen's Disease

Dr. Yo Yuasa

Executive and Medical Director  
Sasakawa Memorial Health Foundation

Professor Morizo Ishidate synthesized Promin for the treatment of Hansen's disease, or leprosy, which had been considered incurable until the discovery of the anti-leprosy effect of that drug by Dr. Guy Faget of the United States in 1941. Professor Ishidate was the first to synthesize the drug in Japan in 1946 based on a brief news item in a Swiss journal smuggled in during World War II. For this achievement, he is known as “the father of leprosy chemotherapy in Japan.”

Professor Ishidate also contributed to the global fight against leprosy as the chair of the board of directors of Sasakawa Memorial Health Foundation (SMHF), which he helped to establish in May 1974 with the full financial backing of Mr. Ryoichi Sasakawa, president of the Japan Shipbuilding

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Translation of article in *Yakugaku zasshi (Journal of the Pharmaceutical Society of Japan)* Vol. 117(1997) No. 10-11.

Industry Foundation (JSIF, now known as The Nippon Foundation). Professor Ishidate, with his scientific knowledge as well as his Christianity-based humanitarian concern, advised Mr. Sasakawa how to spend JSIF money wisely for eliminating leprosy and eventually nearly US\$200 million was channeled through the World Health Organization (WHO) and SMHF for this cause. The successful outcome of the global multidrug therapy (MDT) program in the 1980s resulted in the adoption of a resolution by the World Health Assembly (WHA) in 1991 to attain the “Elimination of leprosy as a public health problem by the year 2000.” Both the synthesis of Promin in Japan and promotion of the global implementation of MDT are achievements that can be attributed to Professor Ishidate.

When talking about the life of Professor Morizo Ishidate, one cannot forget his deep commitment to the problems related to leprosy. His contributions to society—academic and religious, and as a Japanese as well as a world citizen—are many, but I assume that in his own reflections on his life, the most proud achievements were most probably his works related to leprosy. His involvement in leprosy as described in his memoirs started in his youth. As the second son of a newly established druggist in the city of Aomori in the northern Japanese province of that name, he started visiting Hokubu Sanatorium for leprosy (current National Sanatorium Matsuoka Hoyoen) in the outskirts of Aomori City during his school holiday season, delivering some drugs to help his father's business. There was no effective anti-leprosy drug in those days. Globally, the most commonly-used drug was chaulmoogra oil, but its medicinal effect on leprosy had never been proven universally. Having no effective drug meant leprosy in those days was an incurable disease and, depending on the type and speed of the symptoms, many patients developed physical deformities and suffered from the stigma of leprosy. This left a deep

impression on Professor Ishidate, who was then a rather sensitive youth. It was quite natural for Professor Ishidate, who became a Christian later, to feel leprosy patients' suffering as his own, and he became deeply interested in finding a cure for the disease.

His contributions to solving leprosy problems could be divided into two categories. One is the development of Promin in Japan as an expert in pharmaceutical science and the other is the manifestation of his Christian love for humanity as the chair of the board of directors of SMHF and his involvement in the global leprosy program.

## 1. Development of Promin

One task given to Professor Ishidate's research lab in the Imperial Tokyo University during World War II was the development of an effective anti-tuberculosis drug, as explained in detail in other sections of this journal. It had been known that Promin, a soluble compound of DDS (diaminodiphenyl sulfone, or dapsone) developed early in this century in Germany, was effective against child TB, but because of its strong toxicity shown in animal experiments it was rarely used in a clinical situation. Since both TB bacilli and leprosy bacilli belong to the same family of mycobacteria, many of the TB drugs had been tested for leprosy in many countries, including Japan. But Promin's apparent effectiveness against *M. leprae* was found only in 1941, during World War II, by a physician, Dr. Guy Faget, who was working at the national leprosarium in Carville, Louisiana, in the United States. Due to the war, his academic paper on Promin was published only in the autumn of 1943.

However, Professor Ishidate learned of that by way of a brief news item,

not a full paper, in an academic publication from abroad. As Professor Ishidate remembered, it was written in German. It is thought that the article was in *Angewandte Chemie*, a Swiss journal probably brought by a German submarine, a common communication method during World War II between Japan and Germany. There is no record of who in Professor Ishidate's lab was actually involved in the development of Promin, but it is assumed to be Dr. Tsutomu Momose, who later became an honorary professor of Kyushu University, as he was engaged in research on homosulphamine, which had a close chemical structure to Promin.

It was in April 1946, a year after the end of World War II, that Promin was successfully synthesized, but for at least three months, it could not be used. During the war, new anti-TB drugs had often been clinically tested on patients in leprosaria. Many saw their leprosy deteriorate as a result of the rather dubious effects of cepharanthine and Koha, and they developed a strong mistrust of new drugs. Because of this, when Professor Ishidate brought valuable, newly synthesized Promin for clinical trials to Dr. Yoshinobu Hayashi of the National Leprosarium Tama Zenshoen just outside Tokyo, it was difficult to find volunteers. However, Mr. Kazuyoshi Minato, who had returned from the war front in China with severe lepromatous leprosy, and two others agreed to the trial, and intravenous injection of Promin on alternate days for 60 days took place. The results were nothing short of miraculous: the disappearance of lepromas on the face and recovery of normal vision from near blindness, as described by Mr. Minato, who is still well today. (Almost a half-century later, on October 25, 1993, a dramatic reunion between Professor Ishidate, then 92, and Mr. Minato, then 80, took place.) Those who witnessed for themselves the miraculous recovery of the three at Tama Zenshoen, and patients in other national leprosaria who heard the news started demanding Promin therapy.

Some sent letters to Professor Ishidate written in their own blood.

Because of the postwar situation it was not easy to collect the necessary raw materials for Promin synthesis. When Yoshitomi Pharmaceutical Company produced the drug under the name of Protomin in April 1948, 600 patients in Tama Zenshoen who wanted the injections had to be chosen by drawing lots. In October 1948, at the 21<sup>st</sup> Japanese Leprosy Association meeting, the effects of Promin were reported and officially recognized. Each national leprosarium started an effort to obtain the drug and the Ministry of Health came up with a budgetary provision of ¥50 million for Promin. Thus in Japan, Promin became the standard treatment in place of chaulmoogra oil. Its production was entrusted to Yoshitomi Pharmaceutical Company alone, and all its products were sent to the Ministry of Health for distribution to national leprosaria. However, insufficient raw materials resulted in mass demonstrations by patients in front of the Ministry of Health, with banners demanding the supply of Promin.

From the beginning of the 1950s, most countries started using DDS, which was taken orally and was much lower in price; but in Japan, Promin was still being used in the 1960s. However, even Yoshitomi Pharmaceutical Company gradually shifted its production of Promin to DDS, and in the 1970s the latter became the main anti-leprosy drug in Japan.

The above is a brief description of Promin and DDS, thus proving that Professor Ishidate is rightly recognized as “the father of leprosy chemotherapy in Japan.”

## 2. Chair of the board of SMHF

What was described in Section 1 for the production of Promin was Professor Ishidate's professional achievement as a pharmaceutical scientist and, because of it, leprosy became a curable disease. At the same time, it became possible to prevent stigmatizing physical deformities. This brought good tidings to all leprosy patients in Japan and was considered to be one of Professor Ishidate's great contributions.

However, one should not forget another of his great contributions during the 22 years when he was the first chair of the board of SMHF. This perhaps could be an even greater achievement on a global scale than the development of Promin. He used to divide a man's life into several stages. When he retired from his regular job at around 60, he was released from his social and familial responsibilities. It was a time when he could do whatever he wished to and thus his true personal value could be judged by what he chose to do.

Many people know that after retiring at 60 from his position at Tokyo University, Professor Ishidate made many valuable contributions in various positions. But I assume that what he himself most likely considered to be a meaningful contribution was to create SMHF together with Mr. Ryoichi Sasakawa of JSIF and take responsibility for the running of the foundation for years to come. It was generally considered that the relationship between Professor Ishidate, an earnest academic as well as a devout Christian, and Mr. Ryoichi Sasakawa, known for his behind-the-scenes influence on politics and finance in Japan, was like oil and water, and thus a joint project between them was seen as an utter impossibility. However, their deep interest in leprosy problems and a strong desire to contribute to the relief of people suffering

from the disease made them comrades in leprosy work.

Their historic encounter took place in spring 1974, when both of them attended a lunch meeting together. Through his childhood experiences, Mr. Sasakawa had been interested in leprosy problems for many years and had visited leprosy institutions both in Japan and abroad whenever he had a chance. On his 75<sup>th</sup> birthday, he decided to establish a Japanese leprosy NGO, using his own funds—the primary condition being that Professor Ishidate become the chair of the board of this new organization and take full responsibility for running it. Thus, without Professor Ishidate's full collaboration, SMHF would never have been established.

There is an interesting episode that sheds light on their relationship. The foundation was established on May 4, 1974 with an opening ceremony at the Tokyo Prince Hotel in the presence of HRH Prince Takamatsu, a younger brother of Emperor Hirohito. Just before the ceremony, without any prior discussion, Mr. Sasakawa told Professor Ishidate, who was waiting to go up to the platform, that he had decided to give anti-leprosy drugs to the top 20 leprosy-endemic countries in the world and would make the announcement in his greetings that day. Professor Ishidate responded immediately, telling Mr. Sasakawa, "Please don't say that. Even if we supply drugs globally, in most countries there are no systems in place to actually deliver the drugs to the patients and to make them take the drugs regularly, thus your goodwill will be wasted." Mr. Sasakawa was apparently upset, but in his speech he did not mention what he had originally intended. I heard this from a senior staff member of SMHF who was there, so this episode was probably true. Mr. Sasakawa never brought up the issue again. Mr. Sasakawa, as he had promised originally, provided the necessary program funds from JSIF and they have been forthcoming ever since; to date, they amount to nearly US\$150 million.

This surely is the proof that, as the then president of SMHF, he had full trust in Professor Ishidate to run the foundation as chair.

As the chair of the board with two faces, one as an academician—an expert in pharmaceutical science—and the other as a devout Christian, Professor Ishidate believed that the fundamental principle of running the foundation must be based on humanitarian love, but, at the same time, on up-to-date medical knowledge and technologies. He taught us that often people approached leprosy work based on goodwill alone, without adequate medical knowledge and skills, and he was keen to avoid that situation in SMHF's program.

As an expert on drugs, he had a clear vision for the leprosy chemotherapy program of our foundation and he was often directly involved in it. At the first-ever workshop organized by SMHF, held in Manila in January 1977 on the subject of leprosy chemotherapy, the issue of DDS resistance was taken up. It was becoming a global issue and the workshop recommended giving up DDS monotherapy or other anti-leprotics, and utilizing two or more drugs simultaneously, at least for multibacillary cases. This was more than three years before WHO's recommendation on MDT came out. Based on this Manila recommendation, SMHF started Joint Chemotherapy Trials (JCT) in the field with people in charge of leprosy in South Korea, the Philippines and Thailand, together with Japanese chemotherapy experts.

Professor Ishidate, being a researcher himself, was very keen to support leprosy research activities, and was generous in the financial support he gave out of our funds, sometimes on a scale that looked too generous to someone like me. When Mr. Sasakawa offered us US\$7 million on his 88<sup>th</sup> birthday, Professor Ishidate decided to construct an up-to-date research building with animal facilities for the Ministry of Health of Thailand. It became a useful

facility for research on leprosy and other diseases, including HIV/AIDS.

Other leprosy programs, however, were handled by other experts within the foundation and Professor Ishidate was not directly involved in the decision-making. What the foundation was mainly concerned with in those days was the training of leprosy field workers in leprosy-endemic countries of East and Southeast Asia. After this training for the implementation of proper chemotherapy, SMHF began providing the necessary drugs to these countries and thus Professor Ishidate was able to fulfill Mr. Sasakawa's original wish.

Professor Ishidate had served as chair of other overseas medical missions and saw the limitations in starting small-scale overseas field projects with a few doctors and nurses dispatched from Japan, so he was quite sure of his ground. Of course, he was aware of the merits of doing such work and did not oppose some groups in Japan from doing so. But in responding to Mr. Sasakawa, who was interested in solving the problem of leprosy on a global basis, Professor Ishidate directed SMHF to contribute to achieving that objective. At the start, it was only a dream, but in order to achieve it, he thought SMHF must work to strengthen the national leprosy control programs run by the central governments of leprosy-endemic countries, rather than starting our own projects in the field. At the same time, he emphasized the need for international collaboration and he insisted that SMHF must develop close collaborative relations with WHO as well as ILEP (International Federation of Anti-Leprosy Associations).

One more noteworthy development was his proposal that JSIF provide financial support to WHO's leprosy program as an alternative to Mr. Sasakawa's original plan to offer drugs to leprosy-endemic countries. JSIF has provided a yearly contribution ever since 1975, amounting to nearly US\$120 million over the last 22 years. This amount is the largest ever given to WHO

by a non-governmental organization. It is important to know that while WHO's leprosy budget has increased nearly 15 times by now, almost 90% of that increase is due to this JSIF contribution.

Since 1982, the main effort of global leprosy control was based on WHO-initiated MDT. Because of MDT's unexpected effectiveness in curing the disease, the 1991 World Health Assembly unanimously adopted a resolution, "Elimination of leprosy as a public health problem by the year 2000." This means that all leprosy-endemic countries, which then numbered around 120, will achieve leprosy prevalence of less than 1/10,000 at the national level by 2000. Since the average leprosy prevalence was around 1/1,000 in those days, this resolution will reduce prevalence to one-tenth of the 1991 level in nine years. Today, with three more years remaining until the year 2000, the possibility of that goal being achieved is very high. After smallpox eradication, the elimination of leprosy will be an outstanding achievement in which WHO's leadership will be most important. That will be made possible by the annual financial contribution from JSIF.

Of course, this still means that there will be 500,000 or more leprosy patients beyond the year 2000 and there will remain several million people cured of leprosy but who continue to endure social, economic and psychological sufferings. The global leprosy problem will persist. However, this is a great stride toward attaining Mr. Sasakawa's dream of leprosy eradication, and this is all due to Professor Ishidate's appropriate and courageous leadership guiding SMHF as chair of the board for 22 years.

There are many other contributions made by Professor Ishidate that are described in detail in the recently published book *Ishidate Morizo* by Keizo Ebina, to which readers may refer.

# 10

## Quest for Dignity

Dr. Yo Yuasa

Executive and Medical Director  
Sasakawa Memorial Health Foundation

It is quite natural to assume, in the context of this exhibition, that the “dignity” in question is of the “people affected by leprosy” and that it is in some way useful for them in their struggle to be integrated into normal society and gain economic advancement.

When this title was first chosen, I had understood it to mean that and had thought it nice, even fashionable. Once I started thinking about it a bit more carefully, however, especially after being asked to make a speech for this occasion, I began to ask myself the question, “**Whose dignity, and for what?**”

Dignity is something created within oneself. It is not something that can be given to nor received from someone else. One is totally responsible for whatever dignity one possesses as a core of one’s character. In ordinary life,

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Launching of the Quest for Dignity exhibit, produced by IDEA (Integration, Dignity and Economic Advancement) in collaboration with WHO and SMHF/TNF, at the United Nations, New York City, USA, 30 October 1997

one's dignity is seldom considered, let alone questioned. I suppose many people can and do spend their whole lives without ever questioning the matter of dignity. I do not recall any occasion before now when I pondered on a dignity within me.

On what occasion are individuals likely to face the question of dignity? It is when they come up against adverse conditions of an extreme degree. Many Jewish people in Nazi concentration camps faced that situation, as did many Allied soldiers in Japanese prison camps in Southeast Asia during World War II. We learned of extreme courage and sacrifice, which must be an expression of the dignity they possessed.

Many people affected by leprosy have been put in a condition not too different from those of Jews or Allied soldiers, and many have shown, and are showing, their dignity in spite of their past and present adverse circumstances. They have been tested and have proven their worth—their dignity—as many of the marvelous photos exhibited here attest.

Perhaps the “Quest for Dignity” should be primarily for those of us here who are not people affected by leprosy. One can often judge the presence or not of dignity in a person by the way they behave. I do not think there was any dignity among Nazis who sent so many Jews to death camps, nor among Japanese soldiers who mistreated Allied prisoners. There was no dignity, either, among bystanders who watched these people suffer.

How about our own behavior toward minorities among us, including people affected by leprosy? Probably most of us have to admit that our past behavior toward these people clearly shows our own lack of dignity.

So perhaps this quest is really for the benefit of the rest of us, so that we, as individuals as well as members of society or various groups, can behave in a more civilized way. We must make sure that people belonging to minorities

do not suffer just because they are different from the majority, for reason of their physical or mental condition, their nationality or religion, or for any other reason.

The subtitle of this exhibition is “A victory over leprosy,” which is a statement not quite for the present but for the future. Yes, the elimination program led by WHO has achieved much, as shown in the exhibition, and we should be proud of that. But it has been mainly a medical victory in dealing with leprosy as an infectious disease. As this exhibition shows, however, leprosy is as much, or even more of, a social problem. We are far from winning a victory in that respect, although considerable progress has been made in various parts of the world.

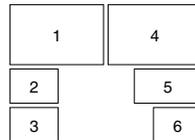
As the president of the International Leprosy Association, I am responsible for organizing the next International Leprosy Congress in Beijing, the People’s Republic of China, in September next year. It is the fifteenth congress to be held within the last 100 years, the first one being in Berlin in 1897. The fifteenth congress will be the first to have a main theme, which is “Working toward a world without leprosy.”

The progress made during the past 100 years makes it possible to have such a theme. We have not yet defined what is meant by “a world without leprosy.” But I can assure you that it certainly means a victory, not only in the medical field but also with regard to the social aspects of the disease. We are striving for a world in which people affected by leprosy are integrated into society, live with dignity and gain economic advancement. I sincerely hope that all of you here, both people affected by leprosy and those who are not, will support this effort in the years to come.

Thank you.

Now, I am privileged to introduce the next speaker, Mr. Morimoto from Japan, a friend of mine who has been affected by Hansen's disease. I met him exactly 40 years ago, at the start of my work in leprosy. He was a student at a high school that had been specially established for teenagers suffering from the disease. Some of them wanted to go to university in preparation for possible social rehabilitation, although this was done in strict secrecy, and they needed extra tutorials in English to pass the rigorous entrance examinations. He was successful and entered one of the most prestigious private universities in Japan. The rest of his story you should hear from him.

There are several pictures of Mr. Morimoto, with his wife, in the exhibition downstairs, with some notable quotes. One of them reads, "Unless we change, society will not change." He is one of foremost examples of such a transformation. His change, believe me, was a painful one.

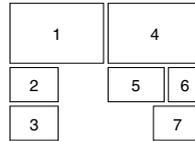


1. Dr. Yo Yuasa (standing) addresses the 1<sup>st</sup> International Workshop on Chemotherapy of Leprosy in Asia, Manila, Philippines (1977). To his left is Dr. Jacinto J. Dizon and to his right are Dr. Ricardo S. Guinto and Dr. Fernando A. Jose Jr.
2. Opening ceremony, 1<sup>st</sup> International Workshop on Chemotherapy of Leprosy in Asia, Manila, Philippines (1977)
3. ILEP Medical Commission meeting, Carville, Louisiana, USA (1978) Those seen with Dr. Yuasa (front row, far left) include Dr. Stanley Browne (2<sup>nd</sup> from left), Professor Michel Lechat (3<sup>rd</sup> from left), and Drs. Colin McDougall and Felton Ross (2<sup>nd</sup> row, 1<sup>st</sup> and 2<sup>nd</sup> from left).



4. Dr. Ma Haide (left) meets with Mr. Ryoichi Sasakawa (right) in Tokyo, Japan, with Dr. Yuasa interpreting (1984).
5. WHO Western Pacific Region Leprosy Meeting, Manila, Philippines (1982). Those in the photo with the author (front row, 3<sup>rd</sup> from left) include Dr. Hiroshi Nakajima, regional director, WHO WPRO (4<sup>th</sup> from left) and Dr. S. T. Han, director of program management (end of front row).
6. Visiting a clinic in Sulawesi, Indonesia (1984)





1. The author (2<sup>nd</sup> from right) visits Mr. and Mrs. Kong Haobing and Mr. Chen Guanzhou (far right) in Hongwei leprosy village, Foshan city, Guangdong, China, together with Dr. P.K. Gopal from India (2<sup>nd</sup> from left) and Mr. E. Ishihara from Japan (4<sup>th</sup> from left) (1996).
2. Observing case diagnosis in Non Som Boon leprosarium, Khon Kaen, Thailand with Dr. Teera Ramasoota (right) and Dr. Charoon Pirayavaraporn (left) (1984)
3. With Professor Le Kinh Due, Hanoi, Vietnam (1994) In the background is the Ho Chi Minh Mausoleum.

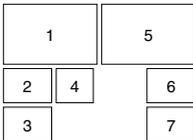


4. Examining a patient with foot ulcer, Bihar, India (1996) Photo: Masao Inukai
5. Addressing ILEP's 30th anniversary celebration in the presence of Diana, Princess of Wales, London, UK (1996)
6. Field visit in Myanmar (1996)
7. Field visit in Benguela, Angola (2003)





1. 3<sup>rd</sup> International Conference on Elimination of Leprosy, Abidjan, Cote d'Ivoire (1999)  
The author (2<sup>nd</sup> from right) is seated next to Mr. Yohei Sasakawa (3<sup>rd</sup> from right).
2. Monitoring leprosy control in Tamil Nadu, India (1997) Those in the photo include Professor M. Lechat (seated, 2<sup>nd</sup> from left), Dr. M. Adhyatma (dark shirt, back to camera) and the author (seated, 3<sup>rd</sup> from right).
3. Monitoring MDT implementation in Surabaya, Indonesia, with Dr. Yamin Hasibuan (far left) and Dr. S.K. Noordeen (2<sup>nd</sup> from left) (1997)



4. With Mr. Arega Kassa Zelelew, a founding member of the Ethiopian National Association of Persons Affected by Leprosy, at the Quest for Dignity exhibit, New York City, USA (1997)
5. The author with Mrs. Yuko Yuasa at the Damien-Dutton Award Ceremony, New York City, USA (2002)
6. Asian Leprosy Congress, Agra, India (2000)
7. The author (right) shares a light moment with Dr. S. K. Noordeen at WHO headquarters, Geneva, Switzerland (ca. 2005).

# Working toward a World without Leprosy

Dr. Yo Yuasa

Executive and Medical Director  
Sasakawa Memorial Health Foundation

## I. Where We Are Now

### 1. 1<sup>st</sup> and 15<sup>th</sup> International Leprosy Congresses

The title given to me for this presentation is identical to the title of the forthcoming 15<sup>th</sup> International Leprosy Congress to be held in Beijing, People's Republic of China, from September 7 to 12 this year.

The first congress was held in Berlin in 1897, exactly 101 years ago. Not many international medical congresses have such a long history. That congress was rather hastily organized to solve an urgent problem of many leprosy cases coming into Memel District of Prussia among migrant workers from Russia. In fact, at their peak there were only 34 cases, but even that number caused

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Workshop on the Elimination of Leprosy, WHO Western Pacific Regional Office, Manila, Philippines, 8-11 June 1998

a kind of social uproar similar to what was seen recently in the face of Ebola fever in Africa or plague in India. People with little understanding of the true nature of leprosy were clamoring for the health authorities to do something.

It was 25 years after Dr. Armauer Hansen's discovery of *M. leprae*, which had proved that leprosy was an infectious disease, contrary to his father-in-law Dr. Danielsen's view of leprosy as a genetically inherited disease.

It is most interesting to find out the contents of discussions among medical authorities of the time, including Dr. Hansen himself, but also among such well-known medical figures of the day as Neisser, Kaposi, Ehrlich and Virchow. Having no real chemotherapy tool except chaulmoogra oil, their recommendation on isolation of patients was a logical conclusion of the meeting. Their discussions on how strictly it should be done, on its acceptability and on police involvement form an interesting historical record, while other discussions on skin-to-skin contact versus air passage entry through nose and mouth mucus membranes for infection, or the relative importance of clinical signs versus microscopic evidence of *M. leprae*, make the proceedings well worth reading even now to learn many lessons, both negative as well as positive, for our current and future use.

The first congress, therefore, was organized to solve actual problems they were facing at that time and was not for abstract academic discussions only, as many scientific congresses, including that of leprosy, have tended to become. The editor of the proceedings of the Berlin Congress proudly pronounced that the congress was an important historical milestone toward eventual control of leprosy. The coming congress of ours, the fifteenth, is trying to recapture some of the original spirit and make it forward looking, action oriented and integrated, because we are again facing a very big and important question on what we should be doing once we reach the goal of the currently ongoing

“elimination” program by the year 2000, which is only two and a half years from now.

## 2. “Elimination of leprosy as a public health problem by the year 2000”

The current program, when its targets are reached, makes leprosy no longer a public health problem according to WHO’s definition. So the first question we should face is: “Do we need to do any more for leprosy?” The answer partly depends on the position of the person who is answering. If that person is a member of a leprosy-related NGO, the answer must be a resounding “yes.” However, if that person is a staff member of a public health authority, as many of you in this audience are, it could be “no,” although perhaps expressed somewhat non-emphatically or even hesitantly. It is quite understandable that if leprosy is no longer declared to be a public health problem, why should they worry, in the face of many other urgent public health problems such as TB, malaria, dengue fever and hepatitis, which obviously need more attention than leprosy.

Therefore, before I start discussing the what, how and when of “a world without leprosy,” it is perhaps useful to consider the “elimination program” we are currently engaged in, and for which this regional workshop is being organized.

As you are fully aware, MDT (multidrug therapy), which is the primary tool of the elimination program, was recommended for global use by the first Chemotherapy Study Group held in October 1981 and its report published in April 1982. The main reason or perhaps the only real reason for that recommendation was to prevent the further spread of leprosy with dapsone-resistant *M. leprae*, which was rapidly increasing around the world; it was not

at all to improve the efficiency of chemotherapy as such. However, the MDT recommended by WHO proved to be not only very effective in preventing any drug resistance developing, as intended, but also, to the great delight of many of us, turned out to be very effective and efficient chemotherapy against *M. leprae* infection. As a result, the duration of MB treatment was shortened from the original recommendation of “until smear negativity” to a fixed duration of 24 monthly doses over 30 months, then down to only 12 monthly doses now.

Many MDT implementations in various parts of the world are undertaken in far from ideal settings—thus presumably with not very high compliance, as far as daily unsupervised doses are concerned—but have still produced satisfactory overall results, which has made WHO term its MDT as very “robust.” This global phenomenon made us think of systematically controlling leprosy in the field with the possibility of target setting with a time-limited program. The currently ongoing “Elimination of leprosy as a public health problem by the year 2000,” based on the resolution of the 44<sup>th</sup> World Health Assembly of 1991, is well known.

