

FOR THE ELIMINATION OF LEPROSY

A MESSAGE FROM THE SPECIAL AMBASSADOR

Reaching the Unreachable

We are continuing our special focus on India for this issue. In India, there were 473,658 new cases of leprosy in 2002, amounting to 76 percent of cases worldwide. The numbers prompt experts to say, "If India fails at elimination, we will all have failed."

The task of finding patients from all strata of society in all regions of the country and providing a cure — in a country with more than a billion people and over 100 languages — isn't an easy one.

Beyond the medical issues, social stigma is also a serious problem in India. The deeply rooted stigma attached to leprosy has made many of the leprosy-affected in the country nearly unreachable.

To overcome these barriers, efforts have focused increasingly on broadening the base of trained people who can look throughout the country for new cases. One example is the integration of leprosy services into General Health Services, with village health workers now going from home to home. Another example is the promotion of communication through school education. As explained in this issue's Report From India, schoolchildren are taking home simple drawings of the human body, on which they record any skin blemishes of family members and then bring the reports back to school.

These steady efforts are having a strong cumulative effect. More people are being reached than ever before. Still, new groups of people with no awareness of the cure are continually being discovered. Due to issues of language, geography and social structure, these groups are proving hardest to reach with the message that leprosy is curable. But until India has reached all of these people, we cannot say that we have succeeded. And without an awareness of the curability of the disease, there will remain many affected people who are reluctant to come forward to be examined. We must encourage people to visit nearby health centers when they find patches on their skin. For that, the messages, "Leprosy is Curable," "Free Treatment is Available," and "Social Discrimination has no Place" must be delivered to all strata of society. The challenge we must not fail to meet is how to reach the unreachable both with these messages and with the cure.



Yohei Sasakawa
WHO Special Ambassador
President, The Nippon Foundation

Leprosy is Curable.

Free Treatment is Available.

Social Discrimination has no Place.

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REPORT FROM INDIA

Pilot Project at School in Uttar Pradesh

By Leena Nandan



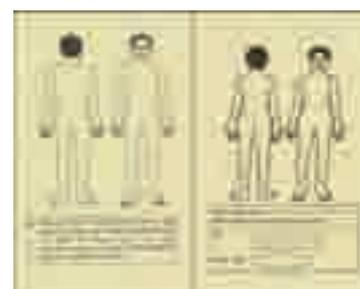
Leena Nandan was project director for the National Leprosy Elimination Program, in the state of Uttar Pradesh (UP) in 2002–2003. Her previous positions for the Indian Administrative Service include Managing Director for Women's Welfare, UP, where she was responsible for formulating the Women's Empowerment Project. Ms. Nandan has extensive experience in working for rural and urban poor. The following article highlights a successful and practical approach to fighting leprosy.

Amarnath, a bright and alert child, 10 years of age, takes school very seriously. His family belongs to the urban poor strata of society and, although most of his brothers have attended school, they have had to drop out due to economic reasons.

Amarnath is the second-youngest sibling in a family of four boys and one girl. Despite the fact that his second brother was diagnosed with leprosy a few years ago and underwent treatment as a PB (paucibacillary¹) case, their mother did not realize that the telltale patches on her own skin, as well as Amarnath's, were indicative of the fact that they were also MB (multibacillary) leprosy cases. It was only the School IEC²/Diagnostic campaign, launched as a new initiative in the government-run primary schools of urban Lucknow (the capital of UP), which brought these hidden cases to light. When Amarnath was asked why he responded to the IEC card distributed in the school, his simple answer was "Because my teacher asked me to take the card home and show it to my mother." What exactly is this IEC card, and what is this *pilot project*?

Pilot Project Background

Yohei Sasakawa, president of The Nippon Foundation and WHO Special Ambassador for the Elimination of Leprosy, visited Uttar Pradesh (a northern state of India — population 166 million) on December 6th and 7th, 2002. In the course of discussions held at that time, Mr. Sasakawa suggested that since school-children are an invaluable medium for IEC, they could be used even more effectively. In order to attract their interest and make the IEC effective, a new format based on drawings of the human figure could be developed. On the basis of this idea, a school IEC card was designed and printed as a two-page leaflet. On the cover page is a drawing of a male figure and on the reverse, a female figure. Simple instructions have been given on the cover, explaining that if anyone in the family has skin patches lacking sensation, their location should be indicated by sketching a patch on the figure. On the reverse side of the cover, below the drawing of the female figure, there is space for the name and address of the child, names of people having skin patches and space for the signature/thumbprint of the parent/guardian.



The second page of the card is detachable, and has information on leprosy, namely that it is fully curable, drugs are available at all government health centers free of charge, and so on, written on both sides. The detached part is to be retained by the child, so that he/she can read

1 Leprosy is classified as paucibacillary or multibacillary leprosy based on the number of patches. PB is usually non-infective while MB is infective.