What is not so well known, even among the participants of this meeting, is the fact that a similar resolution was passed by the Western Pacific Regional Leprosy Workshop held in October 1989 here in this building, calling for “Elimination of leprosy as a major public health problem” by the year 1998 at the national level and by the year 2000 at sub-national levels. The member countries of the Western Pacific Region therefore started on an identical elimination program at least a year and a half ahead of the rest of the leprosy-endemic countries in the world.

Time constraints prevent me from going into the details of how it started, but I must mention a critical role played by Dr. S. T. Han, the current regional

director, who had me and Dr. Jong-wook Lee, the predecessor of Dr. L. Blanc as the regional advisor in chronic diseases, come up with this plan for that workshop in 1989. We had strong support from Dr. R. Jacobson of Carville, Louisiana, the birthplace of the modern chemotherapy of leprosy because of the usefulness of Promin, a sulphone drug, which was discovered there by Dr. Guy Faget in 1941-42. Without Dr. S.T. Han's strong personal interest, the leprosy elimination program as we know it may not have started at all, or at least not as soon.

So what does the "elimination program" try to achieve? As clearly stated, it is trying to reduce the prevalence rate of leprosy to less than one case per 10,000 population at the national level in every leprosy-endemic country by the year 2000. It is obviously tackling leprosy as an infectious disease and trying to reduce the number of active cases, hoping that the lowered caseload will lead to smaller sources of infection, thus eventually leading to a reduction of incidence—a much more difficult to determine but nevertheless more significant indicator for control of an infectious disease. At the same time, it is hoped that early and effective MDT could reduce the incidence of nerve involvement, thus at least partially addressing a problem of leprosy as a deformity- and disability-producing disease. But one could say that this is only an added benefit and not the main objective of MDT implementation.

You already heard from Dr. Noordeen and Dr. Blanc this morning as to the global and regional results. What we need to do now is to recognize those results for what they are. It is a magnificent achievement of which all of us involved in the program should be proud because we have reached a significant milestone in our age-old struggle against leprosy. At the same time, however, we should honestly accept the fact that a milestone, however significant, is only an interim target on the way to the final goal.

I used to talk about “eradication” of leprosy as our final goal, in the same way that smallpox was eradicated. In the case of smallpox, the causative organism, the variola virus, no longer exists on the surface of this Earth except in a few vials or dishes, which are kept in the United States and Russia, and these will be destroyed simultaneously during the next year, 1999. Thus human beings will be forever freed from the scourges of that dreaded disease.

Eradication of leprosy similarly needs total elimination of *M. leprae* from this Earth, but unlike the variola virus for which humans were the only host, *M. leprae* exists in some wild animals such as the armadillo or certain monkeys and apes in Africa, and it may even exist in soil, as some experts insist. Thus eradication of leprosy is not possible with the currently available tools in our hands, and even if new technologies emerge that are capable of achieving this, it probably is totally out of proportion, in terms of needed resources, to justify such an attempt. Therefore, eradication of leprosy is likely to remain, and perhaps should remain, as one of the dreams for future generations. What, then, should be our final goal, which is both worthwhile and justifiable? “A world without leprosy” is my answer, because unlike “eradication,” which has a precise and an unambiguous definition, “a world without leprosy” is suitably vague inviting various interpretations and definitions.

## II. What, How and When of “a World without Leprosy”

Now I come to the main topic of my presentation: the what, how and when of “a world without leprosy.” Since it is my personal view, which could be different from my colleagues such as Dr. Noordeen, Dr. Blanc or Dr. Jacobson, I shall state my views rather succinctly, without too much detail. I hope this will become a worthy topic for anyone involved or interested in leprosy, to be

discussed, debated and argued from now on until there is no more need for discussion as we will have reached “a world without leprosy” by some means, sometime, hopefully within the first half of the new century.

## **1. Leprosy, an infectious disease as well as a deformity- and disability-producing disease**

It is extremely important to stress at the very start that when we talk about “a world without leprosy,” it means both medically and socially. Thus it is altogether quite different from the “global leprosy elimination program” in which leprosy is considered only in terms of an infection, consciously excluding any consideration of leprosy as a deformity- and disability-producing disease with grave social implications.

For a person who has leprosy, this separation is meaningless, but in terms of dealing with associated problems this artificial separation makes both understanding and handling of the disease easier and perhaps more effective. For instance, leprosy as an infectious disease is an obvious public health concern while leprosy as a deformity- and disability-producing disease may not be a public health concern, especially in developing countries.

## **2. Medical aspects of leprosy**

### **2.1 Public health aspects**

So let us first consider leprosy as a public health problem. The best way to deal with any problem is to prevent its occurrence, and therefore the best way to deal with leprosy is also prevention. Even though we do not have an effective prophylactic vaccine except BCG as a possible public health measure, we could consider a prophylactic chemotherapy, as is currently implemented in the Federated States of Micronesia and in a few other places. The problem of

any preventive measures is the difficulty of identifying suitable risk groups. For a disease with less than 1/10,000 prevalence rate, this is not easy and eventually may prove to be totally non cost effective.

Next to that, and perhaps even better as a practical strategy, is a sustained effort of the current elimination program, hopefully with more effective early case finding and more efficient chemotherapy undertaken by the general health services as a part of their regular routine activities. It requires wide-scale training of all health workers both in the private and public sectors, in addition to maintaining expertise on diagnosis and case management at certain levels of the health service hierarchy, and provision of adequate supervision and monitoring at all levels. How to maintain necessary commitment by health authorities in order to secure necessary resources for a disease that is openly declared to be no longer a public health problem is a question we must face fairly soon. Therefore, marketing strategies are almost as important as technical ones. Effective public health awareness campaigns, if the messages are right, could be a great help.

## 2.2 Other medical aspects

How to deal medically with leprosy as a deformity- and disability-producing disease is even more difficult. Some health authorities may refuse to deal with that aspect of leprosy on the grounds that this is not a public health responsibility. Even if they are interested, dealing with nerve involvement at a time of reactions, for instance, is far more complicated and needs individual attention quite different from implementation of standardized MDT to a whole group of patients. Fortunately, however, “prevention of disability” is increasingly being accepted as part and parcel of MDT implementation, and thus a part of a public health responsibility.

When it comes to dealing with established deformities by physiotherapy or surgical interventions, the whole affair will become even more varied and complicated technically, besides being rather expensive.

Although all of the above are both difficult and costly, we are at least developing some standardized technology, which hopefully could keep improving so that its application becomes easier for wider implementation. One critical point that needs our careful consideration is whether it is justified to implement these physical rehabilitation activities for sufferers of leprosy only, or should they be undertaken as part of whatever such procedures are available for those who are physically handicapped due to causes other than leprosy. The answer must be an emphatic “yes” to the latter.

One of the causes of difficulties both leprosy patients and leprosy workers have had to deal with up to now was due exactly to this separation of leprosy work from general health activities, and that was one of the very causes of leprosy as a whole being segregated and stigmatized. The only exception to the above integrated approach must be a situation when there is already a functioning good physical rehabilitation program for leprosy while hardly any exists for the handicapped in general—in other words, there is nothing with which existing leprosy work can be integrated. In that case, an eventual reverse integration of general work into the existing leprosy program must be the way for the future, while maintaining leprosy-only work for the time being.

### 3. Social aspects of leprosy problems

In terms of social aspects, leprosy sufferers are in double jeopardy. They are handicapped because of their physical deformity and disability. In addition, they are further handicapped by being leprosy sufferers. This second part

is almost unique in human history, because there has hardly ever been another situation, regardless of religion, race, nationality or culture, where stigmatization, rejection and ostracism are so universally targeted at one particular group of people. Therefore, the social aspect of leprosy sufferers must be dealt with at two levels.

### 3.1 Removal of stigmatization

The usual and rather simplistic answer to solve this problem is the health education of the public. Education is normally effective in imparting knowledge. It is not at all difficult for people to learn about leprosy: that it is a mildly infective bacterial disease; that it is not due to a curse of God; nor is it inherited, nor due to bad sexual conduct.

For removal of stigmatization, however, knowledge alone is of no use. A new knowledge must lead to a changed attitude and, most importantly, to changed behavior.

Most of the health education effort falls short of reaching the desired goal. Therefore, health education as such must be reinforced by suitable demonstrations. People change their behavior more readily by witnessing with their own eyes the right behavior demonstrated by others. Even so, changed behavior seldom occurs, unless it actually brings benefit to them.

### 3.2 Care to meet patients' economic, social and spiritual needs

There is nothing special in the economic, social and spiritual needs of leprosy sufferers to separate them from others with similar needs, but it must be always kept in mind they are in double jeopardy, as mentioned above. If that aspect is not taken care of, whatever support you provide economically, socially or spiritually may not produce expected results.

Of course, one possible benefit of spiritual support given by existing religions could and often does offer one way of solving, if only partially, the problem of stigmatization by enabling leprosy sufferers to change their outlook on life, so that they may be able to better handle the unchanging and unfriendly social milieu.

Again, whatever services are provided should be a part of a system open to anyone in need and not for leprosy sufferers only.

#### 4. "A world without leprosy-related problems." Could this be our goal?

Perhaps what we should be pursuing is not strictly "a world without leprosy" but rather "a world without leprosy-related problems," both medical and social, and both quantitatively and qualitatively.

##### 4.1 Medical

As WHO is currently proposing, we should sustain our elimination effort at the sub-national level, once the national goal is achieved. There is no reason not to continue that effort at even lower levels. Eventually, in terms of numbers, it should come down to the level currently seen in the United States, with a few hundred new cases among more than 200 million population, or better, to the current level of Japan, with about 10 new cases a year among 120 million population, making the case detection rate less than 1 per 10 million.

At that level, leprosy is definitely not a public health problem, with little chance of resurgence and a good chance of eventually dying out. Please remember, the prevalence rate of leprosy in Norway was higher than 2/10,000 in the mid 19<sup>th</sup> century, but the disease died out 100 years later before dapsone became available widely. By the way, 1/1,000,000 was the level the U.S. Public

Health Service was once hoping to achieve in regard to TB by the year 2010, when we were discussing our regional leprosy elimination program in 1989.

In terms of medical quality, I am unable to comment on the situation of the United States, but in Japan, it is far from satisfactory. Case detection is evidently delayed and treatment, both involving chemotherapy and handling of nerve involvement and prevention of deformity, is far from satisfactory. This is one of the difficulties leprosy-endemic countries must face in the future; as their caseload comes down, so will the availability of expertise required to look after those fewer cases. Smaller numbers are no excuse for lower quality. In fact, it should be the opposite.

#### 4.2 Social

Dealing with the medical problems of leprosy is much easier than dealing with its social problems, however, as briefly discussed before. A diminishing number of leprosy cases does not mean diminished prejudice within society. There may be fewer opportunities to express these prejudices, but often they are not forgotten but simply internalized. This sometimes makes the prejudice stronger, so that rare encounters with isolated leprosy cases can trigger wholesale social uproar. Past examples in Japan clearly demonstrate that danger, although the situation is improving. As new generations with no personal knowledge of, let alone actual encounters with, leprosy gradually replace old generations, the whole matter may gradually die out.

*M. leprae* is known to persist in a dormant state until the host dies. Prejudice can also persist in a dormant state, and far worse it may be passed to the following generations. A terrible picture of leprosy, often grossly distorted, may form a part of common folklore passed from generation to generation, so that people who have had no personal encounter with leprosy may still

harbor some form of prejudice almost unconsciously. A good example is the shameful British media coverage when Princess Diana shook hands with leprosy patients in Indonesia. Here, enlightened public health education may help—first by exposing such dormant prejudice and then by trying to illustrate the flaws in such reasoning, rather than just condemning it.

## 5. Conclusion

What I have been saying is nothing new. I am not offering any new strategies or any short cuts to spectacular solutions. Leprosy control work, which really took off after the discovery of sulphone drugs, has been one long, hard slog by field workers who in those days did not see much change in the situation or the end of the road in sight. Those of us in the MDT era have been much more fortunate, for we could witness the situation changing all around us.

The recent “elimination program” is making leprosy activities almost fashionable by getting an unusually high priority among health programmers. It also made it possible for us to contemplate the eventual end point of our activities, as we are doing now. For me, that end point is best expressed as “a world without leprosy-related problems, both medical and social.” It sounds rather mundane. It does not sound as glorious as “eradication of leprosy” or even “a world without leprosy.” But I believe it is a more honest expression of what we are likely to be able to achieve and, more importantly, we will have no excuse for not achieving it.

## Closing Remarks at 15<sup>th</sup> International Leprosy Congress, Beijing

Dr. Yo Yuasa

President  
International Leprosy Association

Dr. Zhang Wen Kan, the minister, Dr. Cao Rong Gui, the vice minister, honorable guests, dear colleagues, ladies and gentlemen:

“This was certainly something different. This was no usual international conference with empty meeting halls and a full reception room; a potpourri of speeches, reports and superficial discussions. This was a serious conference with a clear theme and a practical purpose, attended by participants anxious to go deeply into questions, and to set practical actions on the right road.”

The above is a slightly paraphrased version of Dr. Jessner’s introductory summary to the proceedings of the 1<sup>st</sup> International Leprosy Congress in Berlin in 1897. I am happy to say that I can use almost these exact words to describe what we have done over the last six days. It was indeed a serious,

a very serious, gathering—certainly on the part of the organizers and, according to my observations, on the part of many participants as well. We had a clear, unifying main theme, “Working toward a world without leprosy,” with the practical purpose of undertaking actions that will lead us to this goal. There was a remarkable degree of active participation, as shown at the first day’s open forum on “The Future of ILA” or at the Q&A session after open panel discussions in the morning on days 2, 3 and 4, or at the plenary sessions on day 5. With that first congress in Berlin, the modern fight against leprosy started and it has made noteworthy progress and brought us to where we stand now. With this 15<sup>th</sup> Congress in Beijing we are starting the second century of our fight, which should hopefully take us to our stated goal.

Obviously, to my great relief, the radically altered structure of the daily program has been accepted, at least on this occasion, perhaps more actively than just passively, making this congress more “integrated” and “participant friendly” than before. The “forward-looking” and “action-oriented” nature of the congress has also been apparently understood, accepted and mostly realized in general, thanks no doubt to the efforts of three moderators on days 2 to 4—Professor Smith, Dr. Walter and Dr. Krahenbuhl—and with the active collaboration of the speakers on the “current issues,” the members of the panels, and the chairpersons and members of the workshops. I am grateful to the participants who tolerated inconveniences due to schedule alterations. Of course there were a number of criticisms: the shortness of workshops was one heard most frequently, but it was part of more general complaints about overcrowding of programs in six days. If we had the luxury of 10 days or two weeks, we could have organized the program with more breathing spaces in between and less concurrent sessions. As I mentioned in the program guide, this congress was an experiment, and we, the organizing committee,

have learned much from this experiment in order to plan better for future congresses. As the chairperson of the organizing committee of this congress, I would like to thank all the participants for their understanding, patience and collaboration, which made this congress a success as far as it went, and now I am uncrossing my fingers with a great sense of relief.

Dr. Jessner's introduction also had the following. "At this conference there was a will to work, knowing that it was not preaching to deaf ears or preparing worthwhile material just to be quietly filed away, knowing rather that its outcomes would be put into practice as soon as possible." The first congress 100 years ago was organized in response to the German government's need to do something about the sudden influx of leprosy patients among Russian migrant workers. The government was eager to receive the recommendations of the congress.

Our situation today is almost the opposite. With the successful "elimination program," many governments are lowering their political commitments, if not totally losing interest. Indeed, we may be preaching to deaf ears in some cases.

So what happens after this congress? If anything happens at all, it depends on how each of you, the participants, takes initiatives in putting what we have identified as important items into practice. The real value of this congress will be judged by what happens over the next five years as a result of this meeting. Judging from serious discussions that took place during the congress, I am rather optimistic that something useful will take place. But in order to ensure that happens, I have asked the members of the new ILA Council to take responsibility in following up the recommendations of the workshops. In this connection I was happy to observe that many of you have attended sessions outside of your specialty. By participating in most of the plenary sessions, you

now have a better understanding of your own future contribution within a total context of “Working toward a world without leprosy.” One new feature of this congress was the involvement of so many persons affected by leprosy themselves as regular participants and not just as guests. I trust that their potential contribution as our partners in our future work is now recognized and accepted.

“A nation without vision will perish” says the Book of Proverbs in the Old Testament. So too will an association. Our vision is to achieve “a world without leprosy.” Some people may have some confusion as to our exact goal, however, because of my presentation on the opening day. I shall be most happy if we can reach “a world without leprosy,” but to be honest, it is most unlikely that we will reach such a utopian state in any foreseeable future. But that is not a reason to discard such a goal, as long as we acknowledge it to be an ultimate goal. Hope is a great promoter of our endeavor. “A world without problems related to leprosy, both medical and social” is a much more down-to-earth goal as against a celestial goal of “a world without leprosy.” It is more likely to be achievable. It enables us to plan realistic actions, which could solve these problems one by one.

This congress has identified many issues that need our immediate attention and has made suggestions for solving some of them. It is up to us to take up these challenges. If we fail to solve them, we have no one but ourselves to blame. This congress stressed the need to form and strengthen partnerships or alliances among those involved in leprosy. ILA certainly will try to be a trustworthy member of the group, together with WHO, ILEP, ILU, IDEA and hopefully many others. I trust that all of you here are the willing partners of our work over the next five years. Therefore, I look forward to meeting with you in Brazil in 2003 to report what progress we have made on the issues

this congress has identified as important; then to plan for the future actions needed in order to get ever closer to “a world without problems related to leprosy, both medical and social.”

Before closing, I would like to thank the Ministry of Health of the People’s Republic of China, our official host and supporter, and its officials and staff members, especially Professor Yin Dakui and Dr. Wan Zhao of the organizing committee and Mr. Cai Dong Qian of the local secretariat. Without their full-hearted collaboration, this congress could not have been organized as well as it was. I also wish to reiterate my thanks to our cosponsors, WHO and ILEP. The way we managed to work together for this congress indicates mutually profitable future collaboration toward our common goal.

I now wish you a safe journey home and a successful undertaking of activities in your chosen field. Thank you for your kind attention. I now declare the 15<sup>th</sup> International Leprosy Congress closed.

# 13

## What Should ILA Be? A Personal View

Dr. Yo Yuasa

President  
International Leprosy Association

### 1. Introduction

Although I am its president for the second term, I must confess that I am still incapable of defining the current International Leprosy Association (ILA) accurately. My first contact with it was in 1958, when the 7<sup>th</sup> International Congress of Leprology, which was the title of our congresses in those days, was held in Tokyo. I was appointed as a liaison between ILA (represented by Dr. H.W. Wade, its president, Dr. E. Muir, its secretary, and Dr. J. Ross Innes, its secretary designate and the *de facto* secretary of the congress) and the Japanese organizing committee. In fact, it was those three doctors who, immediately after the congress, persuaded me to go to medical school at the

age of over 30, saying that I should have a medical qualification, especially if I wanted to work overseas, even if my main interest was in the social aspects of leprosy. I am forever grateful to these three eminent doctors in leprosy, plus Dr. S.G. Browne, who became my mentor after the untimely death of Dr. Ross Innes, for their advice and subsequent support in making me what I am today. However, somehow it never occurred to me to join ILA, even after starting my leprosy work by joining The Leprosy Mission in 1970. I thought rather vaguely that ILA consists of people whose interests are somewhat different from my own—the rather down-to-earth daily care of patients as a clinician in a developing country—whereas those of ILA members, judging them mainly from the *International Journal of Leprosy (IJL)*, were rather at a stratospheric height of leprosy study.

I had to join ILA when I was asked to be the secretary of the association by Dr. Wayne Meyers, my predecessor as the ILA president. The reason for my acceptance of that post was a sense of indebtedness to those four outstanding ILA officers, and serving a term as secretary was meant to be a symbolic repayment. It is amazing how things can develop unexpectedly, and I ended up as the president at the Orlando Congress. To be honest, I have never been really comfortable either as the secretary or the president over the last 10 years because I was never sure of what ILA is, at the same time becoming more and more aware of the probable discrepancies between what I think it has been and what I believe it could and should be. The acceptance of my second term as ILA president, due to strong external pressure from an unexpected corner only a few months before the congress, when I was having discussions with a potential successor of my own choosing, was of course ultimately my own choice, and the reason then was my very personal sense of duty to a necessary reform of the association, as I see it.

As many of you have witnessed in Beijing, some with delight but others with horror, the format of the 15<sup>th</sup> Congress was changed quite drastically. I did that because I was told by my fellow officers that it was a president's prerogative to decide what sort of congress we should have. Although ILA is mainly responsible for organizing the congress, it had two cosponsors in WHO and ILEP with their own firm ideas. Besides, two thirds or more of the participants in recent congresses have been non-ILA members. Thus, without too much fear, I could organize the Beijing Congress to suit what I considered to be the needs of prospective participants. I am now getting responses to the questionnaires that were sent out to all the participants, and they clearly show that the majority of them definitely liked the new format but, equally, the returns indicate that many ILA members, especially those in research in the West, definitely did not like it. There is no surprise in that at all, although it is a difficult and, at present, almost insoluble problem to reconcile the needs of two diverse groups in a single one-week meeting. Perhaps we should run two congresses concurrently, one smaller and scientific and the other much larger and nonscientific (meaning control and social aspects), with only the opening and closing sessions together.

However, trying to change the character of ILA itself is quite a different matter altogether. It needs the consent of a majority of the current members, and the president has only a single vote to cast, like any other member. There are a number of current members, some within the council, who favor some changes, changes even more radical than mine. They are the more vociferous members of ILA, willing to come to the general meeting of members on the final day of the congress and openly demand some changes. But if my guess is correct, they are still a minority within the association, leaving a silent majority who are either satisfied with the current ILA and thus wishing no

change, or perhaps do not care much one way or the other, provided the “status quo” is maintained.

Fully realizing this state of affairs, I am starting a series of events that I have already described in the foreword to this issue. If all goes well according to my plan, it will end in a postal referendum in the summer of the year 2000, the result of which will be considered and appropriate actions, if any, taken at the full council meeting, which I am calling on the occasion of the ILA Asian Congress in India in October/November 2000. If at all, I shall propose changes in technical details of the bylaws only, while leaving the changes in the constitution, such as objectives and memberships, to the general meeting of members at the time of the 16<sup>th</sup> International Leprosy Congress to be held probably in the year 2002 rather than 2003 somewhere in Brazil.

## 2. Why changes now?

At this point, it is necessary to consider the reasons for changes now. Apart from the reasons to be explained in the next section, which one might call ideological, there are more mundane but rather urgent reasons that are primarily financial.

The size of our membership is slowly but steadily contracting, mainly due to loss of our scientific colleagues for very understandable reasons. They seem to find less interest in and/or opportunities for engaging in leprosy research. This trend, which is certainly regrettable but beyond our control, is likely to continue. Thus, our income from membership fees of self-financing individuals is steadily being reduced. There seem to be ample opportunities for a large increase in membership from leprosy workers, both medical and social, in endemic countries, whose activities are likely to continue. But for

them, the current membership fee, tied to the *IJL* subscription, is simply prohibitive. It is suggested that US\$10 to \$20 annually would be an affordable level for them. Thus, an increase in membership does not necessarily help financially.

Reduced membership together with the increasing cost of producing and mailing the *IJL* are threatening our ability to keep producing *IJL* as it exists today. The publication of a scientific journal on leprosy is the only activity specifically assigned to our association by the ILA constitution. Its publication nowadays is almost entirely at the mercy of the members of ILEP, and there is a constant questioning of the wisdom for them to keep supporting two international leprosy journals of similar contents and quality in English, thus increasing financial support from that source seems totally out of the question.

Each of the above, by itself, does not allow us the luxury of “no action” until the next congress. Added to these, the reasons to be stated in the following pages make it imperative for us to take some action soon. We cannot afford the “status quo” that ILA seems to have enjoyed—or suffered, depending on one’s view—for far too long. I am not expecting everyone to agree with my reasoning for changes on “ideological” grounds, but I hope everyone will realize that, without some changes, financial reasons alone could doom the future of our association.

I am fully aware that some members of the association, including a few in the council, are of opinion that if ILA is doomed to die it is best to let it do so without much disturbance now. Others say that if ILA is not meeting the needs of the current leprosy world, it is better to create another association specifically able to meet such needs. I happen to disagree very strongly with such ideas. I firmly believe that both the name and the substance of ILA are

worth preserving because, at least in my view, the founding fathers of our association made sure, in our constitution and bylaws, of our continued existence and expected contributions to global leprosy work. Creation of such an organization was seriously debated and a special committee was created at the time of the first congress in Berlin in 1897, but it took more than 30 years to actually establish ILA. Surely we should not abandon such an organization so readily, not while I am its president, for sure.

Now let me come to my personal views on “What is ILA?” and “What should ILA be?”

### 3. What is ILA?

As I have said already, I am not capable of defining either the nature or the *raison d'être* of the current ILA accurately. It is said that it has to be an association of “professionals,” with which I am inclined to agree, although without being able to define “professionals” exactly. It is also said that it is an association of “scientists” and “academics.” Here I tend to disagree, although I am equally unclear as to what those two terms mean, while recognizing that many of the current members seem to belong to these two categories.

The existing ILA constitution does not seem to stress that the association must be “scientific” or “academic,” although it may vaguely imply that it should be an association of “professionals.”

It states that the members are: 1) persons holding recognized medical or scientific degrees; 2) or other professional qualifications; 3) or persons who are, or have been, actively connected with leprosy work. The underlining is mine, and a very loose and all-inclusive membership it is indeed. If you take these criteria literally, anyone with a medical, scientific or some other

qualification could be a member, even if not engaged in leprosy work at all. At the same time, anyone associated with leprosy work, currently or in the past, could be a member without any qualification.

Why such loose criteria? I suppose in the early 1930s, the number of people genuinely interested in leprosy was so few that almost anyone wishing to join the newly established association was welcome. Is the current situation that much different? I wonder.

As to its objectives the constitution states: 1) to encourage collaboration between persons of all nationalities concerned in leprosy work; 2) to facilitate the dissemination of knowledge of leprosy and its control; 3) to help in any other practicable manner the anti-leprosy campaign throughout the world; 4) to publish a scientific journal of leprosy; and 5) to cooperate with any other institution or organization concerned with leprosy.

Again, very broad objectives indeed, except for No. 4, which is very specific. Almost any activity of leprosy including its control and the anti-leprosy campaign, from finding individual patients to rehabilitation of those affected by the disease, as well as more scientific activities to find new tools required for such activities, or elucidating basic structures of *Mycobacterium leprae* and their functions, could all be considered as its legitimate concern.