2 IEC — Information, Education and Communication

the messages later, and continue to benefit from the information.

This IEC card is distributed to schoolchildren by schoolteachers and health workers, who explain its purpose to the children. On taking it home, the children tell their parents what the symptoms described on the card are and how the card has to be filled in. They then return the card to their teacher. All the returned cards are collected by a health worker from the school and studied to see which of them have skin patches indicated. These are followed up individually, and after the medical officer confirms the diagnosis, treatment is started.

Pilot Project

With a view to utilizing this IEC/diagnostic school card, a pilot project was initiated in the urban areas of Lucknow. It was launched by the Principal Secretary of Medical, Health and Family Welfare (of the Government of UP), on January 30th, i.e. Leprosy Day. After the cards were distributed, the children held a rally, holding placards on leprosy and its cure.

During Leprosy Week, 17,268 cards were given to 216 government schools in the urban areas of Lucknow, and distributed to students from third grade through eighth grade. This was done with the joint efforts of health workers and school authorities in coordination with the Basic Education Department. A total of 15,114 cards were then returned by the children to the teachers.

Each card was examined to see what the children had indicated. 276 of the returned cards indicated skin patches. So in the months of February and March, each suspected case was investigated and, after diagnosis, eight people were confirmed as leprosy patients.

Out of these eight cases, one patient, whose daughter had drawn patches on the card, indicated that he had been diagnosed in October 2002 and was already receiving treatment. The remaining seven were new cases.

Of these eight patients, six are living either in urban slums or in nearby villages. Four are from a low-income group and four are living below the poverty line. When asked individually, they said that messages in the form of banners, handbills, billboards and advertisements have no impact. Similarly, they do not listen to verbal announce-

ments, and even if they do, for the most part they are unable to comprehend the messages. The parents are illiterate or semiliterate and were diagnosed only because the children faithfully followed the instructions given by the teachers during the School IEC.

The paramedical workers who were involved in the above IEC/diagnostic activity expressed their view that this was a useful and effective way of detecting patients. Since children played a key role in the detection, they will take an active role throughout the treatment process, thus reducing chances of default.



Social Workers in Uttar Pradesh

Conclusions/Recommendations

School IEC activities so far have been confined to organizing debates, quiz competitions, and the physical examination of schoolchildren. No doubt physical examination of children leads to detection, but the advantage of a focused school IEC/diagnostic campaign is that it simultaneously addresses the schoolchildren and their family members.

The cost of printing the 17,268 cards at the rate of 23 paise per card was only 3,979 rupees (\$87). This proves that result-oriented IEC need not necessarily be cost intensive.

Any media tool for IEC should be designed with the impact of the tool in mind. Identification of the target group (in this case children and families) and the best way to approach them has to be the underlying strategy.

Traditional methods of IEC such as distribution of

handbills, banners and billboards cannot reach that part of the target population which is illiterate. Verbal announcements are also not very successful, as many people are unable to comprehend the messages broadcast via loudspeakers.

Since 36% of the UP population lives below the poverty line, they are unable to benefit from TV spots. Either they don't own a TV or they are too preoccupied with their daily needs to listen attentively.

A few additions to the School IEC can be made in order to enhance the impact. The children could be given a pencil each to stimulate their interest. Also, instead of relying only on the health workers to explain the exercise to the teachers, printed guidelines could be circulated to the teachers as well, enabling them to understand the campaign better, and guide the children accordingly. □



Children in West Bengal

With Faith and Confidence

By Hiramani Nayak — Health Worker

We thank Dr. Shridhar Kadam, WHO coordinator in Orissa for this story. Dr. Kadam commented, “I love these female workers. They are so good and dedicated to the work. We owe a great deal to them.” In order to reach the nearly unreachable people living on the periphery of society, the effort of people like Hiramani Nayak is indispensable.



Hiramani Nayak

I am a health worker at the Konark Subcenter of Public Health Center Konark in the Puri District of Orissa State. Under my jurisdiction there are ten villages with a total population of 5,495. I have been in this service for the last twelve years and am educated up to higher secondary school.

On Wednesday, Immunization/Clinic Day at the subcenter, I do routine immunizations, ANC (Antenatal Clinic) check-ups and immunizations, as well as treatment of minor ailments like malaria, anemia, scabies, etc. On the same day, I also distribute MDT³ to leprosy patients. On other weekdays, I go to villages for home visits. I prepare route charts to visit the villages ahead of time, and visit every village fortnightly. All the services that I provide on Wednesday at the subcenter, I also provide during visits to people in the villages who are unable to attend a subcenter.

I have been working in leprosy since the integration in 1998. I have been trained in leprosy and participated in all four Modified Leprosy Elimination Campaigns. I have been doing routine leprosy work (i.e. taking suspected leprosy patients to a PHC Medical Officer for confirmation, giving MDT to leprosy patients and maintaining records) since 2000. At present there are three leprosy patients under treatment at my subcenter. All are MB cases and they are taking MDT regularly. They take MDT when they come to the subcenter, but if someone isn't able to come to me, I give the MDT to that patient during a home visit.