From the existing constitution, if it had not been drastically revised meantime, which I rather doubt, it is obvious that the founders of the association felt a need to establish a network of people working in leprosy in order to improve leprosy control and strengthen the global anti-leprosy campaign, thus helping individual patients under their care. Perhaps they could not afford to be too restrictive in terms of membership qualifications or objectives of their activities because there were only a precious few who, in their eyes, could be members of the new association they are creating.

Is the current ILA doing those above-mentioned jobs well? In my personal view, the answer must be negative—almost totally negative, I am afraid. Certainly, quite a large number of individual members are contributing greatly to promote some of the activities mentioned above, working within WHO, ILEP, other international or national NGOs, and technical or academic institutions. The association itself, however, is not doing anything. Evidently many members think that the association has no business taking any action at all, but that view seems to be in conflict with the objectives stated in its constitution.

There are two types of association. One is inward looking; its only reason for existence is to meet the needs or cater to the tastes of its members, whatever they may be. The other is outward oriented, and it exists basically to do something collectively, primarily for the benefit of others, although by so doing the members are likely to derive some satisfaction for themselves. I feel somewhat uneasy with ILA because to me ILA seems more of the former than the latter. For that reason my original intention was to leave ILA once my term as president was over at the Beijing Congress. But, as I explained earlier, I felt I have to continue, not so much for the sake of ILA as such but for the sake of leprosy in a broader context. Once I decided to accept a second term, it became a matter of conscience to try to be an active president, and that meant I must try to reform ILA, although the eventual outcome of my effort rests squarely on the majority opinion of the current members and, thus, is mostly out of my control.

## 4. What should it be?

In the past, there was no demand on ILA to take a strong stand concerning the global leprosy situation or show strong leadership in the global leprosy program, although at some congresses it produced some timely and useful recommendations, suggesting ways to improve or strengthen existing leprosy work.

Clearly, the founding members felt a need for closer communication among the few leprosy specialists in the early 1930s, practically all of them clinicians dealing daily with leprosy patients. Perhaps they felt their isolation, both in physical/geographical terms as well as in a professional sense, to be a great disadvantage to their work. Therefore, the exchange of ideas and experiences among the members was obviously the felt need among them, and perhaps a newly born sense of fraternity among them was enough in the beginning. The absence of technologies that could dramatically change the global picture of leprosy, even with the discovery of sulfone therapy in the early 1940s, was enough to keep ILA rather static over the next 50 years.

The appearance of multidrug therapy (MDT) has changed the global scene completely. Unlike Promin and dapsone, MDT has proved to be really effective in controlling leprosy in the world under field conditions, at least as an infectious disease if not as a deformity- and disability-producing disease. A need for strong leadership to direct such a global movement became apparent which, by the nature of activities required, had to be carried out by the field workers of leprosy-endemic countries. The logical choice of such leadership fell on the Leprosy Unit of WHO and, to their great credit, they have performed their function very well, with the “Elimination of leprosy as a

public health problem by year 2000” nearing its end. Whatever its detractors may say, there is no question that by reducing the global caseload by 85% or more, the global leprosy scene in the year 2000 will be quite different, quantitatively as well as qualitatively, from what it was in the early 1980s when MDT was first introduced.

But the very success of this program itself, plus the rather unexpected fundamental restructuring of WHO, means that WHO is unlikely to be able to exercise the kind of leadership required for future global leprosy activities after the year 2000, which will be vastly more diverse and complex, requiring many different tools and technologies and involving a variety of workers, unlike the relatively simple and uniform MDT implementation up to now.

There is another strong group, as a potential leader, called the International Federation of Anti-Leprosy Associations (ILEP), formed by 20 or so of the international NGOs, with combined financial resources of around US\$70 million to \$80 million annually. They have been the major supporters of the global implementation of MDT so far and there is good reason for them soon to become even more important supporters of the global leprosy program, in which social aspects must have an increasingly larger share. But there are two reasons, one inherent and thus unavoidable and the other structural and thus possibly alterable, which make them not quite suitable as a world leader, at least at present. One is the fact that they are basically donor agencies, and two donor agencies, the International Monetary Fund (IMF) and the World Bank, are increasingly being criticized nowadays for their behavior. Donor agencies have a tendency to dictate the use of the funds they provide in a way not necessarily in the best interests of the recipients. Another is structural, and as a federation it is difficult to have united action among its members.

If both WHO and ILEP are unsuited to be the global leader, then who else?

As far as I can see, there is no one at present and the only possible candidate is ILA, not as it exists now but as a reformed ILA. Of course, some people, including many current members of ILA, could question the need for global leadership after the year 2000. But I, for one, happen to believe in our mission to work toward our final goal of “a world without leprosy,” and for that goal to be reached within the foreseeable future, say not later than the year 2050, then globally a concerted effort by all concerned is required, which naturally calls for effective leadership.

I use the term “effective” rather than “strong” because the leadership of ILA is likely to be by persuasion only. ILA is unlikely to have a fund of its own sufficient to undertake any activities by itself. The only way it can function as a leader, in my current view, is to form a kind of “think tank,” or several of them, primarily working by correspondence (which modern technology is making ever easier and speedier on a global scale) and not requiring a large sum of money. ILA also will have to be able to market those ideas that come out of our “think tanks” if they are to be accepted by those who are capable of taking actions, such as member organizations of ILEP, other national or international NGOs, national health authorities, and even WHO, the World Bank and other international agencies that can take large-scale actions by themselves or can prompt such actions to be taken by others.

Of course, one great advantage of ILA that it already possesses is that many individuals who are likely to be responsible for taking action in leprosy are those likely to be the current and future members of our association, although at the moment not enough people in the endemic countries are members nor are the experts in the social aspects of leprosy work.

Therefore, the ILA of the future, in my personal view, must be 1) an association that is both sensitive to the needs and capable of understanding

the existing problems that prevent those needs from being met; 2) an association capable of coming up with ideas and even actual plans to solve those problems effectively and efficiently, and skilled in “marketing” those ideas so that someone capable of taking action will accept those ideas; and 3) an association of strong and clear advocacy for further leprosy work in all aspects in order to reach ever closer to “a world without leprosy.”

In other words, I want to make ILA a proactive association relevant to the global needs of leprosy of the times, and responsible in realizing our common goal, thus bringing satisfaction to individual members who, in turn, should feel proud of their membership in the association.

Am I too ambitious? I do not think so. I believe we could and should try to create such an association, in the name of ILA.

## Keynote Address at 21<sup>st</sup> Biennial Conference of the Indian Association of Leprologists

Dr. Yo Yuasa

President  
International Leprosy Association

Good morning, honorable guests, my colleagues, ladies and gentlemen:

I feel extremely honored to be invited to what is undoubtedly one of the most important meetings in relation to leprosy work in the world, since you are, as a group, responsible for looking after nearly 70% of the current global caseload of leprosy. Further, I feel it is a great privilege for me to be given an opportunity to speak on a subject of my own choice related to leprosy.

As most of you know, I am not a leprologist as such and I have no special message of scientific importance for you this morning. Instead, I have chosen a topic that is becoming rather fashionable with everyone involved in leprosy nowadays, which is the expression “Elimination of leprosy.” Even though I myself was responsible for its use in the early days, in 1989, I am becoming

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“Elimination of leprosy—What should it mean and what should we do? A personal view,”  
Chandigarh, India, September 1999, printed in *Indian Journal of Leprosy*, Vol. 72 (2000)

more and more concerned with the usage of that term now, because people seem to be using it without full understanding of what it means, or rather what it should mean.

I am sure that all of you are aware of the difficult task ahead of us, even to bring down prevalence or incidence of leprosy to a level we think tolerable, which is far from elimination or eradication of leprosy in the scientifically accepted sense.

Some points I raise are likely to be rather controversial. My intention is not at all to persuade you to accept my personal view, but rather to draw your attention to some issues that I think are important enough to merit some careful thinking, some constructive discussion, and, if possible, some consensus building among our colleagues working in various areas of leprosy.

## 1. Elimination of leprosy

WHO is now proposing to form a “Global Alliance for the Elimination of Leprosy” for a period of six years from year 2000 to 2005. This is a sort of extension of the current global leprosy elimination program that started in May 1991 with a historic World Health Assembly (WHA) resolution and is supposed to finish by the end of 2000. Perhaps you will recall that the 15<sup>th</sup> International Leprosy Congress in Beijing had “Working toward a world without leprosy” as the main theme. Both sound nice and grand, like battle cries. But for those of us actually engaged in leprosy work, much more precise definitions of what those terms mean are necessary. I needed to clarify my own thoughts on that subject, and I thought they might be of interest to you as well.

Of course, there is no doubt that any disease adds burdens to the

community as well as the individual concerned. Therefore it is quite natural that people in general wish to get rid of any disease that afflicts them, if at all possible, just as people talk loosely about a world without war or elimination of nuclear weapons.

However, very few of the diseases actually become a target of some serious international undertaking because elimination of a disease, meaning a zero incidence, is quite a substantial undertaking, involving huge amounts of resources. Therefore, before attempting to eliminate a disease, the economic implications need to be considered very carefully, apart from the more obvious medical and social consequences.

We have managed to eradicate, which is permanent elimination globally, only one disease so far, namely smallpox. The economic advantage of that was quite overwhelming, because it made annual expenditure of the several hundred million US dollars needed for global vaccination unnecessary. Similar calculations are much more difficult and complicated for most other diseases, because the cost of dealing with the diseases as well as the economic loss due to the diseases are not so simply expressed in monetary terms. The latter is usually calculated in terms of productivity loss to the community due to early death or deformity-related incapacities, and expressed in such terms as DALY, disability adjusted life years. Of course, there are the actual costs of dealing with the disease itself, including case finding, drugs and patient care.

What is the advantage of eliminating leprosy from a macroeconomic point of view? Probably not very great, because the risk of the general population developing clinical leprosy is fairly small, and of course there is also the almost universal availability of MDT (multidrug therapy), which effectively cures the majority of patients. Beside, broadly speaking, the disease usually occurs in the less productive population in relatively less productive countries of the

world, unlike other diseases such as TB or AIDS, which could involve the most productive people in the most productive countries. So an economic consideration alone does not encourage us to undertake the expensive attempt to eliminate leprosy.

Of course, even before economic considerations, there is the matter of technical feasibility. Do we have an adequate knowledge about leprosy, and do we have effective tools in our hands to eliminate leprosy? We must, at present at least, give negative answers to both, although they will undoubtedly come sooner or later. Well, we do not have the means to eliminate leprosy at present, and we think there is not much economic advantage in doing so, even if it became feasible. So is that the end of our argument, concluding that elimination of leprosy is really a nonstarter?

Before proceeding any further, it is better to agree, at this point, on the definition of the term "elimination." WHO had sponsored an international conference in Atlanta, Georgia, in February 1998, involving more than 40 experts from all over the world, on the theme of global disease elimination and eradication as public health strategies. This meeting was preceded by a preparatory meeting on the eradication of infectious diseases with 40 experts gathered in Berlin, Germany, in March 1997 for the 81<sup>st</sup> Dahlem workshop. In that meeting, they defined four stages of medical intervention in dealing with a disease, namely, control, elimination, eradication and extinction. "Elimination" is zero incidence of a disease in some part of the world at a given time. Polio has been eliminated in different parts of the world up to now. "Eradication" is permanent zero incidence globally, and smallpox is the only example we have managed to achieve so far.

"Extinction" means the total disappearance of a causative organism, thus humankind is forever freed from that particular infection. Both the American

and Russian governments officially, and possibly someone else clandestinely, still keep variola viruses, but when they are all destroyed—originally planned for this year as far as the Americans and Russians are concerned— we could say that smallpox had become extinct.

Any other interventions, however massive or widespread, are termed “control.” “Elimination as a public health problem” of leprosy, or lymphatic filariasis, or Chagas disease, all proposed by WHO, belong to the “control” category. The most important feature of “control” is that as soon as there is a relaxation of the intervention, the disease could come back and in a few years or in a decade or two, depending on the nature of the infection in question, the situation could be just as bad as when the control effort started, or even worse with a drug-resistant strain of pathogens becoming dominant.

The use of the term “elimination” of a disease, unless it means zero incidence, however clearly and carefully defined, has the inherent danger of being misunderstood by the public and even by the health authorities, leading to a false sense of security. “Elimination of leprosy as a public health problem by the year 2000” is a very good example, and the matter of our immediate concern.

Naming an intensive control effort to bring down the prevalence rate to less than 1 per 10,000 as an “elimination” and putting a target date of the year 2000 was a brilliant marketing maneuver by LEP/WHO. They succeeded well in selling the program to normally reluctant or uninterested health authorities of many leprosy-endemic countries and having them join the global campaign by adopting WHA Resolution 44.9 in May 1991. This opened a window of opportunity for us to do far more than we are normally able to do so, using health resources far in excess of what leprosy would normally attract in traditional health services rankings. It is probably good to remind

ourselves that no health services are in possession of resources adequate to do all they want or even need to do. A special emphasis on a single disease is likely to come at the expense of some other disease.

Many health authorities did a very good job indeed, and the number of countries whose leprosy prevalence rate was nationally above 1 per 10,000 came down from 122 to 29 last year and is likely to be down to 12 to 15 by the end of the next year. What now deeply concerns me is that when that goal of a prevalence of less than 1 in 10,000 is achieved, and leprosy becomes no longer a public health problem by WHO's own definition, health authorities of those countries which managed to reach the target have a legitimate excuse or even justification for neglecting leprosy work after that. Should we complain about that? We certainly cannot allow that to happen, but we must learn to deal with leprosy within a context of general health services. We used to complain about inequality, meaning leprosy getting less attention than many others. But equality also means getting no more than others. We must be careful not to demand too much if leprosy workers wish leprosy to obtain a rightful place within the general health services.

Unfortunately, your country, India, is one of those 10-odd countries that require several more years of intensive activities even to reach that goal, which, as I have mentioned already, is only a good control and far from true elimination as defined by those two authoritative meetings. Even to sustain that elimination of less than 1 per 10,000 at the national level, let alone to make further reduction in prevalence calls for a considerable effort, and you yourselves are much better than I am at predicting what is likely to happen to the leprosy situation in India, say in 10 years or even in 50 years from now.

For your information, Japan had only five indigenous new cases, and six imported cases last year among 120 million population. However, no one

in Japan dares to predict when leprosy will be eliminated. Since practically all indigenous new cases in recent years are in their 50s, 60s or even 70s, indicating that they were most probably infected in their youth, but developing the clinical disease now in their old age, it may take another 20 or 30 years for leprosy to disappear even in Japan.

By the way, at that Dahlem workshop 21 diseases, such as measles, polio or Guinea worm were considered to be potentially eradicable. Leprosy, together with 26 other infections, was considered currently non-eradicable. Reasons given for leprosy are inadequate interventions and inadequate diagnostic tests. Non-human reservoirs, which were cited for many other diseases, were not mentioned for leprosy.

Coming back to where I started—the question of whether leprosy should be eliminated—I am curious just how many of you say “yes” and how many “no,” even if necessary technologies are developed. My own answer is a firm “no” and I hope you will understand the reason why by the end of my presentation.

It is not at all easy to rank various diseases in terms of their priority from a public health point of view. However, no health authority is likely to put leprosy very high on a priority list, let alone making it within the top three or even top five.

So what should we do? Shall we be satisfied with relatively good control, say a national prevalence or incidence of 1 per 100,000, or try to do more? I just said “no” to elimination of leprosy as such. But I am a very strong believer in doing ever better control of leprosy in order to lessen and perhaps to eliminate as much as possible problems, both medical and social, related to leprosy. I hope you can see the difference between actively trying to eliminate leprosy itself, and trying to solve all problems associated with leprosy so that

it will become a relatively harmless infection to the extent that there is no real urgent need to eliminate it. In my view, the latter course of action has a much better chance of succeeding and there is an infinitely better justification for pursuing it.

We already have quite a good tool to cure the disease, in the form of currently-utilized MDT, and we have several more drugs in our hands that may improve the efficacy of chemotherapy in the future. Early case finding and complete chemotherapy are undoubtedly contributing to the prevention of deformities significantly, although it is not easy to give figures. More specific prevention and control of nerve damage is still a big challenge for us, but there is no reason to doubt that we can do a better job in the future. Similarly, case-finding technologies could improve. Prophylactic vaccine or chemotherapy are definite possibilities, although only for a limited number of people among the risk group. Prevention and care of leprosy-related deformities are improving. Socioeconomic rehabilitation and empowerment of persons affected by leprosy are getting more attention.

The solving of leprosy-related problems could be achieved by the sum total of all of these efforts, already taking place and being improved. Much more is needed, of course, but unlike elimination of leprosy itself, elimination of leprosy-related problems, both medical and social, are infinitely more 'do-able' jobs with tools already in our hands or likely to be available in the future. That is why I say that we should put all our effort in solving leprosy-related problems, rather than dreaming of or worse actually consuming a large amount of resources attempting to eliminate leprosy itself. Besides, there is a small additional point. If you keep mentioning the necessity of eliminating leprosy, people in communities could easily get the wrong idea that leprosy is such a terrible disease that it cannot be allowed to exist, enhancing and

perpetuating wrong notions such as “leprosy is incurable”—precisely the opposite of what we are saying nowadays.

## 2. History of leprosy

There is another very compelling reason, at least in my view, why an attempt to eliminate leprosy itself is not justified at present. I realize that this view of mine is a very controversial one, not readily acceptable to many, but let me try to explain.

The most important reason for me in advising not to try to eliminate leprosy itself at present is that I strongly feel there is still an important unfinished task for us that must be accomplished before leprosy disappears altogether, one way or other. That task is for all of us to learn from the history of human behavior toward leprosy and its sufferers—which, in a word, was shameful—and to change our own behavior, not only toward people affected by leprosy, but to anyone belonging to minorities, anyone different in appearance from us, and indeed anyone we instinctively consider not belonging to us for whatever reasons.

I am sure that all of us are horrified with so-called “ethnic cleansing” that is being repeated in so many parts of the world nowadays. The wholesale, frightfully efficient killing of millions of Jews during World War II was the most well known and universally condemned act of this kind. I am sure many people thought that event must be the last example, and mankind would surely not repeat such inhuman deeds again. That naïve trust in human nature has been broken many times already. Recent events in the Balkans, first in Bosnia Herzegovina and more recently in Kosovo, or what happened in Rwanda and elsewhere in Africa, indicate what men are still capable of doing to fellow

human beings, even now, 50 years after witnessing and condemning the Holocaust.

Apparently we are capable of disassociating ourselves from these horrible events. We say it was the Nazis who were responsible for the Holocaust; it was Serbians who attacked Albanians; Hutus and Tutsis who were killing each other.

So are these acts limited to those people, being provoked by some historical reasons? I do not believe that. I think they are merely some overt examples of what all of us are capable of doing under certain circumstances. In other words, they are manifestation of basic human nature common to us all, throughout history and everywhere on this Earth.

To me, the best example of this inhuman behavior is very close to us, which was and still is the common man's attitude toward leprosy and its sufferers. It is remarkably consistent wherever one goes on this Earth and has persisted through different ages of our history. Of course, manifestations of this behavior are not as spectacular as recent cleansing events. But they are very insidious and the damage they inflict on the victims are just as devastating.

When someone develops leprosy, that person who has been a friend or a neighbor up to then suddenly becomes a person completely different from the rest of the people in a community. As terms such as people who dwell "without the camp" in old English usage or "Aussatzigen" even in modern German, clearly indicate, a person with leprosy becomes a total alien, no longer a regular member of the community to which that person had belonged. They became an outcast.

In practically any culture or under any religion, leprosy has been considered as a sign of God's wrath or disfavor, so that the person with the disease has to be regarded as a condemned person, to be avoided. I believe

it is the result of an ill-attempted effort of our ancestors to justify their own behavior, which even to them was not that easily acceptable, and they must have felt extremely ill at ease with themselves. It was provoked by facing a mysterious change in the appearance of a person, for which people did not have any rational explanation. What they did not understand, they feared, and what they feared, they wanted to isolate and cast away from their own community. Heavenly punishment must have been a readily acceptable explanation, or in fact an excuse.

Rejection of something different is a common and basic biological instinct. Preservation of the status quo is the key to biological survival of both individuals and the species. The human body shows that quite clearly. It has a powerful and usually quite efficient immune mechanism, so that if something considered to be alien or foreign comes into our body it is immediately attacked, destroyed, and cast out. For the preservation of our body this mechanism is essential and normally works well. I believe there is a similar mechanism at work in our mind, dictating our normal behavior. Here I believe the effect is quite negative, if our normal behavior toward a different-looking person is to shun or even to destroy.

We are supposed to be superior to the rest of the animals by possessing intellect. The degree of our advance from the primitive stage of cavemen must be judged by the extent to which our intellect has control over our basic or primitive biological behaviors, one of which as I have just mentioned is an instinctive rejection of something seemingly different in appearance.

Modern human beings at the threshold of the 21<sup>st</sup> century should be much better masters of our own behavior. We should be able to see inside an apparently different outward appearance. We should be able to see in a person affected by leprosy a normal person exactly the same as us with feelings,

aspirations and sensitivities no different from our own. Although the physical condition due to leprosy needs medical care, the real person inside that body needs our fellowship as an equal partner in life.

Religion used to a powerful tool for dividing people into Hindus, Buddhists, Christians, Moslems, etc. But in the last several decades, there are remarkable ecumenical or inter-religious movements, overcoming differences, although as recent global events show that kind of harmony is still fragile. Nationality too was and still is a powerful cause for dividing people. But with the League of Nations, United Nations, European Community and others, we are learning to do away with national differences. All these are group activities with some outstanding leaders showing the way for the rest of the members in the group. To change one's personal attitude toward other persons has to be done individually by one's own efforts. So can we do it? I certainly hope we can, provided we acknowledge first the existence of such a problem, and consciously work to remedy the situation.

All of us here are engaged in leprosy work. As a profession we are very close to people affected by leprosy. Let us consciously learn to be their equal. That is altogether different from being kind or helpful. It is not difficult for persons feeling superior or more powerful to be benevolent to persons considered to be inferior or weaker. To feel equal to another person is in fact not that easy even among normal people who do not have leprosy or any other handicaps. But if all of us manage to regard every other person as equals and behave accordingly, we may achieve an even greater victory than the elimination of leprosy itself; we may in fact contribute significantly to creating a truly friendly and peaceful world. Working closely with people affected by leprosy, I believe it is our duty to lead the world in this human revolution. We know what had happened, or even now is happening to persons affected by leprosy.

Too many of them suffered for too long. We owe them a debt to learn from that mistake and put things right.

The International Leprosy Association has started a “history of leprosy” project. It aims not only to document spectacular medical achievements of recent years, but also to collect and preserve those records of sufferings due to the inhumane behavior of ordinary men and women, so that all of us now and our future generations to come will be able to learn a valuable lesson.

Leprosy may disappear in one way or other, but there are bound to be other newly emerging diseases that will play the same role as leprosy. AIDS is sometimes called the modern leprosy, not because there are any similarities between them, but because its victims are often feared and rejected, just like leprosy patients. We have a responsibility to prevent that from happening. To learn from the history of leprosy is not only to change our attitude toward a person affected by leprosy, but also as I have tried to explain above, to learn how best to behave toward anyone seemingly different from us that our basic instincts tell us to be wary of and avoid. Before being a leprosy worker, we are all human beings, and we should learn how to face fellow human beings, whatever their appearance.

Well, that is all I wanted to say this morning. To put it in a nutshell, I am advocating that we put all our professional energy into eliminating medical and social problems related to leprosy, rather than attempting to eliminate leprosy itself, which is our task as leprosy workers. But we are more than leprosy workers. We are, first of all, human beings or citizens of the world. As such, I think it is extremely important for all of us to learn from the shameful history of our handling of leprosy in the past, so that we will know how to live harmoniously on Earth, treating everyone on equal terms and establishing a peaceful world. Thank you for listening.

# Sasakawa Memorial Health Foundation and The Nippon Foundation

Their Contributions to Leprosy Work, 1975-2000

Dr. Yo Yuasa

Executive and Medical Director  
Sasakawa Memorial Health Foundation

Mr. Ryoichi Sasakawa, president of the Japan Shipbuilding Industry Foundation (JSIF), who always showed deep concern for the global leprosy situation out of his personal childhood experiences, started systematic financial support for the global leprosy program in two ways in 1974. First, he created a leprosy-related NGO named Sasakawa Memorial Health Foundation (SMHF) in Tokyo, Japan, in commemoration of his 75<sup>th</sup> birthday, with full financial backing of JSIF.

Then, following some advice from a member of the SMHF board, he approached WHO with an offer of US\$1 million for leprosy. The global smallpox eradication program was at the closing stages, but WHO was lacking the necessary funds at that time. Dr. H. Mahler, then WHO director-general,

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WHO informal consultation on the development and implementation of MDT over the last 25 years, Geneva, Switzerland, 22 June 2001

requested that 50% of that US\$1 million be given to smallpox eradication, while accepting the remaining half for leprosy—with considerable hesitation, in his own words, for he was not at all confident that WHO could show some positive result with that fund. There was no exchange of MOU or any other written agreement. It was based only on a verbal commitment, but remarkably that contribution has continued for over 25 years up to now, not only without interruption but also in a steadily increasing amount.

Thus did Mr. Sasakawa initiate a two-pronged support for solving global leprosy problems, using the same source of funds, and this turned out to be a very good strategy. It is perhaps worth noting the absence of the word leprosy in the name of SMHF, reflecting the basic idea of treating leprosy within a context of general health problems from the start.

The initial grant for leprosy in 1975 out of the US\$1 million (US\$1.004 million, to be precise) was US\$502,000, at a time when WHO's regular budget for leprosy was only around US\$300,000. The WHO budget for leprosy has remained at more or less the same level over the last 25 years, while JSIF's contribution increased to US\$1.5 million in the following year and eventually to US\$4 million. JSIF, which is now called The Nippon Foundation (TNF), even made an additional contribution of US\$50 million for the purchase of MDT drugs for global distribution through WHO from 1995 to 1999. At the inauguration of the Global Alliance for the Elimination of Leprosy (GAEL) in November 1999, Mr. Yohei Sasakawa, a son and the successor to Mr. Ryoichi Sasakawa, announced that TNF would make a further contribution of US\$24 million over the period up to 2005.

WHO, as a part of the U.N. structure, has a readymade access to, as well as technical expertise over, the health authorities of leprosy-endemic countries, although sometimes it has to overcome cumbersome bureaucratic procedures

that take time and is bound by age-old precedents, making its actions rather rigid and inflexible.

SMHF, on the other hand, as an NGO, has much more freedom and flexibility in its actions and, by becoming a member of ILEP (International Federation of Anti-Leprosy Associations) from the very beginning, became part of a global network, which made entry into a number of leprosy-endemic countries, especially those in East and South East Asia, easy.

In the second half of the 1970s, when SMHF began its work, there was not much actual collaboration between the Leprosy Elimination Program, or LEP/WHO, and SMHF in terms of the field projects they supported; however, the fact that the medical director of SMHF acted as a de facto liaison officer concerning JSIF's annual contribution to WHO made an understanding of each approach much easier.

Each year, he was invited to Geneva by LEP/WHO to discuss the possible utilization of the JSIF contribution and assisted LEP/WHO in analyzing, planning and drawing up a letter of request to JSIF for the following year to be sent with the director-general's covering letter to Mr. Ryoichi Sasakawa. Without any functioning national leprosy control program in most leprosy-endemic countries, utilization of US\$1 million was not easy at all. In fact, in the late 1970s, when JSIF suggested doubling their annual contribution to US\$2 million, Dr. H. Sansarricq actually refused to accept it, saying that he could not take responsibility for its effective use. The working relationship became much closer in 1982 in terms of actual collaboration between LEP/WHO and SMHF after the publication of the report of the Chemotherapy Study Group Meeting of 1981 on MDT, because SMHF's financial support to leprosy-endemic countries became concentrated around MDT implementation in those countries. Dr. Sansarricq also said he could now accept a larger donation

from JSIF and from then the amount was increased to US\$4 million annually.

SMHF supplied dapsone to countries such as the Philippines, Indonesia and Myanmar. Myanmar was facing difficulty due to the withdrawal of UNICEF, which had supplied it with dapsone over a 10-year period. SMHF took over that responsibility, until the recommendation on MDT by WHO was published, when the supply of drugs was switched from dapsone to MDT.

One opportune and significant undertaking was the conducting of international Joint Chemotherapy Trials on lepromatous leprosy, involving experts and patients of the Philippines, South Korea and Thailand. This was in response to the recommendation of the International Workshop on Chemotherapy of Leprosy, organized by SMHF in Manila in 1977, in face of impending disaster due to the spread of dapsone resistance in the field.

It was at about the same time that WHO started action for the same reason, by creating THELEP (the Working Group on the Therapy of Leprosy), which became a core member of TDR (the Special Programme for Research and Training in Tropical Diseases). The involvement of a few key members of the THELEP group in the SMHF Joint Chemotherapy Trials was most beneficial.

In terms of actual scale, the trials were much more modest and the combination of drugs used was very much restricted. One contribution these trials made, however, of which SMHF was quite proud, was the annual standardization workshop held at the Leonard Wood Memorial Laboratory in Cebu, the Philippines, for doctors and lab technicians not only of the three countries directly involved in the trials but also for those of other countries such as Vietnam, Indonesia, Myanmar and Nepal.

When the WHO recommendation on MDT was published in 1982, three countries, to different degrees, knew what MDT meant, and some field workers had firsthand experience of MDT implementation, although the

actual regimen recommended was different from what they had known. One of the main reasons for these countries to start implementing MDT fairly early and smoothly, compared to the rest of the leprosy-endemic countries in other parts of the world, was undoubtedly due to their involvement in this project.

Another, perhaps more decisive, reason for these countries to start implementing MDT successfully was an offer from SMHF to supply MDT drugs rather than dapsone. From the very start, SMHF's policy was to supply MDT for multibacillary (MB) leprosy for two years only. We clearly stated that whatever extension they wanted beyond two years, mostly until BI negativity, had to be using drugs from other sources and not ours.

One interesting episode related to this was that the then health minister of Indonesia, Dr. M. Adhyatma, who was the only known former head of leprosy services to be elevated to that position, requested permission to use MB MDT for one year only. His reason was that there were so many MB cases that would otherwise go without any MDT. At that time, SMHF did not agree, but with the hindsight, if we had agreed to his idea at that time, Indonesia could have been the first country, around 1985, to use the 12-month MB regimen, a year ahead of the rest of the world.

This supply of MDT drugs by SMHF to up to 20 countries in the world during the late 1980s and early 1990s continued until 1995. This is when the extra contribution of US\$50 million from TNF started providing the required amount of MDT globally, so that SMHF's need to fulfill this function ceased.

Initially, Dr. H. Sansarricq and later Dr. S. K. Noordeen, head of LEP/WHO, and SMHF/TNF could work together very closely for common objectives. Dr. H. Nakajima, first as regional director, WPRO, and later as WHO director-general, was very much behind the MDT program, reflecting

his previous positions, and his understanding and cooperation were a great help in SMHF/TNF's collaboration with LEP/WHO. We jointly planned to have the first International Conference on Elimination of Leprosy in Hanoi, Vietnam in 1994, which was followed by a second conference in New Delhi, India in 1996 and a third conference in Abidjan, Cote d'Ivoire in 1999, which was the start of GAEL (the Global Alliance for the Elimination of Leprosy).

TNF's contribution covered a major portion of the leprosy budget of WHO in each of the 25 years since 1975. Without that contribution, the global leprosy situation might be quite different from what it is now. As stated already, SMHF, after 1982, channeled the major portion of its financial support to leprosy-endemic countries, under categories such as training, monitoring, transport facilities, and equipment, to support MDT implementation in the countries concerned.

Perhaps it is useful to point out that SMHF, although it is an NGO and a member of ILEP, decided from the very start to support the leprosy control program of the national health authorities and avoid starting its own field projects or supporting projects of other NGOs. This principle was based on the belief that the national health authorities were ultimately responsible for the health of their citizens, and support from outside, whatever the extent or however long, could never meet the needs of the whole nation permanently. In other words, SMHF always tried to strengthen national capability so that even when its support came to an end in the future, the national program would be better off than before. In the 1980s, SMHF's support had some provisional time limit, in the order of three or five years. After 1991, its support was until the elimination target was achieved by the national health authorities.

## 2002 Damien-Dutton Award Acceptance Speech

Dr. Yo Yuasa

Mr. Crouch, president of the Damien-Dutton Society, Mrs. Deeley, chairperson, distinguished officers and members of the board, ladies and gentlemen:

My wife and I are most grateful for your kind invitation to be with you today. Mr. Crouch wrote me a letter early in June this year, simply announcing your decision that I was to be given the Damien-Dutton Award for this year, the fiftieth since it started in 1953. The news came totally out of the blue and I was quite stunned.

I learned of the existence of this award way back in 1958, when the 7<sup>th</sup> International Leprosy Congress was held in Tokyo, and Dr. H.W. Wade, then the president of the International Leprosy Association, was given the

award during the closing ceremony. As I was acting as a liaison between the International Leprosy Association officers and the local organizing committee, I had to invite a bishop from Yokohama to make the award presentation. That congress was the start of my career in leprosy, although I still had a long way to qualify as a medical doctor.

I am not at all convinced that I deserve this prestigious award, the highest recognition a leprosy worker can receive. I feel that the only justification for my accepting it is not as a reward for whatever I have done in the past, but rather as an encouragement or even an enticement for me to do further work in leprosy, which I am happy to oblige. I am certainly honored to be counted as one of the recipients of this award, because I have been more than a casual acquaintance of at least 25 of them, starting with Dr. Wade and ending with my good friend Michel Lechat, the recipient last year. I am very happy to have three of the past recipients, Wayne Meyers, Felton Ross and Anwei Law with us on this occasion.

My first contact with leprosy was in 1946 when I visited a Japanese leprosarium where I met two persons: the world-famous Dr. Kensuke Mitsuda and a remarkable patient, Mr. Fumio Tanaka, whom I consider to be one of the pioneers in social rehabilitation, at least in Japan. After being discharged from the leprosarium in the 1970s, he entered a mayoral election in his own home town in spite of obvious residual deformities due to lepromatous leprosy, narrowly losing by only a small percentage of the total votes. They introduced me to a world of leprosy and opened my eyes and heart.

I owe many people for what I am today, including the above two Japanese, but I would like to mention only four more names this morning: Dr. Wade, Dr. Muir and Dr. Ross Innes, who actually persuaded and helped me into the medical aspects of leprosy work after the congress in Japan, and Dr. Stanley

Browne. Dr. Browne was responsible not only for my joining The Leprosy Mission to work in Hong Kong, then in Nepal, but he later urged me to join a newly created leprosy organization in Japan called Sasakawa Memorial Health Foundation, saying with remarkable foresight that perhaps I could make a greater contribution to global leprosy work. He supported me and the foundation until his last day. Three of the above six received the Damien-Dutton Award. There are many others, of course, who made me what I am now, including three of my dear colleagues who are present here.

But perhaps the person who contributed most to the honor I am receiving today is my wife, Yuko. We were married in 1960 but knew each other for about four years prior to that. During these long years, I have had at least two major failures or crises, entirely due to my own doing, which really threatened my professional future. But Yuko stood fast by me and helped me to overcome the difficulties. Without her support, I am quite certain that I would not be here today. So please allow me to use this public occasion to give my very personal thanks to my wife.

Before closing, let me touch on a subject that is dear to me, the question of the final goal of leprosy workers. For the 15<sup>th</sup> International Leprosy Congress in Beijing in 1998, Wayne, Felton and I jointly came up with a main theme for the congress, which was “Working toward a world without leprosy.” The term was accepted immediately and almost unanimously, and is now being used widely by many people in leprosy work. But even before the closing of the congress, I started having doubts about the appropriateness of that goal. That term, “a world without leprosy,” is commonly used almost synonymously with “eradication of leprosy” by most people. That has to be accomplished by eliminating *Mycobacterium leprae* from the surface of the Earth. My questions were, and still are, “Is that necessary?” and “Is that justifiable?”

Of course, “eradication” is not possible with currently available technology. But this could change, judging from the tremendous advances in scientific technologies and engineering in recent years. However, the development of tools is no guarantee of reaching the goal for which the tools are created. World health statistics show that each year 3 to 4 million children are dying from diseases for which prophylactic vaccines are already available.

Let us go back to the question, “Is eradication necessary?” My answer is “no,” because I am quite confident that with improved case detection and treatment—both of the infection itself and of accompanying nerve damage—we should be able to cure most of the patients and prevent the majority of physical deformities and impairments. Thus, by solving medical problems associated with leprosy, it should not be difficult for us to co-exist with *M. leprae* quite well. The problems of leprosy these days are not so much medical ones, as most of you realize, but largely and primarily social ones, by which I mean negative social reactions to what *M. leprae* does to some of the people affected by leprosy.

By being preoccupied with the desire to eradicate the disease as a medical problem, we are in great danger of neglecting the social aspects of leprosy that, by the way, are entirely of our own making. I am a firm believer that what we have not created, we have no right to destroy, but that we should be 100% responsible for what we have created. What we can do medically for leprosy has already advanced quite well. It is basically dependent on brilliant minds and dexterity of hands, which we do not lack in the world. However, the social aspects of leprosy, which basically are an issue of human rights, dignity of individuals, equal opportunities for self-expression, acceptance of individuals by the community and others, are matters for sensitive minds and warm hearts, which are not found in abundance, unfortunately.

A short summary of my current thinking is that what we should really be aiming for at present, when the successful global leprosy elimination program has amply shown that it is possible to reduce the number of active cases of leprosy infection, is to establish “a world without leprosy-related problems, both medical and social,” with double underlines below the latter. In comparison to our medical successes, our efforts to seriously tackle social problems related to leprosy are still in their infancy, in spite of a gallant pioneering effort by Father Damien and others, now being vigorously pursued by people such as Anwei Law and her colleagues.

At the risk of being misunderstood, or possibly even offending some people, I personally think that the collective sufferings of leprosy-affected persons are something comparable to, if not more than, those of the victims of the Holocaust. The Holocaust was a spectacular manifestation of human evil at one time in human history in one place on Earth and perpetrated by one group of people, thus everyone took notice and it was unanimously condemned. Social injustice, meanwhile, is methodically perpetrated on millions and millions of leprosy-affected persons, occurring more insidiously, throughout millennia of human history even to today, by every group of people, everywhere on this Earth. It has not been so spectacular, however, and thus has not received the due consideration nor condemnation it amply deserves. The problems that urgently need addressing are those of the victimizing just as much as those of the victimized.

Therefore, I now firmly believe that what we really need to eliminate is not leprosy as a disease or *M. leprae* as its causative organism, but the fundamental cause of the social problems of leprosy, which is one of our basic failings. The all too common human prejudice and consequent injustice have caused, and are still causing millions of people to suffer because certain

groups of people are considered different for whatever reason, including being affected by leprosy, which results in their marginalization, persecution, or even destruction.

It is quite natural for us to think of leprosy-affected people as a most severe example of such victimization, but just as being preoccupied with medical aspects and consequently neglecting the social problems of leprosy is wrong, it is also quite wrong for us to forget about millions of non-leprosy affected people currently suffering similar injustices in many parts of the world. However, more important for us to acknowledge is the issue of human dignity that is common to both groups. It is as much an issue for the victimizing groups, which is often not recognized, as it is for the victimized groups. Therefore, when facing problems related to leprosy, we should consider them first of all, as human problems affecting all of us, rather than the specific medical or social problems of the people affected by the disease, requiring only our professional skills as doctors, nurses, physio-technicians, social workers, basic scientists or our other relevant categories of expertise. The solution needed calls not so much for professional expertise, but for commitments of common citizens.

Thus, leprosy workers now have truly unique opportunities to tackle these universal human rights problems, not by doing something for others, but by changing and improving ourselves. It is for the benefit of not only persons affected by leprosy, which admittedly is our immediate concern, but it is for ourselves and for the whole future humanity, if we set our goal right. Our task is enormous, but I trust that most of you would agree that it is our duty, worth devoting our time and energy trying to reach that goal as closely and quickly as possible.

Thank you for your attention.

## Leprosy in Angola

Dr. Yo Yuasa

Executive and Medical Director  
Sasakawa Memorial Health Foundation

The Republic of Angola, a former Portuguese colony, has, since independence, suffered from a series of lengthy civil conflicts and has had a relatively poor health care system in general, compared to the countries in the southern part of Africa, a majority of which were either British or French colonies before their independence. As a result, Angola is one of only six countries in the world yet to achieve the WHO's leprosy elimination target, the others being Brazil, India, Madagascar, Mozambique and Nepal.

The latest official number of registered cases in Angola was 5,245, making the national prevalence rate 3.54/10,000. This indicates some improvement, since in 1973 it was reported to be 5.2/10,000, yet progress has been very slow, casting some doubt on the potential to lower it to less than 1/10,000

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The author visited Angola in August 2003. The article was written for Issue #5 of the *WHO Special Ambassador's Newsletter for the Elimination of Leprosy* (December 2003)

within the two and a half years remaining before the end of the current WHO global leprosy elimination program. Additionally, the deformity rate among newly detected cases was a relatively high 13%, indicating some delay in case detection.

The child rate among new cases was 11.9%. Again this is somewhat high, but considering the young demographic profile of the country, it is perhaps not overly high, although it certainly indicates existing active leprosy transmission.

It was only in 1994, much later than in most other countries, that multidrug therapy (MDT) was introduced. It then became available in all provinces by 1998. At present, 75% of existing health units are reported to have implemented MDT.

One notable phenomenon is the recent increase in case detection. This does not indicate an actual increase in new cases, but is a reflection of an increase in field activities. This resulted in a case detection rate of 12.49/100,000 in 1998, 17.62/100,000 in 2001 and 28.83/100,000 in 2002. This trend will hopefully lead in the near future to the detection of all backlog cases, resulting in a case detection rate closer to the actual incidence rate, which in turn should be much lower than the current figures.

According to the ministry of health's three-year strategic plan for leprosy (2003-2005), three main areas need to be tackled:

1. Training of health staff, so that all health units can implement MDT, improve efficiency of case detection, and achieve higher accuracy in diagnosis and classification.
2. Strengthening social mobilization with better IEC material, so that people will have more interest in and a better understanding of leprosy.
3. Improving POID (Prevention of Impairment and Deformities) and "care

after cure” activities so that fewer patients will suffer from residual physical or social problems.

The ministry would like to accomplish the above through the following methods:

1. Integration of all leprosy control activities into the general health services to improve accessibility to patients, as well as attain sustainability of leprosy activities.
2. Better coordination of all potential partners, especially in view of the existence of the long and committed involvement of NGOs.

It was heartening to observe several excellent medical and social programs, as good as any in the world, being run in Angola by some church-related NGOs; at the same time, in some other areas, armed conflict has nearly destroyed whatever they had in the past, and large numbers of refugees have created additional problems.

As in most developing countries, leprosy is by no means the top priority health issue in Angola. However, because it is a chronic, non-lethal and deformity-producing disease, it remains one of the more serious social burdens, which tends to hinder improvement of national living standards, far beyond the relatively small number of actual cases.

Angola is not a highly developed country, but that in itself should not prevent it from improving health care. With carefully chosen priorities and attention to logistic details, health services can improve. I certainly hope that the health authorities take advantage of the existence of some committed national and international NGOs and try not only to achieve the elimination of leprosy in time, but also to provide improved healthcare for those in need.

# Monitoring and Evaluation of Leprosy Control in the Post-Elimination Era

Dr. Yo Yuasa

Advisor

Sasakawa Memorial Health Foundation

First of all, please allow me to express our foundation's real appreciation to the health authorities of India, who managed to accomplish a vast and significant work in leprosy. They utilized their own large financial resources and manpower and, through effective coordination, secured much support from domestic and international NGOs, particularly the International Federation of Anti-Leprosy Associations (ILEP), and other national and international agencies, especially WHO and the World Bank.

In the 1970s and 1980s, the estimated number of leprosy patients globally was 12 million or more, of which at least 10 million were considered to be in India. Your last published figure for registered patients was 82,801 and although there have been some discussions about that figure, there is no

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WHO/SEARO and NLEP/GOI informal consultation on Monitoring and Evaluation of Leprosy, Chennai, India, 5-6 November 2007

doubt that India managed to achieve the greatest reduction of leprosy cases within the last 15 years. This has assured the entire world that we have now entered a new era in which leprosy can be considered one of many public health problems, to be dealt with primarily by multipurpose health facilities of the general health services and not by a specialized vertical service.

The integration of leprosy activities into general health services in order to ensure wider geographical coverage as well as more regular and frequent contacts by health workers was done at the expense of much expertise of the vertical leprosy service. The introduction of multidrug therapy (MDT) with a time-limited regimen together with simplified categorization of leprosy patients into multibacillary (MB) and paucibacillary (PB) cases made possible the handling of leprosy cases by general health services staff.

Sasakawa Memorial Health Foundation (SMHF) was established in Japan in May 1974 by Mr. Ryoichi Sasakawa, the founder and the-then president of The Nippon Foundation (TNF), known at the time as the Japan Shipbuilding Industry Foundation, or JSIF. Mr. Sasakawa, who had a strong interest in and concern for leprosy patients out of his personal experiences in childhood, was already giving some ad hoc support to leprosy programs both in Japan and abroad. When he approached WHO proposing financial support for the leprosy control program, Dr. Mahler, the-then director-general of WHO, was initially reluctant to accept, since he knew there was no effective way to do leprosy control. But he asked Mr. Sasakawa to use part of his proposed funding for the smallpox eradication program, which was at the very final stage. Mr. Sasakawa replied, saying, "This is WHO's money, so you may use it in whatever way you think necessary." Dr. Mahler greatly appreciated this and used the money to send Jeeps to Africa to distribute vaccine.

From that time, both TNF and SMHF started working for the global

leprosy program as a close working partner of the Leprosy Unit of WHO. SMHF, from the very beginning, had one key policy, which was “not to start any project of our own, but to support the national leprosy control program of the central government where it existed or to support the central government of leprosy-endemic countries to start such a national program.”

This was because of our firm belief that the health of the citizens was the responsibility of the central government and that any work by NGOs, especially from overseas, could never meet all the needs of the country nor would be long lasting. At the time, among the 20-odd members of ILEP, which SMHF joined in 1975, we were the only member that did not have its own program in leprosy-endemic countries, instead giving all our support to the central governments through WHO. We were often criticized or even ridiculed by other ILEP members, who said we were wasting our funds, but we kept to our policy the whole time. As MDT expanded, other ILEP members also started supporting the national programs, which eventually contributed greatly to achieving global leprosy elimination, led by WHO.

Among leprosy-endemic countries, numbering 122 in the mid 1980s, China and India had considered leprosy to be much more than a matter of public health. Both countries equated the existence of leprosy among its citizens as a sign of cultural backwardness. Aspiring to join the industrialized and developed societies of the West, they wanted to get rid of leprosy and so the disease became a political issue.

Under Dr. Ma Haide, who had the rank of vice minister of health and was in charge of “basic eradication of leprosy,” China started on its program even before the introduction of MDT. In 1953, after the communist regime took over the central government, it documented 500,000 cases. The number of cases declined steadily and by 1991 China’s prevalence rate was already less

than 1/10,000. The latest figure now available is 0.03/10,000.

India, I believe under Mrs. Indira Gandhi, also started a leprosy eradication program, although less systematically and with less resources. In 1974, when SMHF was founded, our original area of interest was East and Southeast Asian countries as far west as Nepal and Myanmar, but excluding both India and Bangladesh. However, when Mr. Ryoichi Sasakawa was invited to the opening ceremony of the International Leprosy Congress held in New Delhi in February 1984, our support for India's program started. I have happy memories of discussing, on many occasions, the problems with Dr. K.C. Das, the-then head of the leprosy unit of India. I even had the privilege of spending two whole weeks sharing a car with him and making visits to many leprosy centers between Chennai and Ranchi, including Wardha.

In the mid 1980s, SMHF was supporting more than 30 leprosy-endemic countries in Asia, Africa and Central and South America, in some cases just by providing MDT drugs, but often involving the training, supervision and monitoring of the programs. India, unlike most other endemic countries, had enough leprosy experts of its own, so most of my visits were for observation of what was going on, to learn many points that I could transmit to other national programs.

India managed to eliminate leprosy as a public health problem basically by its own efforts and its own resources. There was a strong demonstration of government leadership and commitment, although undoubtedly the support it received from its international working partners influenced both the timing and quality of its achievements.

As I said earlier, SMHF did not run any field leprosy programs but we were instrumental in coordinating and advising TNF's funding for the global leprosy program through WHO by its technical inputs to the countries.

In the case of India, other than supplying the country's total quantity of MDT from 1995 to 1999, the largest amount of TNF funding for the global leprosy program, made available through WHO, was channeled to India supporting the work of the central leprosy unit as well as work at the state and zonal level as the government of India expanded MDT implementation through its general health service. India's success lies in the government's determination to integrate the leprosy eradication program into the general health system and I must praise the government for its commitment and demonstration of "ownership." SMHF is happy to have been part of its achievement, but we also know that India is a vast and complex land, in effect more than just one nation. Therefore achieving elimination at the national level cannot be the final solution. It still has highly endemic areas as well as areas of much lower endemicity. The fact that the government is now convening this meeting is a proof of its continued commitment. SMHF and TNF have just renewed their continuation of support through WHO to various countries, including India, to sustain leprosy services for some years under the integrated environment.

"A world without leprosy-related problems, both medical and social" is what I have been advocating. I look forward to India showing the rest of the world how to do that, rather than wasting valuable time and limited resources on "leprosy eradication" as such, which to me is not only unnecessary but even unjustifiable.

As to the discussion on "Monitoring and Evaluation of Leprosy Control in the Post-Elimination Era," I am quite happy to leave the matter in the hands of the many internationally recognized experts assembled for this meeting.

There is just one point I would like to make, which is that leprosy will no longer be the subject we have been enjoying over the last 20 years or so. We are a victim of our own success. Leprosy's priority listing among public health

problems is likely to be lower than 20, just like in the 1970s or before, and its implementation agent will be the general health service. Since this meeting is for leprosy experts, you will no doubt be considering what you think is best for the program and for the patients. However, unless you can defend and in fact sell your recommendation in the whole area of public health services, where financial and manpower sources are limited, no actual program can take place.

“Elimination of leprosy as a major public health problem” was started in the WHO’s Western Pacific Region in October 1989, nearly two years ahead of the 1991 World Health Assembly resolution. Dr. Jong-wook Lee, the previous director-general of WHO, who was the head of the region’s leprosy program at that time, and I needed more than one whole day to come up with a suitable title for the program, because we had to sell the idea to health authorities and leprosy-endemic countries in the region. As a rule, 30 or so countries in the region had no particular interest in, and certainly no commitment to, leprosy work. Our sales talk succeeded in that region in 1989 and the same sales talk succeeded in Geneva in 1991. Today, “leprosy elimination” is apparently a dirty word in some leprosy circles, but without that title and without the target, public health programs would not have been mobilized and we could still have several million leprosy cases today.

There is one last point that I would like to mention. Perhaps you are already aware that SMHF considers leprosy-affected persons as working partners of any leprosy program. This is especially so in today’s context, where the number of leprosy cases is decreasing and services are integrated. It is those who have personally experienced the disease, and their families, who can be vital partners in creating a meaningful program. I am not suggesting that every leprosy meeting, especially technical ones, should invite their representatives.

But as this particular meeting is to discuss the post-elimination era agenda, which covers topics such as rehabilitation and patient care, I would have liked to have seen them represented. You will be discussing the “burden” from the viewpoint of people who have or have had leprosy, as you describe in the new WHO Global Strategy. The absence of the key stakeholder will unmistakably be felt. This is especially so in India as we know there are groups and networks of people affected by leprosy already in existence.

Before closing my remarks, please accept our foundation’s best wishes for the success of this important meeting and of the post-elimination program of the government of India.

# A Working Partnership for Leprosy

35 Years of Collaboration between Raj Pracha Samasai Foundation of Thailand and Sasakawa Memorial Health Foundation of Japan

Dr. Yo Yuasa

Advisor

Sasakawa Memorial Health Foundation

## 1. Introduction

It is a great honor and a pleasure to be able to write the following short article to be included in the commemorative publication of the 50<sup>th</sup> anniversary of the Raj Pracha Samasai Foundation (RPSF). This was done in response to the kind invitation of the foundation's Dr. Teera Ramasoota to the president of Sasakawa Memorial Health Foundation (SMHF), Dr. Shigeaki Hinohara, requesting us to submit an article on the partnership between RPSF/Thailand and SMHF/Japan.

I joined SMHF in 1975, shortly after its establishment in May 1974, as its first and only medical director. I retired from this position after 30 years in

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Written in November 2009 for the 50<sup>th</sup> anniversary of Raj Pracha Samasai Foundation, which was established in 1960 under the Royal Patronage of H.M. the King of Thailand

2005 and now act as a part-time medical advisor. Thus I was fully involved in establishing and maintaining our close and productive working partnership with Thai colleagues, represented by Dr. Teera Ramasoota, from the very beginning.

In the 1970s and 1980s, Thailand was one of 122 leprosy-endemic countries in the world, defined by the World Health Organization (WHO) as having more than one case per 10,000 population. However, unlike most developing countries whose national governments had only a weak leprosy unit, if they had one at all in those days, Thailand already had quite an active national leprosy control program, reflecting His Majesty King Bhumibol Adulyadej's royal concern for and commitment to leprosy problems in Thailand.

SMHF of Japan, a country in which the imperial family also takes a deep interest in leprosy, was established in 1974 by Mr. Ryoichi Sasakawa, the founder and the first president of Japan Shipbuilding Industry Foundation (JSIF), now known as The Nippon Foundation (TNF). He was a powerful and rather complex figure—industrialist, financier, philanthropist—whose lifelong motto to live by was “The world is one family; all humankind are brothers and sisters.” He happened to have a deep personal interest in and concern over the leprosy situation in the world, and the welfare of individual leprosy patients, out of his own childhood experience, and he was doing his best to contribute to a solution. On his 75<sup>th</sup> birthday he decided to give more systematic support to global leprosy activities, simultaneously deciding to establish SMHF and to begin contributing, totally unsolicited, quite a substantial amount of funds to the WHO's Leprosy Unit.

Over the last 35 years, Mr. Ryoichi Sasakawa and now one of his sons, Mr. Yohei Sasakawa, have been supporting the global leprosy program through these two channels, using more than US\$200 million in JSIF/TNF funds.

Initially this was to eliminate leprosy as a public health problem, but since 2005 the main focus has shifted to the social aspects of leprosy, in particular the human rights issue of leprosy-affected persons.

SMHF was created to support and strengthen the national leprosy control programs of the central governments of leprosy-endemic countries. This was and still is quite unique among NGOs, because normally these organizations are formed to do some leprosy work of their own, away from government programs. However, the founders of SMHF believed that the health of citizens was a responsibility of national governments. They also thought that the effectiveness of an NGO, especially one from overseas, in solving a long-standing and nationwide problem such as leprosy was rather limited both in terms of coverage and duration.

This meant that in order for SMHF to be effective, we needed someone within leprosy-endemic countries to act as a working partner. In Thailand, thanks to the above-mentioned royal concern and leadership, we could readily find such persons, including Dr. Teera Ramasoota of the Raj Pracha Samasai Institute (RPSI). Dr. Teera was one of the two delegates from Thailand at both the 1<sup>st</sup> and 2<sup>nd</sup> Seminar of Leprosy Control Cooperation in Asia, organized by SMHF in October 1974 and August 1975 in Japan as the first two programs of the newly established foundation. I attended these meetings as a delegate from Nepal, where I was working as a member of The Leprosy Mission (TLM), before joining SMHF as its medical director in December 1975. My friendship with Dr. Teera as well as SMHF's working partnership with the Ministry of Public Health (MOPH) of Thailand and RPSF thus goes back nearly 35 years.

SMHF's actual working partnership with the national leprosy program of Thailand could be described under several headings, as follows.

## 2. Training of leprosy workers

At the 1<sup>st</sup> Seminar of Leprosy Control Cooperation in Asia, organized by the newly-established SMHF in November 1974, a shortage of adequately trained field workers for leprosy was identified as a top-priority concern of all the participating members of the seminar. The participants consisted of program managers of 12 leprosy-endemic countries in Asia, including Thailand; representatives of WHO from both headquarters and the Western Pacific Regional Office (WPRO); and the European Federation of Anti-Leprosy Organizations (ELEP), which is now the International Federation of Anti-Leprosy Organizations (ILEP). It was at the first seminar that the training of leprosy workers was also confirmed as the subject of the second seminar held in August 1975.

One of my first jobs as SMHF medical director, therefore, was to determine how to pursue these training needs in our program and I decided to organize an international workshop on the training of leprosy workers, somewhere outside Japan. I already knew that Thailand had both training experts and excellent facilities, and I was fortunate enough to secure the full cooperation of MOPH. It agreed to be an official cosponsor of the workshop, providing two experts as resource persons as well as an excellent venue at the Asian Institute of Technology.

This proved to be such a useful meeting that two more meetings, the 2<sup>nd</sup> and 3<sup>rd</sup> Workshops on the Training of Leprosy Workers, were held in Bangkok in 1979 and 1982, under the global expert on leprosy training, Dr. Felton Ross of American Leprosy Missions (ALM). All of these training workshops undoubtedly assisted leprosy-endemic countries in Asia to improve and

strengthen their own leprosy training programs for health workers in the field. The English-language proceedings to result from these workshops were quite extensive, containing not only all speeches and lectures but also substantial summaries of various discussions that had taken place. This was done to make the proceedings both an accurate record of what had transpired as well as, and perhaps more importantly, possible teaching and reference materials for leprosy training in any leprosy-endemic country.

These three training workshops are early examples of the effective working partnership between Thailand and Japan through MOPH/RPSF and SMHF for the benefit of leprosy-endemic countries in Asia.

SMHF also assisted MOPH of Thailand by providing scholarships and fellowships, so that many young Thai doctors and other health workers were given opportunities to go abroad for necessary training. Some went to Europe or the United States, others to India, Japan and elsewhere in Asia. A quick check showed at least 98 persons received such financial support in the first 20 years up to 1995. Our records also show that SMHF financially and materially supported quite a number of national trainings on leprosy, for up to 1,000 participants, again within the first 20 years of our partnership.

One of SMHF's popular programs was to send field workers, who normally did not have a chance to go abroad, to neighboring countries to observe how MDT was implemented. Quite a number of leprosy workers from other Asian countries, such as Myanmar, Vietnam and Indonesia, came to Thailand and our colleagues in Thailand assisted us in their training. A similar service was provided to many other leprosy-endemic countries, mostly in Asia.

### 3. Chemotherapy of leprosy

The first chair of the board of SMHF was Professor Morizo Ishidate, who was known in Japan as the “father of leprosy chemotherapy” because of his successful synthesis of Promin in 1946 when he was the head of the Pharmaceutical Science Department of Tokyo University. His achievement was quite independent of the patented Parke-Davis product that Dr. Guy Faget used at Carville in the United States. The chemotherapy of leprosy was thus SMHF’s main concern from the start.

We organized the 1<sup>st</sup> International Workshop on Chemotherapy of Leprosy in Asia in January 1977. Held in Manila, it was the first such meeting in the world where both researchers and field workers sat together to discuss an issue of common concern. We chose the Philippines as the venue because of the presence of the Leonard Wood Memorial Laboratory (LWML) for leprosy research in Cebu, a well-known international center for both the chemotherapy and epidemiology of leprosy.

Consisting of a group of national leprosy program managers of Asian countries and chemotherapy experts of the world as well as representatives of WHO, ILEP and two pharmaceutical companies, the meeting reached a similar conclusion, in essence, to that of the WHO Chemotherapy Study Group Meeting of 1981 that would be held four years later. Namely, it stated that due to rapidly expanding drug resistance, dapsone monotherapy, which had been the global standard up to then for treating leprosy, must be abolished and two or more anti-leprosy drugs must be utilized simultaneously.

Since our workshop could not offer any regimen at that time, it suggested that some chemotherapy trials be undertaken as a matter of urgency. In

response, SMHF took up the challenge and decided to organize Joint Chemotherapy Trials with Thailand, the Philippines and South Korea, with Japanese experts assisting.

In May 1978, in Anyang, South Korea, an international symposium on Joint Chemotherapy Trials was held, setting trial regimens as well as extensive and detailed protocols for the three countries. In order to assist the training of health workers involved, as well as to maintain close technical collaboration on the trials, it was decided to hold an annual standardization workshop at the LWML in Cebu under Dr. Ricardo Guinto, with close technical assistance from Dr. Michael Waters of the British Medical Research Council. Dr Waters was a dapsone therapy expert who had a long association with the Sungai Buloh leprosy sanatorium in Malaysia and was a key member of the Working Group on Therapy of Leprosy (THELEP) of the Tropical Diseases Research and Training Program (TDR) of WHO/WB/UNDP.

The Joint Chemotherapy Trials began in 1979, but before the expected conclusion was reached in 1983, with five more years of follow-up until 1988, WHO in April 1982 published the conclusions and recommendation of the Chemotherapy Study Group Meeting held in Geneva in the previous October. MDT as recommended by the study group became the global standard, regardless of any other trial results, including our own. Our annual standardization workshops in Cebu, which were held from 1979 until 1986, did become very important venues for training both young doctors and laboratory technicians in MDT, however—and not only from the three countries involved in the Joint Chemotherapy Trials but also from many other Asian countries, including Vietnam, Indonesia, Myanmar and Nepal.

SMHF started supplying MDT as early as 1983 in place of the dapsone it had been supplying since 1974, just after it was established, to replace the

UNICEF supply. As a result, many Asian countries could begin implementing MDT quite extensively compared to most other leprosy-endemic countries in the world. In terms of the 44<sup>th</sup> World Health Assembly (WHA) resolution calling for the “Elimination of leprosy as a public health problem by the year 2000,” many of the Asian countries managed to attain that goal ahead of time. Thailand was one of the earliest countries to reach that goal, in 1994. SMHF feels quite proud to have been able to contribute quite significantly to MDT implementation in the world, being involved at some stage and to some degree with around 30 leprosy-endemic countries, especially in Asia but also in Africa and Latin America. Thailand soon became a world leader in MDT implementation.

Our Thai colleagues assisted us in organizing a number of important leprosy meetings, including one of the coordinating meetings of countries—including Mexico, Brazil, Nigeria and Zambia—that were receiving MDT from us in 1991. SMHF was also involved in the chemoprophylaxis of leprosy in Micronesia for some years. We also supported financially the study of relapse after 24 doses of MDT in MB cases at the LWML for some years.

#### 4. Other areas of leprosy control

Although MDT has been the most significant tool in our hands for the elimination of leprosy as a public health problem, there have been many other aspects of leprosy control—from case finding, including contact surveys and school surveys, and case holding to health education of the public and training of field workers and others—requiring our attention.

SMHF’s approach to these problems, as in the case of training and chemotherapy, was the same; first, by organizing international workshops of

leprosy experts as well as national program managers of Asian countries to raise the issues and try to find solutions, and then by assisting the countries according to the recommendations of those meetings.

Thus, SMHF organized five more international workshops on leprosy control, jointly sponsoring them with MOPH. These were: “Role of Voluntary Agencies” (Jakarta, Indonesia); “Community Participation” (Kathmandu, Nepal); “Case-finding and Case-following Methodologies” (Taipei, Taiwan); “Evaluation of Leprosy Control” (Kuala Lumpur, Malaysia); and “Urban Control” (Singapore). At all of these workshops there was at least one regular participant from each country, such as Dr. Teera from Thailand, Dr. Do-Il Kim from South Korea, Professor Le Kinh Due from Vietnam and Dr. Andy Louhenapessy from Indonesia. We soon felt a real partnership and friendship among us whenever and wherever we met at meetings sponsored by SMHF, WHO, the International Leprosy Association (ILA) and others. Sadly, after almost 35 years, only Dr. Teera and myself remain from this original group. To this group of national program managers of Asian leprosy-endemic countries, I would like to add two global leaders of leprosy work in the 1970s and 1980s, namely Dr. Stanley Browne of the United Kingdom, known as “Mr. Leprosy,” and Professor Michel Lechat of Belgium. Both fulfilled such important roles internationally through WHO, ILEP and ILA, and were with us at SMHF-sponsored meetings from the start. Perhaps I should add two more names, Dr. Felton Ross of the United States and Dr. Colin McDougall of the United Kingdom. With such powerful backup, practically all of our meetings, wherever they were held and on whatever aspects of leprosy, were bound always to be useful and followed by publication of the proceedings.

One more notable contribution SMHF made was publication of *An Atlas of Leprosy* with the help of Dr. Guinto of LWML and *A New Atlas of*

*Leprosy* with Dr. Colin McDougall of Oxford. More than 100,000 copies in 10 languages were produced—no doubt a best-seller on leprosy, although they were all given away free.

Apart from organizing nearly 40 international meetings on various aspects of leprosy—more often than not jointly sponsored with WHO of late, and in most of which Thailand has been an important participating member—SMHF's contribution to various leprosy-endemic countries, including Thailand, consisted of supplying equipment, especially vehicles such as cars, motorbikes and bicycles, laboratory facilities such as microscopes, as well as sending leprosy experts from other countries for monitoring and evaluation of programs.

One other specific project on which SMHF contributed to the leprosy program of Thailand was by providing several Japanese experts under Professor Tonetaro Ito of Osaka University to the leprosy epidemiological surveys in Phuket, Mahasarakham and Uthai Thani over a five-year period, similar to the WHO-assisted survey in Khon Kaen.

## 5. Leprosy research

Probably the most symbolic and clearly visible example of Thai/RPSF and Japan/SMHF/TNF collaboration in leprosy during the last 35 years is the Sasakawa Research Building (SRB), graciously named by HM King Bhumibol Adulyadej, on the large compound of MOPH located in Nonthaburi outside Bangkok.

In the late 1980s, there was a suggestion from the Thai side that it would be good if SMHF could make some substantial contribution to leprosy work in Thailand to commemorate the 60<sup>th</sup> birthday of H.M. King Bhumibol

Adulyadej. Around that time, SMHF happened to have a large extra-budgetary fund. It had been given to us by Mr. Ryoichi Sasakawa out of a collection made by his followers and admirers on his 88<sup>th</sup> birthday, a particularly auspicious occasion in Japanese life. Professor Morizo Ishidate was the chair of the board of SMHF at that time. Always very keen on research, he decided to use part of this fund to donate an up-to-date research laboratory, primarily for leprosy, to MOPH of Thailand as a way of expressing our felicitations on the occasion of HM King Bhumibol Adulyadej's birthday.

A three-story building containing a P3 safety-level laboratory attached to an up-to-date animal house to accommodate a large colony of nude mice was completed in October 1998 and opened in the presence of HRH Crown Prince Maha Vajiralongkorn. SMHF financially contributed to leprosy research until a few years ago, as well as covering maintenance costs of the building for the initial eight years. We also supported the work in Thailand with Thai colleagues of Professor T. Ito and Dr. K. Kosaka of the Research Institute for Microbial Diseases, Osaka University, and Dr. T. Hirata of the National Institute for Leprosy Research, Tokyo. They spent a number of years in Bangkok, even after retiring from their previous positions.

A shortage of Thai research staff and technicians hampered the full utilization of SRB for the initial few years, but the laboratory later became an important research center for leprosy in Asia after drastic changes were made based on the scientific advice of two world experts—Dr. Louis Levy of Israel, formerly of the United States and a specialist in the use of mice in leprosy; and Professor Patrick Brennan of Colorado State University, a top immunologist in leprosy. SRB hosted many national and international meetings and workshops related to leprosy research. SRB also was very useful for Thailand-Japan collaboration on HIV vaccine development. SRB now

fully belongs to MOPH of Thailand and how it is used is up to them, but there is an understanding that the facilities will be made available whenever there is a need for leprosy research.

By the way, SRB now offers office space for RPSF, and Dr. Teera Ramasoota often comes to the building.

## 6. Postscript

The foregoing is a brief summary of what SMHF has been doing in leprosy since its establishment in 1974 in Tokyo, Japan. MOPH and RPSF of Thailand have been very close and powerful partners from the very beginning, not only for our work in Thailand, but also for our work elsewhere in the world, especially in Asia.

In 2007, SMHF and TNF were jointly awarded the Damien-Dutton Award, the most prestigious recognition any leprosy worker could wish to receive. We are sure that this was possible mainly because we have been blessed with trusted and friendly partners such as RPSF of Thailand.

We offer our heartfelt best wishes for the 50<sup>th</sup> anniversary of the Raj Pracha Samasai Foundation and look forward to its future development with high expectations.

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In 2010, HM King Bhumibol Adulyadej gave a special audience to a number of leprosy workers of Thailand as well as a few selected foreign NGOs who had contributed to leprosy work in Thailand. SMHF was selected as one of the NGOs and was invited for this royal audience. In 2014, on the occasion of Bi-annual Scientific Meeting for Disease Control and Prevention organized by DDC/MOPH Thailand, SMHF was awarded a plaque of appreciation from HRH Princess Soamsawali for its contribution toward leprosy control in Thailand over the past decades.

## Future Leprosy Works

### What More Should We Do for Leprosy? A Personal View

Dr. Yo Yuasa

Advisor

Sasakawa Memorial Health Foundation

The great success of the WHO-led project “Elimination of leprosy as a public health problem by the year 2000”—even though there were some criticisms and questions and the target date was extended to 2005— has, by curing close to 15 million cases (WHO, 2009) and reducing the global leprosy load from nearly 6 million registered in the mid 1980s to around 220,000 in 2008, given people an impression that a hoped-for “world without leprosy” is near at hand.

The writer of this article, however, is one of many leprosy workers who believe that there are many more things to be done—probably taking as long as 20 to 30 more years—before we reach that hoped-for state, and he now seriously considers that the popularly accepted final goal stated above is

perhaps not an appropriate one and in need of reexamination. The following is a brief review of what has been achieved within the last 40 years since the late 1970s, and proposals on what should be done to achieve a more practical and meaningful goal, which is likely to be a “world without leprosy-related problems both medical and social,” hopefully within the 21<sup>st</sup> century, if not by mid-century.

## I. What Has Happened in the Last 40 Years?

### 1. Declaration of leprosy elimination by the Indian government

According to some ancient documents, leprosy is known to have existed in India for a long time; even today, leprosy and India are inseparable in many people’s minds, given that the country has nearly 70 percent of the global caseload. Mahatma Gandhi, the father of Indian independence, had a deep compassion for people affected by leprosy, personally looking after a patient in Sewagram Ashram near Wardha, in the state of Maharashtra.

Therefore, when the Indian government made an announcement (Noordeen, 2006) in January 2006 that it had “eliminated leprosy as a public health problem,” based on the statistics of December 31, 2005, the rest of the world was astonished and offered congratulations, although not a few people doubted the accuracy of the announced figures of 95,000 cases registered and 161,000 detected during 2005. With India’s achievement, 25 years of global efforts for leprosy control employing WHO-recommended multidrug therapy (MDT) certainly passed the highest peak on our road toward the final goal of leprosy elimination.

India and also China, which used to have nearly half a million leprosy cases when the current communist regime took over the country in the mid

1950s, regarded the existence of leprosy cases among their nationals not only as a health problem but also as a sign of backwardness, considering that developed, industrialized nations such as those in Europe did not have any leprosy. Hence leprosy had to be eliminated as soon as possible by the national government and their efforts at leprosy control have far exceeded pure public health activities.

This is somewhat similar to what happened in Japan before World War II, when it was trying to be the equal of two superpowers of that time, the United Kingdom and the United States. Japan then had hoped to eliminate leprosy by adopting a plan for each prefecture to achieve “no leprosy” status by sending all leprosy patients to national leprosaria for compulsory segregation. Japan could do that because 13 national and three private leprosaria had a combined capacity in excess of 10,000 to accommodate all known patients; India and China, however, did not have such in-patient facilities.

Under China’s communist regime, however, the disciplined population accepted dapson monotherapy quite well and, under the leadership of Dr. Ma Haide, the country managed to reduce its prevalence to quite a low level even before MDT started. In India, meanwhile, even though the high cost of MDT drugs prevented their nationwide implementation for quite some time, the availability of free drugs through WHO in the second half of the 1990s enabled the country rapidly to bring down the number of registered cases and achieve the elimination goal in January 2006

As mentioned previously, India’s interest in eliminating leprosy goes far beyond a public health requirement. Even in the 1980s, under Prime Minister Indira Gandhi, they were talking about leprosy eradication, although they did not have any means to achieve it at that time. Hence the current Indian government could not be satisfied with achieving the WHO-set elimination

goal at the national level and is now working to reach the same numerical target not only at state level, but also at the level of the country's 604 districts. Although the target date has not been officially announced, 2010 seems likely.

The government also seems to have accepted some responsibility for rehabilitation and social integration of cured leprosy patients. Many NGOs working in India, especially those members of the International Federation of Anti-Leprosy Associations (ILEP), have traditionally been interested in the welfare of individual patients rather than in the more public health-minded approach of the government, so that they could take on a larger share of this work in the future. In India recently, as in some other countries, persons affected by leprosy themselves are starting to show both an interest and willingness to work for their own future economic independence and restoration of their dignity and human rights by becoming active working partners with the government's leprosy control program as well as with national and international NGOs.

In the past, leprosy patients of India were regarded as the largest burden in global leprosy work; but in the near future they could be the leaders of a human rights movement of the world's minority groups. Mahatma Gandhi, when asked to come to the opening of a leprosy institution, said he would rather come to the closing ceremony when it is no longer needed. If leprosy work, especially by NGOs and persons affected by leprosy, develops further, someday he would no doubt have blessed them.

## 2. The role of WHO (World Health Organization)

WHO, established in 1948 as the health-related technical unit of the United Nations, had at least one leprosy expert in the communicable diseases control section from 1958. Within a rather limited budget, it gave appropriate

technical advice or instructions to the national health authorities of leprosy-endemic countries or could recruit and send leprosy experts from various institutions as WHO experts to some needy countries for epidemiological surveys, training of national staff, study of the prophylactic effects of BCG, or study of various types of chemotherapy of leprosy with rifampicin and others. However, the Leprosy Unit of WHO could lead global leprosy activities only after the publication of the report in April 1982 of the historic Chemotherapy Study Group Meeting held in Geneva in October 1981 recommending multidrug therapy (MDT) for multibacillary (MB) and paucibacillary (PB) patients (WHO,1982)

As already described in this book, in 1942, during World War II, Promin showed its effectiveness against *M. leprae*, thus hitherto non-treatable leprosy became a curable disease. Many people prematurely believed in the end of the fight against leprosy as a result of this “miracle at Carville.” However, Promin and its effective component dapsone, being bacteriostatic rather than bactericidal, required regular intake over many years, sometimes for a lifetime. This inevitably resulted in irregular or inadequate taking of the drug, which led to the appearance of secondary sulphone resistance by the late 1950s and, by the 1970s, to the appearance of more serious primary resistance in many parts of the world. Thus, there was a danger of this “curable disease” becoming “non-curable” again, and this threatened the total collapse of global leprosy control.

In order to overcome this serious situation, individual chemotherapy experts in various parts of the world started their own research activities. Dr. H. Sansarricq of the WHO Leprosy Unit formed a team of such scientists called THELEP (Therapy of Leprosy) in the mid 1970s and this group, together with IMMLEP (Immunology of Leprosy), soon became the nucleus

of TDR (Tropical Disease Research and Training) of WHO, the United Nations Development Programme and the World Bank.

The Chemotherapy Study Group Meeting of October 1981 was called to study the findings of the THELEP group in order to come up with measures to prevent the spread of drug resistance of leprosy. There was a similar but smaller meeting four and a half years earlier in Manila in January 1977 called the 1<sup>st</sup> International Workshop on Chemotherapy of Leprosy in Asia, organized by a newly-established NGO in Tokyo named Sasakawa Memorial Health Foundation (SMHF,1997). Both meetings came up with similar recommendations to abolish dapsone monotherapy and utilize two or more anti-leprosy drugs simultaneously; but WHO's meeting of 1981 could actually come up with recommended regimens, because they had research data from the THELEP group, while the Manila meeting of SMHF could only suggest some drug trials in the field. SMHF organized and started such trials in South Korea, the Philippines and Thailand involving national leprosy workers and the patients of these countries as well as Japanese experts. SMHF also started annual standardization workshops on MDT implementation, utilizing both the experts and laboratory facilities of the Leonard Wood Memorial Research Laboratory in Cebu, the Philippines. These MDT regimens recommended by WHO for MB and PB groups are still in use now after nearly 30 years, although the length of treatment has been reduced for both MB and PB cases and classification of PB has been modified (WHO,1997).

These time-limited MDT regimens of relatively short duration and the regrouping of leprosy patients into only two categories of MB and PB, rather than the traditional five classifications of Ridley-Jopling, made it possible for leprosy treatment to be handled by the multipurpose field worker of general health services (GHS) rather than by the vertical leprosy unit, which in turn

made it possible for most of the patients in a country to be covered. The MDT regimens, even after being shortened for MB down to 12 months from the original 24-month minimum and, if possible, until BI negativity, turned out to be very much more effective than originally conceived—not only nearly 100% effective in preventing drug resistance, but also actually curing leprosy, even though the regimens are applied all over the world, often in far-from-ideal field conditions. So, by the end of 1980s, many people began to believe in the eventual end of leprosy control with these robust regimens.

In October 1989, the Western Pacific Regional Office (WPRO) of WHO proposed the “Elimination of leprosy as a major public health problem within 10 years,” and it was adopted at the Regional Leprosy Meeting (WHO/WPRO, 1989). Following this, in May 1991 at the 44<sup>th</sup> World Health Assembly, the Leprosy Unit of WHO under Dr. S.K. Noordeen proposed a resolution “Elimination of leprosy as a public health problem by year 2000,” defining elimination as a prevalence of below one case in 10,000 population, similar to the WPRO resolution, and this was unanimously approved by the assembly (WHO,1991). The adoption of the resolution made the health authorities of the leprosy-endemic countries technically and administratively responsible for the first time for seriously attempting to control leprosy by reaching a set numerical target within the specified time frame, though the latter was extended by five years up to 2005. The resolution also introduced an element of competition, because every year in June WHO announced the past year’s achievement country by country, and the ministers of health of leprosy-endemic countries were pressured to do better than their neighboring countries.

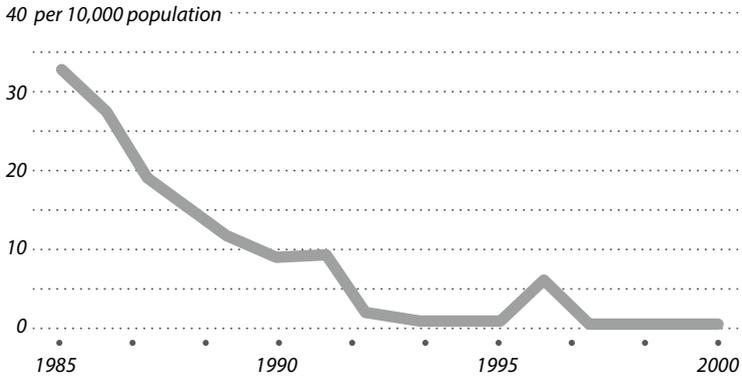
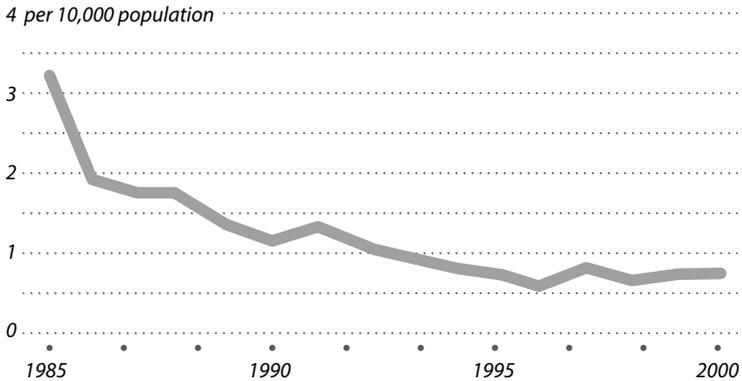
This resolution proposed by the Leprosy Unit of WHO worked very well, bringing down the number of leprosy-endemic countries from 122 in

the mid-1980s to only three today, and curing around 15 million patients with MDT. Moreover, the global figure of leprosy in 2007 is around 210,000 registered cases, down from around 6 million in 1985, and case detection in 2006 was around 260,000. A remarkable achievement indeed and totally unthinkable at the time of the Chemotherapy Study Group Meeting of WHO in October 1981. As a WHO-lead global health movement, this success is next only to the smallpox eradication project (Fenner et al,1988), and was achieved without major financial contributions from the rich industrialized countries, unlike the smallpox project.

**Table 1: New cases reported annually from top 18 countries**

*At the beginning of 2008, the registered prevalence of leprosy globally was 218 605; the number of new cases detected during 2007 was 258 133. The global detection of new cases showed a decline of more than 11 100 cases (4%) during 2007 compared to 2006.*

No	Country	2002	2003	2004	2005	2006	2007
1	Angola	4,272	2,933	2,109	1,877	1,078	1,269
2	Bangladesh	9,844	8,712	8,242	7,882	6,280	5,357
3	Brazil	38,365	49,206	49,384	38,410	44,436	39,125
4	China	1,646	1,404	1,499	1,658	1,506	1,526
5	DR Congo	5,037	7,165	11,781	10,369	8,257	8,820
6	Cote d'Ivoire	1,358	1,205	1,066	NA	976	1,204
7	India	473,658	367,143	260,063	169,709	139,252	137,685
8	Ethiopia	4,632	5,193	4,787	4,698	4,092	4,187
9	Indonesia	12,377	14,641	16,549	19,695	17,682	17,723
10	Madagascar	5,482	5,104	3,710	2,709	1,536	1,644
11	Mozambique	5,830	5,907	4,266	5,371	3,637	2,510
12	Myanmar	7,386	3,808	3,748	3,571	3,721	3,637
13	Nepal	13,830	8,046	6,958	6,150	4,235	4,436
14	Nigeria	5,078	4,799	5,276	5,024	3,544	4,665
15	Philippines	2,479	2,397	2,254	3,130	2,517	2,514
16	Sri Lanka	2,214	1,925	1,995	1,924	1,993	2,024
17	Sudan	1,361	906	722	720	884	1,706
18	Tanzania	6,497	5,279	5,190	4,237	3,450	3,105
	<b>Total (%)</b>	<b>601,346 (97%)</b>	<b>495,773 (96%)</b>	<b>389,599 (96%)</b>	<b>287,134 (96%)</b>	<b>249,076 (96%)</b>	<b>243,137 (94%)</b>
	<b>Total Global</b>	<b>620,638</b>	<b>514,718</b>	<b>407,791</b>	<b>299,036</b>	<b>259,017</b>	<b>258,133</b>

**Graph 1: Prevalence rate from 1985 to 2000****Graph 2: Detection rate from 1985 to 2000**

In fact, the figure of 1 case per 10,000 population has no epidemiological significance for infectious disease control, but a figure of around 210,000 cases globally now from an estimated 10 to 12 million cases (WHO,1988) in the early 1980s indicates that our effort has been in the right direction, and further efforts in the same direction surely will make us reach our final goal.

WHO is now exploring the best way to follow up the successful “elimination” project, including an even more shortened and possibly simplified regimen.

The very success, however, of the effort of the past 15 years has made leprosy no longer a public health problem by WHO definition, at least not a major one. The window of opportunity that opened widely for the leprosy program is now definitely closed, and it is not at all easy for us to find the right place among the health programs of so many health problems.

For us who specialize in leprosy, there is still so much to be done, but as “Mr. Leprosy” Dr. Stanley Browne aptly said at one of the workshops organized by SMHF, we must staunchly resist the temptation to exaggerate the size of leprosy problems within health issues and to demand more than the due amount of resources, financial, material and human. WHO is currently considering how to do the leprosy program in the period from 2011 to 2020, but it seems they have not yet found the right approach, although it is quite certain that in future WHO’s role will become less prominent than in the last 25 years. There could be a possibility that the Leprosy Unit now stationed in Delhi, India under the regional director of the South-East Asia Regional Office (SEARO) goes back to Geneva, but not within CDC but placed under a newly created “Neglected Diseases” section, although the writer considers the name of this section somewhat inappropriate and negative-sounding.

### 3. The role played by the members of ILEP (International Federation of Anti-Leprosy Associations)

Governments normally do not take actions because of the mere presence of problems, unless they have a serious political implication; unfortunately, the presence of leprosy is normally not a political issue. They will act only when there are technical tools to solve the problem and adequate resources—financial, material and human—are available to utilize those technologies. This is quite opposite to the typical response of individuals and NGOs,

who quite often react to the existence of problems, whether or not they are assured of solving them or have sufficient means to do so. Leprosy had been an incurable disease; therefore, health authorities of leprosy-endemic countries were unwilling to do much and put leprosy way down their public health priority settings, certainly below 10<sup>th</sup> and usually below 20<sup>th</sup>, except for China and India as explained in the previous section. Therefore, in most of the developing countries leprosy work had been done by NGOs, mostly international Christian organizations, and the majority of governments in Asia, Africa and Latin America were quite happy to let these NGOs do whatever they wanted from their own perspective, regardless of existing national needs.

After World War II and subsequently, as colonies gained independence, citizens of the former colonial powers were often concerned with the welfare of people in the former colonies, including leprosy-affected persons. In the 1950s and 1960s, many NGOs with specific interest in leprosy were born. Some of these, in the United Kingdom, France, Italy, Spain, the Netherlands and Belgium, as well as in non-colonial powers such as Germany, Luxemburg, Switzerland and the Scandinavian countries, got together and formed the European Federation of Anti-Leprosy Associations (ELEP). This was to avoid duplication of their work in some countries, such as India, and to do an even better job by mutual assistance and exchange of information, even though each had raised funds to cover their own budget within their own country and each had their own board of directors and medical committee. There were no ELEP projects or ELEP budgets as such.

Among the members were two British organizations that were older than the rest, having been established long before World War II. One was BELRA (the British Empire Leprosy Relief Association), which as the name implies

was looking after the welfare of leprosy patients within the empire. It later changed its name to LEPRO. The other was TLM (The Leprosy Mission, formerly known as The Mission to Lepers), which has been active in India for more than 100 years. Another old member was the Leonard Wood Memorial/American Leprosy Foundation, which had been active in the Philippines since the 1920s. In December 1975, two other organizations, American Leprosy Missions, which separated from the Mission to Lepers more than 60 year ago, and the newly-established Sasakawa Memorial Health Foundation (SMHF) of Japan were admitted to the federation, which changed its own name to the International Federation of Anti-Leprosy Associations (ILEP). At its peak in the 1980s, ILEP had more than 20 members, including some from New Zealand and Canada, and its combined budget was around US\$80 million a year, which was probably greater than the combined leprosy budget of leprosy-endemic countries in the world.

Since ILEP members' primary interest was welfare of individual patients and their family members, the large amount of money they spent during these years unfortunately did not have much effect on the strengthening of the public health activities of the governments of leprosy endemic-countries in the world. The only exception was SMHF of Japan. It was established primarily to strengthen the national capabilities of leprosy-endemic countries to do public health activities, totally avoiding starting its own leprosy program. This made the newly-established Japanese NGO readily acceptable to WHO as well as to most of the leprosy-endemic countries. When MDT was recommended by the Chemotherapy Study Group of WHO in April 1982, SMHF started supplying MDT drugs soon after to many countries, as well as assisting in their efforts to implement MDT. In this way SMHF took a leading role within ILEP in the "MDT for all" movement (ILEP,1994), as a leprosy component

of WHO's "Health for all" initiative (WHO,1978). The Nippon Foundation (TNF), then known as the Japan Shipbuilding Industry Foundation (JSIF) established by Mr. Ryoichi Sasakawa and the parent organization of SMHF, approached WHO headquarters in 1974 at the time SMHF was established with an unsolicited offer of US\$1 million. TNF's contribution to WHO and its support of SMHF have continued ever since. In over 30 years it has financially supported nearly 80% of WHO's leprosy budget as well as close to 100% of SMHF's. TNF has thus been functioning as a very important working partner of WHO, strongly supporting the global movement for the "elimination of leprosy."

Of course, the actual work of global leprosy elimination was accomplished by the hard work of field workers of leprosy-endemic countries. They needed outside support, however, which was supplied mainly by WHO technically, while member organizations of ILEP, other NGOs, mainly TNF, and other bodies such as Novartis supplied it financially. With the relatively smaller role of WHO in future, ILEP could take a leadership role in future leprosy work globally. As mentioned already, however, ILEP is a federation of independent organizations each having its own program and its own budget. Besides, many of the members nowadays have substantial non-leprosy projects. How much ILEP as such could assume a leadership role, vacated by WHO, is therefore a big question.

#### 4. Contribution of ILA (International Leprosy Association)

An international conference on leprosy was organized by the Prussian government in 1897 in Berlin (Jessner,1887), bringing together the top medical experts of the time, including Koch, Neisser and Hansen, to discuss how to deal with an emergency situation caused by the presence of a large

number of leprosy patients—actually only 31—among Russian immigrant workers in northern Prussia. At this meeting, Dr. Hansen was officially acknowledged as the discoverer in 1873 of *M. leprae*, the very first pathogenic organism to be identified as a cause of disease in humans, six years ahead of Koch's identification of *M. tuberculosis*. At this meeting, the need for an international association on leprosy was discussed and an organizing committee was established. Nothing materialized, however—then or even at the following leprosy meetings in Bergen in 1909 and in Strasburg in 1923.

In 1931, Dr. H.W. Wade of Leonard Wood Memorial/American Leprosy Foundation working in Culion, the Philippines, took the initiative to form the International Leprosy Association (ILA) (LWM,1931) in Manila together with his British colleagues in India and some others. The main purpose was to improve communications and exchange of information among mostly Western doctors often working alone in isolated locations in Asia, Africa and Latin America, by publishing a quarterly *International Journal of Leprosy and Other Mycobacterial Diseases (IJL)* and holding an international congress of leprosy every five years. The meeting held in Cairo in 1938 (ILA,1938) became the first congress organized by ILA, although it was designated as the 4<sup>th</sup> International Leprosy Congress following the Berlin, Bergen and Strasbourg meetings. Even though advancement of study and research in leprosy, and publication and exchange of findings and reports were the main purpose of establishing ILA as a medical association, the promotion of control and other activities for leprosy were added to its objectives in its constitution. The membership (ILA, 1988) of the association was not limited to those professionals involved in leprosy research, control and teaching but opened to “those interested in leprosy,” a very broad categorization. At one stage there was a move to limit members to those with a medical qualification,

but this idea was soon dropped. There was also a move to change the term “leprosy” into “Hansen’s disease” or “Hansenology” in the 1970s, mostly by those members in the American continents, but that idea too was dropped, so the term “leprosy” still remains as the official name of the disease for ILA, WHO and the majority of professionals in research, control and training, and for health authorities of governments.

The contributions by members of ILA to global leprosy work up to now have been great, but in the past they have been made by individual members and not by the association as a group. However, the 15<sup>th</sup> International Leprosy Congress (ILA,1998) held in Beijing, China in 1998 had a main theme of the congress for the first time—“Working toward a world without leprosy”—and the congress program was worked out closely with WHO to assist the ongoing “elimination of leprosy” project that was nearing its end. For the 16<sup>th</sup> International Leprosy Congress (ILA, 2002) in 2002, in Salvador, Brazil, ILA as a group made an even more significant contribution by organizing the ILA Technical Forum (ILA, 2002) in Paris, six month ahead of the congress. The recommendations produced by the 16 ILA members, who were easily comparable to any WHO Expert Committee members, formed the main papers of the plenary working sessions of the congress over three mornings followed by panel discussions. On the last day, the general meeting of the members officially adopted ILA Forum Recommendations as ILA Recommendations of the 16<sup>th</sup> International Leprosy Congress. Thus, ILA as a group took the initiative and responsibility for leprosy field activities in addition to its academic and research responsibilities.

Starting from the 12<sup>th</sup> International Leprosy Congress in Delhi, India (ILA, 1984) in 1984, many non-ILA members, mostly field workers, started attending the congress and the 14<sup>th</sup> International Leprosy Congress (ILA,1993)

in Orlando, Florida, in the United States in 1993 was the beginning of the attendance of people affected by leprosy, reflecting the growing recognition that they could be a strong and effective working partner and not just a recipient of relief activities. With less emphasis on public health aspects of leprosy work, due to the successful efforts made up to now, social aspects of leprosy work will undoubtedly increase, hence the importance of partnership with leprosy-affected persons in the days to come.

Considering the broad aims for starting ILA, it seems logical to continue ILA as a working group as long as there are any problems related to leprosy, either medical or social. However, membership of ILA underwent two significant changes in the past. In the 1970s and 1980s, with advances in immunology, micro- and molecular biology, genetics and others, there was a large influx of research scientists, many of them dealing with leprosy bacilli and their components only under microscopes or in test tubes, or with leprosy as a disease only on paper, and not dealing with leprosy patients at all, unlike the original members. The second significant change took place from the mid 1990s due to the departure of these research scientists because there was not enough for them to do in leprosy alone and they wanted to have closer working contacts with colleagues in their own specialty.

The first change naturally resulted in a significant increase in ILA membership while the second resulted in a great reduction in members and thus much less income from membership fees. As a direct result of this quarterly publication of *IJL* became impossible and, in spite of some efforts to have it published jointly with other journals or electronically, publication had to stop in 2005. Current regular members number much less than 200 and some feared that the 17<sup>th</sup> International Leprosy Congress (ILA,2008) held in Hyderabad, India in 2008 would be the last ILA congress. Fortunately,

ILA received an official invitation from the Belgian government to hold the next congress, quite possibly in association with the expected canonization of Father Damien as a saint; so, under current ILA President Dr. Marcos Virmond of Brazil, the association will be functioning in some fashion until 2013, the expected time of the next and possibly the last ILA congress, although not much has been happening so far.

When this writer served as the president over two terms from the Orlando Congress of 1993 to the Salvador Congress of 2002, several new programs were initiated in an effort to vitalize ILA, some successful and others not. One of the most successful ones was the organization of the ILA Technical Forum, as mentioned above, which more or less replaced the WHO Expert Committee, which last met in 1998 (WHO,1998), to analyze the current situation and coming up with evidence-based recommendations on all aspects of leprosy work. Since the next WHO Expert Committee meeting is long overdue and there seems to be no move to organize one, another ILA Technical Forum is certainly needed. Another innovation that was long talked about was a regional rather than global leprosy congress, and in year 2000 an Asian Congress (ILA,2000) organized in Agra, India, took place. Dr. S.K. Noordeen, who became the ILA president, organized an African Congress (ILA,2005) in Johannesburg in 2005. Dr. Virmond is currently hoping to organize an American Congress in Brazil sometime before the 18<sup>th</sup> International Leprosy Congress in Belgium.

One more successful innovation was the ILA Global Project on the History of Leprosy (GPHL)(ILA,2002). Funded by the Nippon Foundation, it was conducted over eight years and based at the Wellcome Unit for the History of Medicine, Green College, Oxford University, after a not very successful start in London. Among its various activities, the establishment of a website and

electronic database of leprosy archives featuring more than 600 institutions, libraries, and individuals is the most valuable product of this project and its maintenance and updating are currently being planned. By the way, another project to publish a recent history of leprosy to cover the activities of the last 60 years, with special attention to the WHO-lead global “elimination of leprosy” project, is currently being undertaken at the Institute of the History of Medicine and Health of the University of Geneva, to be published in 2011 in collaboration with WHO with funding from TNE.

At some stage in the recent past I thought perhaps ILA, with some suitable structure such as the Technical Forum, could assume global leadership of the future leprosy activities of the world. But with dwindling membership, that looks rather unlikely at present.

## II. What More Needs to Be Done to Reach the Final Goal?

As stated previously, the 15<sup>th</sup> International Leprosy Congress organized in Beijing in 1998 was held under the main theme of “Working toward a world without leprosy” and various discussions took place on how to achieve that goal. This was the first time a congress ever had a main theme. However, there was no serious discussion about the goal itself at the congress, nor has there been since. “A world without leprosy” seems to have been accepted by everyone in leprosy now. This writer was personally responsible for choosing that theme and should be happy with this global acceptance. But after only five days in Beijing, however, a doubt as to its appropriateness arose in my mind and at the closing ceremony, the writer, as the president of the congress, said, “Perhaps our final goal should be stated as ‘a world without leprosy-related problems, both medical and social.’” The reason for that was as follows:

“A world without leprosy” strictly should mean not only absence of leprosy as a human disease but also absence of leprosy-causing *M. leprae* from the surface of the Earth, in human or animal hosts or in the natural environment, which is synonymous with the eradication of leprosy. However, not only is it technically impossible to achieve that goal at present, mainly because of the existence of non-human hosts, but it is unlikely to be justified in the future due to the amount of resources required, primarily financial, to utilize whatever technology becomes available. Smallpox eradication was possible because every major industrialized nation in the world—even though there was little actual danger of the disease spreading within their country—was spending millions of dollars annually for preventive vaccination and they wanted that wastage of money to be stopped. Leprosy, however, is a problem of developing countries and of no concern to the rich Western countries; thus, eradication of leprosy is most unlikely to receive adequate funding from them.

Leprosy, in fact, seems to have become a less severe disease, as Dr. S.K. Noordeen stated in one of his talks, because even among MB patients, those with high BI of 4+ or more are rather few in number nowadays. However, leprosy still could be a very serious disease for a few unfortunate individuals, who develop severe and extensive nerve damage with consequent physical disability and disfigurement, which in turn could lead them into severe social difficulty. We therefore must find adequate preventive and curative means for nerve damage as well as lepra reactions and their physical consequences. Early and effective case detection is a must, but perhaps equally needed is a tool to identify the minority of people, perhaps less than 5% of any population, who lack the natural immunity to prevent development of the clinical disease when infected by *M. leprae*. Development of these tools, including an effective and inexpensive prophylactic vaccine, is something we hope to achieve as soon

as possible for solving medical problems related to leprosy in future. All this research requires scientific expertise, well-equipped research facilities as well as adequate funding, which is mostly available in the industrialized countries of the West, where leprosy is not a concern of their citizens.

As for solving social problems related to leprosy, most traditional leprosy workers are rather ill-equipped because they lack both knowledge and skills to deal with them. Therefore, the involvement of social scientists and workers in sociology, psychology, anthropology and other related fields is urgently needed now. The handling of social problems further requires something beyond knowledge and technique, because it is basically an issue of human relationships, which is fundamentally a matter of the heart. That is why the involvement of persons affected by leprosy themselves is essential, because it requires two-way communication between those who give assistance and who receive such help.

Let us go back to the issue of our final goal and the question of whether eradication of leprosy is required, desirable or even justifiable. The writer's personal view is "no" to all these. Leprosy is known to develop in less than 5% of any population that has had exposure to the disease in the past, which probably means 99% of the population in the world. We have no way to identify them at present, but more than 95% of people do not seem to develop clinical leprosy even when infected by *M. leprae*.

Both Nauru Island in the 1920s (Wade & Ledowsky, 1952) and Pingelap Atoll of the Federated States of Micronesia in the 1950s (Salmon N.R. et al, 1972) had a pandemic of leprosy, affecting over 30% of the population, but it was because they were virgin populations as far as leprosy was concerned; there is no likelihood of the existence of other such populations, perhaps with some exceptions among Amazon peoples and a few others.

Of course, no infectious diseases, even serious ones such as smallpox, pest, cholera and Ebola fever, affect an entire population, as a certain percentage of people will always escape unaffected. But having only 5% of the total population affected still makes leprosy quite unique among infectious diseases. This means that not only those severe infectious diseases but also TB, malaria, dengue fever, hepatitis, HIV/AIDS and even common pneumonia are desirable and justifiable targets for eradication, if at all possible, whereas to spend valuable and never-adequate financial resources for health on leprosy eradication is certainly not justifiable. This is why the writer is now strongly advocating the adoption, as our final goal, of a “world without leprosy-related problems, both medical and social” and the discarding of a “world without leprosy,” although some people, including close working partners of the writer, say that the latter is broad enough as well as vague enough to mean many difference things, including what the writer wants.

### III. Future of Global Leprosy Activities beyond 2010

#### 1. Leprosy as a public health issue

As we have seen in the previous sections, “Elimination of leprosy as a public health problem” as defined by WHO is nearly achieved by now. At present, only Brazil, Nepal and East Timor still have not reached the goal set by the 44<sup>th</sup> World Health Assembly, but they are expected to do so within the next two or three years.

However, the numerical target of one case per 10,000 population at the national level was artificially set by WHO for this global project to encourage health authorities of developing countries to commit themselves, and there is no epidemiological justification for this infectious disease control. Whether

1/10,000 is big or small depends on the viewpoint of different individuals, but compared to most other public health problems such as TB, HIV/AIDS, hepatitis and malaria, leprosy is a minor problem, “a little leprosy niche,” as Dr. Browne said, hence its priority has been low.

Over the last 15 years, thanks to the adoption of the 1991 World Health Assembly Resolution, leprosy has received attention and resources far greater than its traditional priority position from the health authorities of the world. This is because WHO has managed to set a numerical target that is easy to understand and possible to reach; the original time frame of 10 years was acceptable to many health authorities and, most importantly, there were both effective technical tools—MDT, which almost guaranteed the success of the project—and the necessary funding.

Looking objectively at health issues, it is logical to consider the higher significance of controlling, even if not eliminating, HIV/AIDS in most developing countries. Unfortunately, however, it is impossible to set a numerical target or time frame for HIV/AIDS control, and no tools to guarantee its success are available. It is the same for TB, malaria, hepatitis and dengue fever; thus there are no incentives for health authorities of developing countries to do much for these diseases either. It was therefore most fortunate for those of us working in leprosy.

But now that the global caseload of leprosy has come down from 6 million to around 220,000 in 15 years, we can no longer justify insisting on the high-priority privileges and neither is there need for them. As stated previously, the “window of opportunity” for leprosy work has been closed, so we must learn to do what is needed within these restrictions. WHO is calling for an effort to lower the caseload even further while maintaining quality services to the patient, but this is the basic principle of any section of the health services and

not unique to leprosy. What is needed now is to identify which of the various activities must be sustained or even strengthened.

First of all, we must be able to maintain the basic capability to suspect, if not actually to diagnose, new leprosy cases during the daily, routine work of all peripheral health services and establish a reliable route for these suspected cases to be sent to referral centers, either of the general health services (GHS) or of others, including NGOs, for the correct diagnosis to be given. Next, the appropriate treatment, consisting of up-to-date chemotherapy, should be started and the patient handed over to those who can maintain chemotherapy as required and complete the other care needed.

Basically, care for leprosy patients should be at the level of health care that patients of other diseases are receiving. Depending on the level of GHS, that may be lower than leprosy patients have been receiving in the last 15 years. Equality means certainly not less than others, but also not more than others. Therefore, although we would like to have the quality of care given to leprosy patients maintained, if the level of GHS is lower, then we must accept a lower level for our leprosy patients for now, hoping for and assisting in the improvement of the GHS as a whole. Necessary physical care and rehabilitation are the same. Quite often, physical care of leprosy patients was kept at a higher level with the assistance of international NGOs; but here again, such care should be integrated as soon as possible so that all cases are treated equally—a case of reverse integration.

## 2. Leprosy as a problem of clinical medicine

It is nearly 140 years since Dr. Armauer Hansen discovered *M. leprae* and thus proved leprosy to be an infectious rather than hereditary disease. It was almost 70 years ago that Dr. Guy Faget of Carville, Louisiana, in the United States discovered the effectiveness against *M. leprae* of Promin, a compound for TB containing dapson that was first synthesized in Germany in 1907 but was kept on the shelf because of its high toxicity. It is nearly 60 years ago that Dr. Paul Brand of England, working in Vellore, south India, developed reconstructive surgery for paralyzed limbs of leprosy patients utilizing surgical techniques developed during World War II for war casualties.

Currently the majority of newly diagnosed leprosy patients will be cured within a year with no residual deformities and disabilities and can easily return to their previous normal lives. For some people, however, leprosy still causes great damage and suffering, and since there is no way of prognosing these dangers at the time of diagnosis, to be diagnosed with leprosy is still a source of great anxiety.

Our knowledge of leprosy is still amazingly limited. There are some members within ILA who insist that leprosy is not an infectious but a metabolic disease, and that *M. leprae* is not a causative but merely an opportunistic organism. Only recently there was a report of finding a new strain of *M. leprae*, although up to now it has been considered identical throughout the world. The mode of transmission is still debated and the existence of *M. leprae* outside of living bodies, such as in soil and certain types of moss or water, as a source of human infection, is still under investigation.

In more practical terms, better diagnostic methods, better prediction, detection and treatment of nerve damage and lepra reactions; simpler, shorter,

more effective chemo- and immunotherapies; and most of all an effective disease prevention method itself are needed, as described by various authors of previous sections of this book.

Even though the global caseload has come down greatly, as long as there is a possibility of someone developing leprosy somewhere in the world, all the above-mentioned efforts must be continued somehow, possibly in conjunction with similar efforts for other diseases.

### 3. Leprosy as a social problem

Many diseases have their own social implications and often poverty is a commonly associated cause of some diseases, including leprosy. From ancient times up to the present, however, leprosy has drawn an unusual amount of interest from people in every community—east and west, north and south—and usually caused negative reactions among people in almost any culture, religion and nation because of the visible physical deformities and disabilities of some unfortunate patients. Different appearances are the normal way by which most animals distinguish “us versus them, friend or foe, those within a camp and those without.”

At some stage of human development from cave-dwelling primitives to more civilized social beings, people must have started feeling uncomfortable and so segregated the minority group of leprosy patients among them because of their appearance. Needing some commonly acceptable justifications or excuses, they found them in their religions. If some people are made so physically different from the majority within the society, they reasoned, then these leprosy patients must have done something wrong in the eyes of their Gods; hence, the Gods must have punished them by making their appearances so different. With this justification, the whole society could reject them,

punish them or even destroy them without any mercy. Leprosy is almost unique among minority group problems for being a cause for rejection in any society, almost anywhere in the world and at any time in man's history.

The above strongly suggests that if we could solve or overcome social problems related to leprosy, perhaps we would be able to solve any problem related to minority groups, whatever its cause—be it physical, such as skin color or physical features, or social, such as nationality, religion, language, mode of living or food.

Since segregation of persons affected by leprosy went beyond the actions of individual members of society and became discriminatory laws and regulations of countries, it became a political issue as well as an issue of universal human rights, which were supposed to be guaranteed to every individual, however they look, whatever they do and wherever they live. Every human being on Earth is supposed to have freedom of living, traveling, education, occupation, religion, marriage, etc., of their own choice. This concept of universal human rights, though strongly reflecting Christian beliefs, has been accepted and promoted by the United Nations. In Japan, being a non-Christian country and having suffered from militaristic rule both in the Middle Ages as well as in more recent times, this concept of basic human rights is not well established yet, as demonstrated by the reactions of the general public over the Kurokami School or Kurokawa hot spring hotel incidents. Many people anonymously expressed their negative views on persons affected by leprosy, quite contrary to the spirit of the Universal Declaration of Human Rights.

In Japan, these issues were widely reported by mass media, so we know they exist. It is not at all surprising, however, to find similar negative sentiment toward leprosy-affected people in many other parts of the world. The current WHO Goodwill Ambassador for Leprosy Elimination, Mr. Yohei Sasakawa,

chairman of the Nippon Foundation, together with prominent world leaders such as the Dalai Lama, Archbishop Tutu of South Africa and former President Jimmy Carter of the United States announced a joint declaration on the human rights of people affected by leprosy (The Nippon Foundation, 2010). Following this, the newly established United Nations Human Rights Council has taken up the issue and decided to formulate principles and guidelines for elimination of discrimination against persons affected by leprosy and their family members (UNHRC, 2009) to be adopted shortly and to be presented to every government of the world.

One thing we should not forget are the remarkable recent activities taking place in various parts of the world involving the participation of persons affected by leprosy themselves. In the past, leprosy workers had considered these people only as the objects of their activities and recipients of the benefits of these relief activities; and the idea of making them the working partners of such activities was nearly non-existent. That said, within many leprosy institutions, because of their geographical isolation, both patients and former patients were employed to do various chores, and this was the case not only in Japan but in many parts of the world. In the past, the wisdom of employing people known to be susceptible to *M. leprae* infection in places where some people were shedding living bacteria was being questioned or even criticized; nevertheless, they were considered convenient workers—and not working partners—in a place not popular among healthy workers.

The concept and practice of persons affected by leprosy being active and valuable partners of leprosy work was started by a number of people, but one of the most prominent is Anwei Skinsness Law of the United States, the daughter of a prominent American leprologist working in China. She became interested in the people of Kalaupapa leprosy colony on Molokai

Island in Hawaii, famous for Father Damien and Brother Dutton, and during her Master's work there she became a very close friend to many of them. Through that firsthand experience she not only realized that in order to solve their problems of welfare, rehabilitation and human rights issues, their own active involvement was essential; but she also discovered their huge potential capabilities. These discoveries apparently set the course for her own future. She brought a few of them from Kalaupapa to the 12<sup>th</sup> and 13<sup>th</sup> International Leprosy Congresses held in Delhi and the Hague, and for the 14<sup>th</sup> International Leprosy Congress in Orlando, Florida, she managed to bring more than a dozen people from Kalaupapa as participants, who presented their own papers during the congress. Reactions to these happenings were great and widespread. Up to that time, there were few opportunities to listen to the voices of people affected by leprosy—although there was already an awakening realization among these people themselves that little would happen unless they themselves raised their voices and took actions.

In Brazil, the charismatic Francisco Nunes (Bacurau), who had leprosy himself, established an association MORHAN in 1981. In South Korea, a leader S.K. Jung established an association among people living in the resettlement villages that were established for cured leprosy patients by the Korean government in the 1950s with advice from Professor Joon Lew and similar movements in India and elsewhere. Anwei led the movement to establish a global network of, for and by people affected by leprosy called IDEA (Integration, Dignity and Economic Advancement) at Petropolis, Brazil, in September 1994. Arega Kassa Zelelew of Ethiopia, Dr. P.K. Gopal of India, S.K. Jung of South Korea and Bacurau of Brazil became the founding members of the new network, with Anwei as the international coordinator.

What is remarkable about this group in comparison with many other

groups of persons affected by leprosy is that they are totally forward-looking rather than backward-glancing. They are not asking us to remember and compensate for a terrible fate their members suffered in the past, but asking us to join hands as equal partners to build a society in which, whatever their physical condition, each individual is able to live with dignity as a human being and that their life is integrated fully into the society.

In 1997, IDEA, together with WHO and TNF, organized a photo exhibition called “Quest for Dignity” at the United Nations in New York (IDEA,1997), opened by U.N. Secretary-General Kofi Annan. This was the start of public relations activities by IDEA. Since then, similar photo exhibitions have been held in Japan, the United States, Europe, China and elsewhere. The 15<sup>th</sup> International Leprosy Congress held in Beijing, China, had more than 30 members of IDEA registered as regular participants of the congress, and papers and discussions by them as well as their photo exhibition were recognized as regular parts of the congress program.

Since then, IDEA groups have been formed in the Philippines, Angola, Nigeria, Nepal, Japan and elsewhere. Their voices and proposals have been becoming louder, and more constructive, not only in their own countries but at international leprosy meetings, such as the Asian Leprosy Congress in 2000, the 16<sup>th</sup> International Leprosy Congress in 2002 and the African Leprosy Congress in 2005. It is true that unfortunately some members of ILA are somewhat apprehensive about the increased participation and influence of people affected by leprosy; but as already mentioned, the writer believes in the responsibility of ILA not only for medical aspects but also for social aspects of future leprosy programs, hence their stronger voice and increased participation not only in future leprosy programs but within ILA itself are most welcome.

When and if “a world without leprosy” or more realistically “a world without leprosy-related problems, both medical and social” materializes one day, there should be no more human rights issues related to leprosy. But considering basic human nature and the manner in which we have been dealing with leprosy and other minority problems up to now, there are most likely to be similar human rights and other issues with regard to people affected by other diseases or conditions. HIV/AIDS is sometimes referred to as the modern leprosy, because sufferers of that disease have been treated just like leprosy patients.

The very reason for the writer’s suggestion to make a “world without leprosy-related problems, both medical and social” rather than a “world without leprosy” as our goal is precisely because our current leprosy work will likely show us how we should deal with similar problems, either medical or social, in the future. By doing our best on this disappearing disease, we and future generations could make ourselves better equipped for future new problems, thus hopefully making the world a better place to live.

# A Historical Overview of Leprosy Elimination in the Western Pacific Region

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## 1. Introduction

Most of you know that *Mycobacterium leprae* was discovered by Dr. Armauer Hansen of Norway in 1873; but perhaps you do not know that most people did not believe it, because he used an unstained slide of a leproma on which no one else could see the bacteria. Several years later Koch, Neisser and others could show the bacteria by staining the slides, so some people believed that they were the discoverers of *M. leprae* and not Dr. Hansen. It was only at the international leprosy conference called by the Prussian government in 1897 in Berlin that Hansen was officially acknowledged as the discoverer of *M. leprae*, which was the first causative agent of human infection to be identified,

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eight years before Koch discovered *M. tuberculosis*.

Most of you know that the cure for leprosy was found in 1941-42 in Carville, Louisiana, in the United States by Dr. Guy Faget, who showed that the anti-TB drug Promin was effective against leprosy. But perhaps many of you do not know that an effective component of Promin is dapsone (DDS), which was synthesized in Germany as early as in 1907-08. Thus if anyone had tried dapsone for leprosy at that time, leprosy could have become a curable disease 35 years earlier.

Most of you know that currently-used multidrug therapy (MDT) was officially recommended in April 1982 by WHO after the Chemotherapy Study Group Meeting in Geneva of October 1981, but perhaps many of you are not aware that MDT was originally proposed only to prevent DDS resistance, both secondary and primary, spreading globally; during the five-day meeting there was no talk of MDT improving the cure of leprosy over dapsone monotherapy. MDT's effectiveness was to be proven over the following 10 years when it was introduced globally.

All of you know that the goal of "Elimination of leprosy as a public health problem" was unanimously approved by the 44<sup>th</sup> World Health Assembly in Geneva in May 1991, but perhaps many of you do not know that a similar move was first started in this Western Pacific Region in October 1989; thus, most of the countries in this region had a head start and attained the goal before 2000.

Leprosy is one of the diseases known to men for a very long time, being described in ancient documents in China, India, Egypt, Mesopotamia and elsewhere. Because of its unmistakable physical aftereffects on some unfortunate people, which clearly stigmatized them, they became objects of misunderstanding and fear, and subjected to all kinds of mistreatment

by their fellow citizens—what we would call today the worst kind of human rights violations. It is a sobering thought that even if we accept that such behavior happened long before any treatment of the disease was possible, it is definitely not acceptable on the eve of achieving “elimination of leprosy as a public health problem,” which has been made possible by advances in medical science and technology. The gap between the advancement of the human mind on the one hand, in terms of science and technology, and of the human heart on the other, expressed in our relationship with our fellow human beings, is worrisome, if not really frightening at times.

This morning, my job is to describe one of the success stories in leprosy, in terms of medical treatment of the disease. But I hope all of you here will use this occasion to reflect on, or enquire into, the vast social and human issues still associated with the disease because, after all, those issues make leprosy important even today and our efforts really worthwhile.

## 2. Birth of MDT: Why and how

2.1 One of the problems common to chemotherapy is emergence of resistance to a particular drug among the pathogen population. Resistance to dapsone was suspected in the late 1950s and was definitively proven in the laboratory of Sungai Buloh leprosarium in Malaysia in 1964, using the mouse footpad method. This was among patients receiving dapsone treatment, thus it was a secondary resistance. As patients with secondary dapsone resistance increased in different parts of the world, however, signs of primary dapsone resistance gradually began to appear, although it was only in 1977 that it was proven by the same group of people who proved the secondary resistance.

Bacterial resistance to rifampicin, a well-known drug for TB, was already

known to have developed rapidly, and it had certainly appeared among leprosy patients by the 1970s. The only exception so far is clofazimine, and although clofazimine resistance has been reported from time to time, it is still relatively resistance free.

In the late 1970s, even though the effectiveness of dapsone to control leprosy had been questioned, it remained the main and often the only tool of national leprosy control of leprosy-endemic countries because of its low cost as well as the low incidence of side effects—even as ever-increasing dapsone resistance began to threaten the total collapse of field control of leprosy all over the world. This issue was taken up by various groups in the late 1960s and 1970s, and 5<sup>th</sup> Expert Committee Meeting of WHO held in 1977 in fact recommended the combined use of clofazimine and/or rifampicin together with the full dose of dapsone (6-10 mg/kg body weight per week).

This recommendation was not seriously taken up, however, partly because people's awareness of the danger of drug resistance was low, but mainly because of the high cost of these newer drugs. Many governments of leprosy-endemic countries already considered the purchase of dapsone, one of the cheapest drugs on the market costing only US\$2 to \$3 per patient per year, a burden that their cash-strapped public health services could ill afford and thus, for a decade, many had depended nearly 100% on free supply of dapsone from UNICEF. When UNICEF decided to withdraw from this role in the middle of the 1970s, many governments including the Philippines, found it almost impossible—or rather, were unwilling—to purchase the required amount of dapsone. Consequently, some of them turned to us, a new Japanese NGO created in 1974 called Sasakawa Memorial Health Foundation (SMHF), which shouldered the supply of dapsone to the Philippines, Indonesia and Myanmar for seven years up to 1982, when we switched to supplying MDT drugs.

Thus the main reason for WHO's attempt to come up with MDT, as currently known, was the spread of dapsone resistance, both secondary and primary, in many parts of the world, together with the more sporadic appearance of rifampicin resistance, where the drugs were used against leprosy as monotherapy. Problems of drug resistance were well known to public health authorities in connection with TB control and the use of two or more drugs simultaneously was commonly practiced, starting as early as 1950s, and almost universally by the 1970s. It is rather surprising, therefore, that nobody advocated strongly for that with regard to leprosy control until WHO decided to convene the now historic Chemotherapy Study Group Meeting in October 1981 in Geneva.

2.2 The creation of the MDT regimen and the preparations for the Chemotherapy Study Group meeting were carried out by the people associated with THELEP, or the Working Group on the Therapy of Leprosy, one of the scientific working groups and the steering committee for leprosy under TDR, the Special Programme for Research and Training in Tropical Diseases, jointly sponsored by the United Nations Development Programme (UNDP), World Bank and WHO, the last acting as an executive agent of the venture. When TDR was created in 1975, one of its activities was to review the existing global leprosy situation. It noted four problem areas, one of which was "drug treatment, particularly the problem of increasing drug resistance."

THELEP was established late in 1976; by then, the problems of drug resistance had become quite serious. THELEP's responsibility was first to analyze the situation to get a clear picture and then to come up with possible solutions to solve the existing problems. They undertook studies to develop new drugs against *M. leprae* as well as short- and long-term clinical trials of

existing drugs, among others. There were a number of chemotherapy experts in the United States, in Europe—especially in the United Kingdom, France, Germany and Belgium—and a few more elsewhere, in countries such as India and the Philippines, who were already engaged in the area of research that THELEP became interested in, and their findings collectively were the basis for the Leprosy Unit of WHO to decide to convene the Chemotherapy Study Group Meeting so that they could recommend some new regimens to stop and prevent the crisis of drug resistance.

2.3 Twenty-four people, among them eight chemotherapy experts who were associated with THELEP, attended a five-day meeting and they were charged to come up with new combined regimens, which hopefully would stop and prevent the danger of drug resistance in the future. The participants were divided into three subgroups, each responsible for a different patient group and expected to come up with a suitable regimen for them. Group 1 was for newly-diagnosed MB patients without any previous therapy; Group 2 was for MB patients with some previous treatment, usually by dapsone; and Group 3 was for PB patients with or without previous treatment. During the course of the meeting, Groups 1 and 2 decided to merge and come up with a regimen common to both groups. Group 3, which I happened to chair, started by deliberating on whether chemotherapy was needed for PB patients, who were considered non-infectious and thus much less of a concern from a public health point of view, since nearly 80% of them will effect a spontaneous cure, although some would be left with physical deformities. We came fairly quickly to the conclusion, primarily from an ethical point of view, that they too needed chemotherapy, given that if the health services diagnosed a case of an infection, it would be morally bound to give the patient currently available

chemotherapy, even if many such cases would achieve a spontaneous cure. More seriously, we admitted that there was a good chance that some early MB cases could be wrongly diagnosed as PB cases, and that if not given any drugs, they might become a source of infection, which would be of serious consequence from a public health point of view.

As to the actual regimen, we listened to presentations chiefly from Drs. Waters, Pattyn and Ellard, three chemotherapy experts in our group, who explained outcomes of various trials they had been conducting by themselves, mostly under the aegis of THELEP. After several days' discussion, our subgroup came up with a six-month regimen consisting of a supervised, once-a-month 900 mg dose of rifampicin plus an unsupervised 100 mg daily dose of dapsone.

At the plenary session on the last day, when I presented our conclusion, it was immediately criticized by the members of the other groups for recommending 900 mg of rifampicin per month, while they recommended only 600 mg per month. There had been no prior consultation, so our group was unaware of what they were recommending. Besides, our conclusion was based on the data presented by the three chemotherapy experts. In the end, however, our group had to accept 600 mg rather than 900 mg as the majority opinion of the meeting. It was an eye-opening experience for me, not used to "scientific" meetings of WHO, to see how non-scientific reasoning could influence the outcome of the meeting.

In chemotherapy, it is not so much a question of how much is given at a single administration, but rather the total amount of a drug given during the entire course of the therapy. Thus, if a monthly dose of 900mg was reduced to 600 mg, then logically the length of the course should have been increased from six months to nine months. Since those experts in our group did not raise

that issue, however, we meekly accepted the majority opinion without much ado. Now, of course, with hindsight, that decision was not wrong because both the MB and PB regimens appear to be an overtreatment, judging from the extremely low relapse rates.

Having hardly any suitable bacteriological indices sensitive enough to measure the effectiveness of the MDT regimens, we rely on the frequency of relapse after MDT to judge their effectiveness. Zero relapse may be an idealistic goal, but that could mean a gross overtreatment to some patients, and as a public health measure we should really have an acceptable minimum number of relapses. However, this issue was not raised at all at the meeting, although unofficially some of us concerned with field control of leprosy, rather than chemotherapy as such considered that a 10% cumulative relapse rate was quite acceptable, considering the much higher rate for TB or some other infections. In reality, the actual relapse rate found so far turned out to be around 0.1% per annum for MB, and slightly above that for PB. WHO at one time was projecting something like a 3.5% cumulative relapse rate, which certainly should be accepted as excellent, although some people may consider this to be overtreatment.

In fact, there is a very important relapse study currently being undertaken by the Leonard Wood Memorial Laboratory for leprosy research, located in the Eversley Childs Sanitarium in Cebu. Prompted by WHO initially, they are conducting a 15-year follow-up study of 500 MB patients, who have had 24 months of MB treatment with an excellent compliance record. At the last report, when the first cohort had had 12 years of follow-up, there were 15 clinically- and laboratory-proven relapses, the first one appearing after six years, four after 11 years and the others in between. Routinely, relapse studies for leprosy with rifampicin are done with five years of follow-up only. Ten-

year studies are rare. But the Leonard Wood Memorial Laboratory decided to do 15 years of follow-up because, in the 1960s, British experts did a 15-year follow-up of patients after dapsone monotherapy at Sungai Buloh Leprosarium near Kuala Lumpur, Malaysia, and data from that became a reference point for discussion of dapsone resistance.

The rationale for combined chemotherapy is based on two observations. One is that untreated leprosy patients could have up to  $10^{12}$  *M. leprae* in the body; but normally 90% of the bacteria are dead so that viable organisms are  $10^{11}$ . The other observation is that in any natural bacterial population, there are something like  $10^{-6}$  organisms naturally resistant to any chemotherapeutic agent. This means that if a patient is given two anti-leprosy drugs simultaneously, all the bacteria of  $10^{11}$  population should be killed off by one or the other of the two. However, since a patient might be infected by dapsone-resistant organisms, which would be a case of primary dapsone resistance, it is prudent to add a third drug, which would surely kill off all *M. leprae*.

### 3. Implementation of MDT

The recommendations on MDT regimens of the Chemotherapy Study Group were published by WHO as its Technical Report Series 675 in April 1982. By suggesting only two regimens, one for MB and another for PB, with definite time limits, one for two years, and the other only for six months, the chemotherapy of leprosy was very much simplified. As you may be aware, the MB regimen was cut to 12 months and there was a move to further shorten it to 6 months. Trials are now being undertaken at WHO's initiative.

I had one serious objection to that recommendation as published. During the final discussion someone questioned the length of MB treatment, to which

the chairman of the MB group clearly and emphatically responded that two years is the minimum but effective treatment. But the April recommendation referred to a “minimum of two years, but whenever possible until BI negative,” without defining “whenever possible.” To me, it clearly meant that every MB patient should be covered by two years of MDT and then, only if they have more drugs, some of them should be treated beyond two years. But most of the clinicians took it the other way; they said clinicians are ethically bound to give the best available treatment to his/her patients. I have to counter this by saying that there must be an ethical consideration from a public health point of view, which is that all MB cases must be given two years of MDT before anyone receives treatment until BI negativity. I had quite a heated discussion with doctors in Thailand on this. I think this reflects LEP/WHO’s own lack of confidence in the MDT they were recommending in 1982

In this connection I had another interesting episode. In the late 1980s, Dr. Adhyatma of Indonesia, who as far as I know is the only head of a national leprosy program who became a minister of health, approached me about the MB drugs we were supplying. He asked if they could be used only for 12 months rather than for 24 months, because what we were providing was not enough to cover all the MB patients he had. On this occasion I said no because LEP/WHO’s recommendation was still 24 months. If I had agreed with him at that time, Indonesia could have started a 12-month MB regimen several years ahead of the rest of the world.

### 3.1 Implementation of MDT in Vietnam and the Philippines

After that chemotherapy meeting in Geneva, I appointed myself as an unofficial salesman of MDT and tried to promote its implementation ceaselessly and in very strong terms, whenever I visited leprosy-endemic countries, which was

fairly frequently. My own foundation started supplying MDT drugs, not only to the three countries already mentioned, but also, from the middle of the 1980s onward, to up to 30 countries in different parts of the world, although only a few countries depended on us fully.

In September 1982, only several months after the publication of the WHO recommendations, I was asked by WHO to visit both Vietnam and the Philippines to explore the possibility of starting implementation of MDT. I went to Vietnam first and found the country ready to switch to MDT 100% because Professor Le Kinh Due, the national manager of leprosy control, was in that Geneva meeting and he had already started the national leprosy elimination program using dapsone monotherapy. I spent nearly two weeks on my first visit to that country and I was quite certain that Vietnam, working within the financial constraints it was facing, would start MDT implementation as soon and as widely as possible, utilizing its extensive health infrastructure manned by disciplined health workers, common to socialist countries.

Then I came to the Philippines, although I had already made many visits since 1975, mostly to visit my colleagues at the Leonard Wood Memorial Laboratory in Cebu. I suggested, or in fact requested, to the Department of Health (DOH) that we conduct a feasibility study on implementation of MDT on a province-wide scale, and choose two or three out of the top 10 hyper-endemic provinces. They suggested that I visit Ilocos Norte, Iloilo and Cebu. After short visits to each, with my counterpart from the DOH, Dr. Jose Rivella, and discussions with not only public health officers, leprosy workers in sanitaria, and mobile or stationary skin clinics, but also with the rural health dispensaries, we decided to drop Iloilo because of the security problem there at that time, and settled on Ilocos Norte and Cebu. Both belonged to the top 10 hyper-endemic provinces at that time; Ilocos Norte was at the top with

a PR of 4.52/1,000, while Cebu was at the bottom with a PR of 1.08/1,000—although we soon learned that these figures were totally out of date.

The objective of the study was to find ways to implement WHO-recommended MDT in these provinces, primarily depending on general health services (GHS) rather than the existing vertical leprosy service in which more than 1,000 workers belonging to the DOH were involved. We changed the name of the study from “feasibility” to “pilot,” because I was not willing to accept “no” as an answer. More specifically, the three-year study, with the addition of one year for preparations and another for data collection and analysis, writing up the report and planning for national implementation, aimed to:

- a. Identify existing constraints for the implementation of WHO-recommended MDT through the currently operating health care delivery system in the study areas
- b. Devise and adopt a practicable mechanism within available resources (except provision of drugs) to overcome those constraints, so that MDT can be implemented in the study areas
- c. Utilizing the experience gained in the course of the study, prepare recommendations and assist in the formulation of a national leprosy control program, incorporating WHO-recommended MDT, to fit into the existing and emerging general health care delivery system of the country, no longer relying on vertical service.

Actual implementation of the study starting in May 1985 went far better than I had expected, or rather feared, at the start. One chief reason for that, in hindsight, is what I consider Filipinos’ characteristics. In my observation, they were not particularly noted for hard work in the routine activities, unlike health workers in Vietnam or Myanmar, where people managed to accomplish

tasks assigned to them regardless of conditions—probably a result of their political system, with a socialist government. In the Philippines, even though workers were not particularly outstanding in routine activities, once they were put in the right mood by non-routine activities such as the pilot study, with lots of training sessions and meetings, and frequent visits of monitors—not only from the district or the province, but also from the region or even from the department itself, accompanied by an overseas advisor—then they could do an amazing amount of work, far beyond what was expected. My chief concern during the pilot study was not so much what they would do for the study, but rather the consequent neglect of non-leprosy routine work, from barangay up to the provincial level.

The final report of the pilot study published in January 1990 mentioned several lessons learned from the study, such as the critical need for political commitment, for secure and timely availability of drugs at the periphery, where actual contact between patients and health workers took place, and for the presence of adequately trained workers, who could make not only patients but their family and community members understand why particular interventions were being made to get their full cooperation.

One extremely interesting observation I personally made, by a rather informal compliance study, was that in spite of an excellent compliance rate of higher than 90%, which normally suggested that the patients understood the needs and effectiveness of drug taking, we found some patients did not believe they had leprosy nor that the drug given would cure them. The reason for high compliance was simply because they had been told to do so by their own barangay midwives. They said that the health of their whole family was in the hands of the midwives and thus they did not want to displease these ladies. Perhaps an effort to give good training to midwives could be more

effective than all the advocacy, with lots of IEC materials so fashionable now, targeting the general public in the communities.

Our conclusion and recommendation after five years of work was that WHO-recommended MDT could be and should be implemented throughout the country in every province in the Philippines, utilizing the existing health delivery system of the GHS, in which barangay midwives had a critical role of regularly contacting the patient by routine involvement in case finding and case holding until prescribed MDT was completed. Staff members of the rural health units and districts are responsible for supervision and monitoring of these midwives as well as care of referred cases. In the study, existing staff members of the vertical leprosy services were given responsibility in training as well as monitoring and supervision of general health workers, without directly being involved in case finding or case holding. These vertical staff were gradually absorbed in the GHS, with possibilities of doing non-leprosy work.

The DOH was evidently quite happy with the outcome of the ongoing pilot study. Without waiting for the official conclusion of the study itself, the DOH decided to implement MDT throughout the country as a core of the national leprosy control program as early as in 1986, only one year after the start. In 1986, 56,231 cases were registered, of which 38,837 (69%) were classified as active cases. The new national plan proposed at that time was to put 12,000 cases on MDT in 1987, and an additional 16,000 in 1988, and by 1989, all the active cases should be on MDT. This total coverage by MDT has been maintained since then.

I have been involved in MDT implementation in about 20 countries, often as an advisor, but sometimes only as an observer. From these experiences, I consider MDT implementation in the Philippines to be a model case, one of

the best in the world, and whenever I talked about MDT, I often referred to what happened here. I am afraid that status no longer holds now, but with renewed political commitment, as well as some strengthening at the relevant level of the health delivery setup, I have full confidence that this country could again have a leprosy control setup within the general health care delivery system that is as good as any other country can manage.

### 3.2 Contributions made by the pilot study to MDT

The pilot study clearly demonstrated that multipurpose general health workers at the village level who had intimate contact with the people, including leprosy patients, in the community where they worked, were not only capable, but even willing—contrary to general opinion—to be involved in both case finding and case holding, provided they were given proper orientation, adequate training and supplied with effective tools, in the form of MDT drugs. As far as I was aware, there was not a barangay midwife who refused to be involved in the pilot study. On the contrary, I personally heard from several ladies that they had always wanted to help leprosy patients in the area of their responsibility, but were unable to do anything because they were not given necessary training, and there was no drug for them to give. Therefore, they were very happy now to be able to help leprosy patients, whose family members they had been looking after always, and in some cases leprosy patients themselves, but for non-leprosy problems.

Thus the pilot study clearly demonstrated that with proper planning and adequate training, strengthened by effective supervision and monitoring, leprosy control activities of case finding and case holding, previously handled by vertical leprosy services, could be integrated into the GHS, and those activities could be handled by multipurpose health workers, within their daily routine.

Another very important contribution made by the pilot study in the Philippines to global implementation of MDT was the initiation of the first commercial production of the blister calendar packs of MDT drugs, which made both drug delivery by the health workers and daily ingestion of drugs by the patients so much easier. The idea was born from the request from Dr. J. Azurin, the secretary of health in the early 1980s, when I went to see him to get his permission to conduct a pilot study, employing general health service staff.

In those days, he was seriously considering a new national leprosy control program that would have involved putting not only all leprosy patients but all of their family members on Culion Island. He said that giving them a lot of land and assisting them financially for three years would enable them to live without further financial assistance, resulting in a huge saving for the national health budget. He was rather reluctant to accede to my request at first, saying that barangay midwives were already overburdened with 101 chores related to health and sanitation.

He consented only after I promised to simplify the work so that these ladies perhaps needed to devote no more than 1% or 2% of their working hours to it, which should be possible by rearranging their working schedule. Dr. Azurin also said that rifampicin was not yet available for TB patients in the field, so that he could not guarantee that only leprosy patients would receive it as intended, if bottles of loose rifampicin capsules were distributed to the clinics.

To solve these two problems I said on the spot, without fully realizing the possible difficulties, that we would put all MDT drugs in calendar blister packs, so that it would be less time consuming for barangay midwives to distribute them, and it would also prevent misuse of rifampicin outside of the pilot study. To actually get calendar blister packs of MDT drugs was not easy at all. Ciba-Geigy of Switzerland was totally uninterested, saying that to produce

new packaging for only 2,500 patients in the pilot study was not commercially viable, in spite of my suggestion that it would have a huge potential for global usage, as actually happened since then. It was only thanks to the personal understanding of and sympathy toward our study shown by the president of Ciba-Geigy (Philippines), and some help from the regional director of WHO at that time, that the blister packs were eventually produced at a considerable financial loss at the time—although the company later recovered the cost and even made something of a profit when they received a huge order for TB drugs awarded by the Department of Health of the Philippines with help from WHO because of their involvement in our study.

SMHF, soon after its creation in 1974, decided to use the Philippines as our base for activities related to chemotherapy of leprosy, one reason being the presence of experts at the Leonard Wood Memorial Laboratory in Cebu. We have similarly used Thailand for the training of leprosy workers. We organized an international workshop in Manila in January 1977 on Chemotherapy of Leprosy in Asia, inviting well-known experts like Drs. Waters, Jacobson, Browne and Lechat, all closely associated with WHO, as well as Dr. Guinto from Cebu, as resource persons, and leprosy program managers and others from nine Asian countries, in addition to representatives from WHO, Ciba-Geigy and Dow Lepetit. The key recommendation of the meeting at the end was to stop dapsone monotherapy and switch to some kind of combined chemotherapy of two or more drugs in order to prevent dapsone resistance from spreading. This was four and a half years before the WHO Chemotherapy Study Group Meeting in Geneva.

As a follow up, SMHF organized Joint Chemotherapy Trials involving South Korea, the Philippines and Thailand, using the Leonard Wood Memorial Laboratory in Cebu as the operational base and Dr. R.S. Guinto acting as a

focal person of the trials. Actual trials began in 1980 and lasted for five years. It was fairly modest in scale and the regimens tried were not as revolutionary as the ones THELEP were trying, so that the results per se of our trial had rather limited impact. What was important was the annual standardization workshop conducted in Cebu with the Leonard Wood staff acting as trainers in addition to Dr. Waters. Invited were doctors and lab technicians, not only from the three countries mentioned, but also from some other countries in Asia such as China, Vietnam, Myanmar, Indonesia and Nepal, who later became key persons in implementation of WHO-recommended MDT in their own countries, since they knew what MDT meant and how to implement it properly in the field. I consider this annual training in Cebu, which lasted for seven years, to be another contribution that this country has made to MDT implementation globally.

#### 4. Elimination of leprosy as a public health problem based on MDT

Even though the spread of MDT implementation globally was rather slow, much too slow for my taste, it gradually covered most leprosy-endemic countries in the world, as well as a fairly substantial proportion of registered patients in each endemic country toward the end of the 1980s—and with the satisfactory results of zero resistance and extremely low relapses. With these results, many of us concerned about the global leprosy situation gradually began to be convinced—and were not just hoping—that global leprosy control with substantial case reduction had become a possibility with MDT.

In the 1970s and 1980s, our attention was drawn to the much-heralded production of prophylactic vaccine by the discovery that a large quantity of

*M. leprae* could be harvested using armadillos and advances in immunology and microbiology, together with the rapid development of microtechnologies, including genetic engineering applicable to the medical field. Many people hoped rather naively that eventually a leprosy vaccine would finish off the millennia-old human struggle against *M. leprae*, and this overshadowed the rather too quiet and slow implementation of MDT, which in fact had improved the situation quite considerably.

In 1981-82, LEP/WHO was much criticized for proposing MDT because the recommended regimens were not properly based on clinical trials, which normally took seven to nine years. WHO cited the need of urgent action to counteract the spread of drug resistance, and it was fairly confident that the accumulated data from various studies taken together gave sufficient back up for the recommendation. But the medical field in general and so-called “leprosy experts” in particular, were far from convinced.

However, the results of MDT implementation over seven or eight years since 1982 in various parts of the world clearly vindicated WHO’s original conviction. This emboldened WHO to go even further and propose “Elimination of leprosy as a public health problem,” defined as a prevalence rate of less than one case per 10,000 population, as a global undertaking with a target date of the year 2000. This proposal was unanimously adopted by the 44<sup>th</sup> World Health Assembly of May 1991 and health authorities of leprosy-endemic countries, including the Philippines, became duty-bound to achieve that goal at the national level.

Many of you may be happy to know that in the Western Pacific Region of WHO, with its head office here in Manila, such a proposal had already been adopted in October 1989 by the regional conference on leprosy held in Manila, one-and-a-half years ahead of its global acceptance. It was Dr. S. T.

Han from South Korea, the regional director at that time, who told me and Dr. J.W. Lee, also from Korea, that he intended to stay in the position of regional director for 10 years and would like to have a personal accomplishment at the end of his term, one that would be clearly visible to everyone. At the time, I was acting as an STC (short-term consultant) to WHO and Dr. J.W. Lee, who is now the newly-elected director-general of WHO, was then regional advisor on chronic diseases responsible for leprosy and tuberculosis.

I was there to assist Dr. Lee in preparation for the regional conference on leprosy and we had newly collected data on the current leprosy situation from each member country. Careful study of them showed that in the region, most of the leprosy-endemic countries, including Vietnam, Cambodia, the Philippines and Papua New Guinea, all had a national prevalence rate of around one case per 1,000, with an average incidence rate of around 1 per 10,000. Fully aware of the effectiveness of MDT through the pilot study in the Philippines and field implementation of MDT in the member countries, Dr. Lee and I were fairly confident that by intensifying implementation of MDT in all of the member countries, we could reduce the prevalence rate by 90% and approach the existing incidence rate at that time in 10 years. That became our proposal; however, we needed some effective catchphrase to sell this idea to the health authorities of member countries, who as a rule had little interest in leprosy, basically because they thought not much could be done for the disease that affected only a minority in their nation.

At that moment, Dr. Robert Jacobson from Carville in the United States, a well-known chemotherapy expert, and a member of the Chemotherapy Study Group Meeting of 1981, joined us as one of the resource persons to the regional conference that was to open in two days' time. He happened to bring with him a small pamphlet published by the U.S. Public Health Service in April

1989 titled “A Strategic Plan for the Elimination of Tuberculosis in the United States.” It advocated reducing the “case rate of TB to less than one per million population by the year 2010.” That gave us a hint, and in fact emboldened us to call our own proposal, with Dr. Jacobson’s consent, “Elimination of leprosy.” But being naturally cautious, we elaborated on that statement by adding “as a major public health problem,” indicating a numerical target of a PR of less than 1/10,000 population within a time frame of 10 years, meaning 1998 at the national level. The national program managers on leprosy of that regional conference unanimously adopted the proposal as the conference recommendation. All the countries managed to reach that goal ahead of the global target date of 2000, with the exception of the small island countries of the Federated States of Micronesia and the Marshall Islands. Dr. J.W. Lee later told me that he was called to Geneva and reprimanded by Dr. Noordeen of LEP/WHO for making such an important policy decision without consulting him and getting his approval. Later, Dr. Lee and I thought perhaps we are now even as Dr. Noordeen made the proposal to the World Health Assembly for adoption of the elimination program without consulting us.

In the mid 1980s, 122 countries had a leprosy prevalence rate of more than 1/10,000 cases of leprosy and were thus regarded as “leprosy-endemic countries” by WHO’s definition. The highest registered number of cases globally was around 6 million, again in the mid 1980s.

At the end of 2000, the closing date of the original resolution of 1991, 110 countries had achieved the goal at the national level. The momentum was kept alive by a new resolution adopted at the World Health Assembly of 2000, that 12 remaining countries should also achieve the goal by 2005. To assist these countries, a Global Alliance for the Elimination of Leprosy was launched in Abidjan, Cote d’Ivoire, in November 1999.

## 5. What more is to be done? A personal view

For the 15<sup>th</sup> International Leprosy Congress in Beijing, Felton Ross and I came up with “Working toward a world without leprosy” as the basic theme of that congress. Since then, “a world without leprosy” has been adopted by almost everyone in leprosy work, including WHO, ILEP, Novartis and even by many countries. It is not a realistic goal, however, because it is synonymous with “eradication of leprosy.” No technology exists to do that, no financial resources are likely to be available, and more importantly, I feel there is really no need to achieve it. Instead, even at the end of the Beijing Congress, I said in my closing speech as the ILA president that what we should really be striving for is to get as close as possible to “a world without leprosy-related problems, both medical and social,” because we already have many tools to do that, even though those tools need much improvement and we must learn better ways to use them. As members of the medical profession, our primary responsibility is to solve medical problems related to leprosy, even though we should be aware of social problems and assist social workers whenever possible.

Now, after establishing our ultimate goal and our professional responsibility, we should tackle existing problems realistically and effectively. To “eliminate leprosy as a public health problem” was a politically effective goal: all governments joined in and managed to reduce the global caseload down to less than half a million in a 15-year period. This was, indeed, a great public health achievement by WHO, second only to the eradication of smallpox. But because of that success, leprosy now became a minor problem within public health problems. WHO is now putting leprosy into the neglected diseases group. We cannot expect much attention or allocation of resources from the

world's public health authorities. In a sense, our status within public health sectors became almost like it was in the 1960s and 1970s, when leprosy work in each country was either left to a relatively small vertical unit or given to NGOs willing to do the job on behalf of the government.

We have not yet reached that sorry state. Almost all governments say that leprosy work is within the GHS and thus that health care for leprosy patients will be maintained. But how effectively and efficiently? Looking over the global situation, an efficiently functioning GHS is rather rare. In planning for the future, we should be fully aware of reduced interest and resource allocations from government, and plan what we should do accordingly.

The most important point is to decide what minimum activities should be maintained by the GHS for leprosy. Case finding and chemotherapy are two essential activities for which any health authority must be responsible. This most certainly means any rehabilitation of cured patients is excluded and, in many countries, even prevention of deformity, although recognition of that need must be maintained by top public health authorities and they must do their utmost to find either other government services such as social welfare, or national and international NGOs and agencies, to do the job. Case finding is the primary responsibility of public health authorities, but who should carry it out? Most peripheral health workers in a community are likely to encounter a new leprosy case perhaps once in two years or so, or perhaps even less frequently, in a country that has met the national leprosy elimination goal some years ago. Can you really expect these peripheral health workers to correctly recognize leprosy cases? Not really. Therefore, we should divide case-finding activities into two stages. Stage one is to suspect leprosy by seeing some skin or nerve conditions. Not only peripheral health workers but all health personnel at various clinics, hospitals, schools and factories

who have a chance to see the skin surface of a person or muscle movements, especially of the hands and eyelids, at least should have an awareness of the existence of leprosy in their community and enough knowledge to suspect a case of the disease.

Then there must be a well-established and readily available referral system, so that all those suspected of leprosy can be seen by a specialist of a referral unit who can make a definitive diagnosis; then these patients must be sent to the nearest clinic where regular treatment with MDT can be started and completed. The peripheral general health worker who is assigned to the new patient probably needs on-the-spot training, or retraining on how to give monthly MDT, how to watch for possible reactions and how to handle reactions or any other side effects of MDT. If the patient already has nerve involvement or indeed some physical problems such as lagophthalmos or planter ulcers, the peripheral health worker in charge of that patient must be taught how to support the patient. This on-the-spot training should be done by the public health nurse (PHN) or public health workers (PHWs) of the referral unit, who should be responsible for monitoring the progress of the patient's treatment. At the end of the prescribed course of MDT, the patient should be seen by the person who made the original diagnosis and started him on MDT, or at least by a doctor or trained PHN/PHW, before the patient is released from chemotherapy. With a less than 1/10,000 caseload, the chance of most peripheral health units having more than one case regularly is rather slim. A proposal to have at least one worker trained in leprosy at every peripheral health station in many countries is impossible and unnecessary in my view, except in some high endemic areas. There is very little and probably nothing more one can expect these PHWs to do, except perhaps to do a family contact survey once to see if there are other cases. Care of atrophic

ulcers or providing footwear may be done, but the health worker's time may be extremely limited by other public health duties, of which there could be many. In order to ensure that all peripheral workers remain on the alert for leprosy in their locality, it is perhaps necessary to send a one-page reminder on leprosy to every worker at least twice a year. The ministry of public health should be responsible for the production and distribution of the leaflets, with possible financial and/or technical assistance of an interested NGO or other agent, including WHO. The availability of an atlas of leprosy with clinical pictures is also essential.

The above processes require well-established referral centers or units. There are only 18 countries that have more than 1,000 new cases a year, and by 2015 the number is likely to be much smaller. That means in a majority of countries, a referral unit, which should have at least one doctor, one public health nurse and one or two paramedical workers—a physiotherapist or laboratory technician who could also function as a driver—should be at provincial level or sub-national level, covering a few neighboring provinces, and not at district level, and have adequate provision for transport. Each referral unit in these countries will perhaps have less than 200 cases to handle per year, many much less.

Ideally, these units should be a regular unit within the GHS. But in some countries in Africa, the Pacific Islands, Central and South America, and elsewhere, these units may be run by NGOs or dermatological societies and the like, who have both human and financial resources and are willing to collaborate fully with the GHS of the country. Some of these units could well be involved in patient rehabilitation. The suspected patients either go to the unit or the doctor of the unit visits the peripheral center. That unit will be responsible for the patient, by giving on-the-spot training to the peripheral

worker assigned to each patient, and monitoring the work.

Hardly any country, even those within the industrialized group of nations, will ever have enough human and financial resources to fully meet all the health needs of the nation. Therefore, prioritization of their health services activities is always required. Leprosy will never be high on their list, especially from now on, because of our recent success. “Reducing the numerical burden and providing quality care” is a basic requirement of any health service, be it for TB, hepatitis or HIV/AIDS, and is not specific to leprosy. A reduction in both quality and quantity of leprosy services is unavoidable. Therefore, we must clearly set minimum requirements, as above, for government services and plan to meet those requirements; at the same time, we must try to involve whatever additional resources are available and incorporate them into the government plan to improve and increase leprosy services beyond what government alone can provide.

I have an uneasy feeling that so far the future of leprosy services has been discussed among leprosy experts who started their work in 1980s and 1990s, when leprosy was enjoying a privileged position within public health services and a “window of opportunity” was wide open for us. We are proud of successfully utilizing that privileged position and managing to reduce the global caseload considerably. But that success is putting us back into a low priority position and the “window of opportunity” is no longer open. We talk about sustaining our services, but to me it looks more like ensuring the survival of our services. Once we decide on what should be the minimum requirements, we should open our discussion to the GHS and people in other services to see how much they could help us, because the level of leprosy service is unlikely to be higher than that of the GHS in future.

Thank you.

# Playing Devil's Advocate

Dr. Yo Yuasa

Executive and Medical Director  
Sasakawa Memorial Health Foundation

## 1. Introduction

This is a series of statements on leprosy control, especially on MDT implementation, to challenge and provoke the participants to think about and discuss the topic more from the standpoint of each person's position and actual needs. Therefore, the following statements do not beat about the bush; they are deliberately simplistic and direct to make the points quite clear. The speaker is acting more as a devil's advocate than as a promoter of a particular idea, although the whole matter is treated very seriously after due consideration. This approach is strictly personal; WHO and SMHF have played no part and therefore bear no responsibility.

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Date unknown. Possibly written between 1982 and 1985

I consider myself to be one of the most radical protagonists of MDT implementation, much more outspoken than anyone in WHO or ILEP. Unfortunately, I feel rather lonely and frustrated for not having enough colleagues.

## 2. Global leprosy situation

It is a very poor show indeed. Those engaged in leprosy are not performing their duties properly, nor fulfilling the promises the modern techniques brought to leprosy work. We are failing in our task.

There are two failures for which medical professionals must answer. The first is regrettable, but not as serious as the second one; it is “incompetence” or inability to do properly what one is expected to do. Lack of a preventive vaccine, non-availability of a simple skin test or absence of more effective drugs come under this category.

Incompetence is usually overcome with time. Much more serious and inexcusable is the second failure, which is “negligence.” One simply fails to apply the capabilities that are already in one’s hand. Leaving the total number of leprosy cases in the world at 11 to 12 million for over 30 years, while having workable diagnostic methods and effective chemotherapeutic agents, is simply appalling.

With the discovery of DDS as an effective drug, we started proclaiming to the world that “leprosy is curable” and “deformities are preventable.” But the actual picture is that the majority of patients are not being cured and every year more deformities are being allowed to develop.

What is wrong? The cause of this failure is the ingrained belief, conscious or unconscious, among leprosy workers that leprosy is somewhat different

from other diseases and therefore can be handled only by the specialists trained for leprosy.

Another common statement we often make nowadays is that “leprosy is just one of many infectious diseases” and “leprosy patients should be treated the same way as patients with other diseases,” while we ourselves are making sure that leprosy remains separate and in our special domain.

We are quite ready to blame our medical colleagues for not accepting leprosy work, while almost totally failing to make leprosy work more readily acceptable to them. If you insist on prolonged regular treatment for an infectious disease, or expect care for disabilities as a matter of course, then no public health services can accept “care of leprosy patients” as an integral routine part of their public health activities. But what most of us leprosy specialists failed to appreciate is that such necessary or routine care is given only to a fraction of leprosy patients in the world. According to WHO statistics, nearly 50% of patients are being totally neglected. Even among those registered, and thus presumably getting some care, only about 20% so far are getting MDT regimens that WHO considers as the basic regimens. It is signally unfortunate that we do not have more strong-willed public health persons in leprosy.

Traditional leprosy workers are clinicians with added religious or humanitarian zeal. They are often laudable in their devotion and dedication to the patients in their care. They wish to do far more than medical, certainly public health, requirements. Unfortunately, what they totally fail to realize is that such devotion to each of their patients is exactly the cause of the total neglect of tens and hundreds of patients, who are unlucky enough not to be known by such dedicated leprosy workers. We are in fact doing “good” leprosy work at the expense of a huge number of leprosy patients in many

parts of the world, perhaps even in your own country.

What is wrong is to deal with the few with whom we can have direct contact, and leave the rest to someone else. It is wrong because there is no someone else.

Leprosy is an infectious disease that needs a public health approach. There is no sense in treating only a part of the patients, because others will keep transmission going and create new cases, as shown with the undiminished figure of 11 to 12 million cases over the past 30 years. Unless all the cases are put under proper public health (PH) care, any other care is really useless.

What, then, is proper PH care for leprosy? It is simply effective case finding and proper MDT, in order to break the chain of transmission, and equally importantly to prevent drug resistance developing. One important item in the Hippocratic Oath is "Do no harm to the patient." Translating this in PH terms, it surely means prevention of drug resistance development. How can we do proper PH work, which must reach all cases in the world? It is only by soliciting the help of general health services (GHS). No vertical service is large enough to cover every corner of a country. Such a service, if it existed, perhaps should be abolished as a waste or misuse of limited valuable resources available for public health.

How can we make leprosy work acceptable to GHS? By making it no more than what is accepted as routine for any other disease, such as TB. Leprosy must be considered within the total context of the health care of the nation.

The most essential component is proper treatment of known active cases; in other words, for leprosy this means implementation of WHO-recommended basic MDT. Case finding is certainly required, but if GHS in a given country is not doing active case finding for TB, for example, then active case finding for leprosy must wait until the standard of GHS is raised to be able to do that

for both TB and leprosy. Care of insensitive hands and feet or treatment of eye complications probably have to wait even longer, unless a vertical leprosy service happens to be available and the health authority is willing to maintain such a service even after handing over the MDT part to GHS. If you are lucky enough to have an interested NGO, they could be entrusted to do the non-MDT part of leprosy work.

What I am saying here is that we should not expect GHS to do more for leprosy patients if we want to make it possible for MDT to be accepted by GHS, because that is the only feasible way to approach the majority, if not all 12 million cases. MDT should be available to every single leprosy patient living in an area covered by GHS. Remember, equal treatment means certainly no less, but also no more, than others.

Whatever our own feelings, especially for those patients of our own acquaintance, unless we can accept this basic principle, there is no hope of reaching all the cases, which I consider is criminal negligence for which there is no excuse. I can see many faces here and elsewhere who are against what I have just said. I would like to remind them that there is a joke doing the rounds that goes, "To eradicate leprosy, we must eradicate leprologists first." I hope it remains a joke and does not become a reality.

# Dr. Yo Yuasa Biographical Data

## Date of birth

10 July 1926 (Kyoto, Japan)

## Education

Amherst College (USA) BA

International Christian University (Japan) BA

University of Edinburgh, Faculty of Medicine (UK) MBChB

Liverpool University, School of Tropical Medicine (UK) DTM&H

## Professional career connected with leprosy

1958 – 1960 Japanese Leprosy Foundation/Tofu Kyokai (Japan),  
Administrative Secretary

1970 – 1975 The Leprosy Mission International (UK)  
Hay Lyn Chau Leprosarium (Hong Kong), Medical Officer  
Anandaban Leprosy Hospital (Nepal), Medical Superintendent

1975 – 1980 Sasakawa Memorial Health Foundation, Medical Director

1980 – 2005 Sasakawa Memorial Health Foundation,  
Executive and Medical Director

2005 – 2012 Sasakawa Memorial Health Foundation, Advisor



Cape of Good Hope, South Africa (2005)

## Other professional affiliations

- 1978 – 1992 ILEP (International Federation of Anti-Leprosy Associations)  
Medical Commission, Member
- 1982 – 2006 WHO Expert Advisory Panel on Leprosy, Member
- 1988 – 1993 International Leprosy Association, Secretary
- 1993 – 2002 International Leprosy Association, President
- 1994 – 2002 WHO SAPEL (Special Action Programme for Elimination of  
Leprosy) Steering Committee, Chairperson

## Postscript

To reach the age of 88 is an achievement, especially in Oriental culture as the Chinese character for eight signifies ever-widening fortune or happiness. When it is doubled it is cause for special celebration. Born in 1926, Dr. Yo Yuasa at 88 continues to keep in good health, both physically and mentally, although understandably he is not untouched by the wear and tear of time.

In wanting to sum up a life he felt was drawing near its end, he selected a number of papers and speeches he had written since joining Sasakawa Memorial Health Foundation (SMHF) in 1975 and handed them to me with a view to their being published as a collection.

Going over them, I was struck by his resolute commitment to deliver the cure for leprosy to whoever needed it. True, he was backed by the strong “tailwind” of the late Mr. Ryoichi Sasakawa and guided by the “humanism and science” of Professor Morizo Ishidate, the two founding giants of SMHF. Nonetheless, without his passion and conviction, allied to multidrug therapy and its public health application, SMHF would not have been able to play the role it did in three decades of intense global efforts against leprosy.

From the beginning Dr. Yuasa saw leprosy not only as an infectious disease but also as a deformity-producing one. This made him state: “Surely our final goal must not be mere healing of leprosy the disease, but restoration of leprosy patients as whole persons in the community. I submit that the most significant merit of WHO/MDT lies in the possibility of opening the door to this ultimate goal.”

Although there are far fewer cases of leprosy in the world today compared with when Dr. Yuasa began his career, the disease continues to infect tens of

thousands of people each year, and the difficult journey to cover the “final mile” is far from over. History will eventually determine the role he played in the fight against leprosy, but I believe it is appropriate now to compile a record of the strides he took to help us reach this point. It is my hope that this volume will find a place in the modern history of leprosy, especially in relation to the global effort to eliminate leprosy as a public health problem.

Finally, this postscript cannot be complete without a special thanks to Mr. Jonathan Lloyd-Owen for his invaluable advice and help in the organization and compilation of this volume.

Kay Yamaguchi, Sasakawa Memorial Health Foundation  
June 2015



## Publisher's Note

The chapters in this book represent just a portion of the output of Dr. Yuasa when he worked for Sasakawa Memorial Health Foundation between 1975 and 2012. Many of the articles, presentations and speeches have been published previously in different form. The text has been re-edited for style and consistency for publication in a single volume, working from the original manuscripts wherever possible. Readers will find considerable overlap in these pages. Dr. Yuasa appointed himself, in his own words, “as an unofficial salesman of MDT” and took every opportunity to stress the drug regimen’s importance and his belief in the efficacy of the leprosy elimination program.



Benguela, Angola (2003)



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All photos are from Dr. Yuasa's collection unless otherwise indicated.

**L**EPROSY is a disease that has caused misery and suffering through the ages. In the early 1980s, a World Health Organization committee recommended a new treatment that has proven to be highly effective—multidrug therapy, or MDT. Dr. Yo Yuasa, who served as executive and medical director of Sasakawa Memorial Health Foundation between 1975 and 2005 and as advisor until 2012, was, as he himself put it, one of the drug regimen’s “most radical protagonists.” In this collection of his speeches and writings over a 30-year period, Dr. Yuasa can be seen arguing passionately for MDT and making the case for why delivering the cure to all who need treatment should be seen as a moral responsibility of public health policy. In addressing the disease’s social dimension, he offers his thoughts on what the long history of stigma and discrimination associated with leprosy tells us about the nature of humankind.

On the cover: The author, right, in Hanoi, Vietnam in 1983 (main photo); the Himalayas seen from Nepal, where Dr. Yo Yuasa worked before joining Sasakawa Memorial Health Foundation (background image).  
Back cover: A view of the Kamo River in Kyoto, Japan, the author’s birthplace and home

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