I am quite satisfied doing anti-leprosy work because when the patients get treated with MDT, deformities are prevented. These people appreciate what I'm doing very much and become close friends of mine. Other people come to me voluntarily to show me their patches. This faith of people in me gives me job satisfaction. Thus very easy diagnosis and definite cure by MDT is the thing

about leprosy that enables me to work in the leprosy field very comfortably.

One example is a female MB leprosy patient who is presently taking MDT from me. She comes from quite a long distance away because she has faith and confidence in me. MDT has given me this confidence. Thanks to MDT, I know the people of my area. I am confident that they will not hide the disease from me and they will voluntarily come to me to show me their patches. Hence there is little need to actively search for new patients in my area — while some very few new cases may appear, I am quite confident that there will not be any new cases with deformities. □

THE ONLY PLACE I CANNOT GO



I can go anywhere I want to go in the world.
But there is one place I cannot go.
That is my home.

Yasuji Hirasawa, Japan

From an exhibit at the 2003 UN Human Rights Sub-Commission meeting at the Palais des Nations, Geneva

3 MDT — Multi-Drug Therapy

THE SPECIAL AMBASSADOR'S JOURNAL, 2003



Multi-Purpose Health Workers in West Bengal

Following my December 2002 visit to India, I returned in March to visit Jharkhand and West Bengal in the northeast of the country. In the fight to eliminate leprosy in highly endemic areas, the most important factor is the dissemination of accurate information about the disease. Such messages as "Leprosy is Curable," "Free Treatment is Available" and "Social Discrimination has no Place" need to be conveyed, to even the most difficult-to-reach people.

It requires an extreme effort to reach the tribal people in India, because they often do not have access to television, radio or newspapers. Additionally many of them only understand regional or tribal languages. Nevertheless, with the dedicated work by those concerned, more and more new patients are found these days. In West Bengal the prevalence rate has fallen from 16.98 per 10,000 inhabitants in 1994, to the current 3.6. On the other hand, the new state of Jharkhand has a prevalence rate of 8.9, and is in need of further efforts.

West Bengal

I arrived in Kolkata late at night on March 6th, and found myself boarding a train to the far western part of the state at six the following morning. In Asansol and Durgapur I visited PHCs and a subdivisional hospital, and also met with organizations working together toward the elimination of leprosy, including the Asansol Municipal Corporation, the Mines Board, the Department of Health and the Ramakrishna Mission. This joint effort showed me West Bengal's heightened awareness of leprosy elimination activities.

In a Durgapur sub-divisional hospital I was shown a concrete example of integration,

in which leprosy patients are being treated alongside other patients. This was the first time I had seen this in India. I am convinced there is a need for the integration of medical services in this way in order to achieve elimination. Now that leprosy is no longer a disease to be feared, all medical personnel need to be equipped with accurate knowledge and the ability to conduct diagnoses. Treating all patients together in general health wards is a concrete way of demonstrating to people that leprosy is not a disease to be feared.

On March 8th I visited the district of Howrah (a thirty-minute drive from the center of Kolkata). A constant influx of immigrants from the countryside to this area requires vigilance in the search for new patients. I visited two clinics staffed by Multi-Purpose Health Workers wearing their red saris, who are working toward the elimination of leprosy. I then returned to Kolkata and was taken to one of the city's 5,000 slums. There, local leprosy health workers and people from the Hansen Society guided me through the labyrinth of side streets where they go from house to house to reach new patients.

Jharkhand

Following Kolkata, I went to Jharkhand, which has one of the highest prevalence rates in India. This is exacerbated by the fact that 30% of the population live in mountainous areas, speak local dialects, and do not trust modern medicine. It is also difficult to examine migratory people. Further, since an estimated 61% of the state's women are illiterate, print media are not effective. ANM's (Auxiliary Nurse/Midwives), and the Anganwadi Workers (female social workers) are all working hard on the elimination effort but the lack of trained people is another large barrier.

Nevertheless, the commitment and enthusiasm of people in the field, combined with the cooperation of the media, is cause for optimism.

My time in these two states taught me that the road to elimination of leprosy can be a difficult one, but with a spirit of cooperation, we can move steadily forward. □





Panel Display in Palais des Nations, Geneva

SPECIAL REPORT

Leprosy and Human Rights

Meeting at the UN Sub-Commission on the Promotion and Protection of Human Rights, 55th session



Participants at the Geneva Meeting (left to right): Arturo C. Cunanan, Jr., Magdalena Ramirez, Kenzo Kiikuni, Birke Nigatu, P. K. Gopal, Yohei Sasakawa, and Jose Ramirez, Jr.

For too long, people affected with leprosy have suffered social discrimination, yet their voices were not heard and the problem has not been officially dealt with as a human rights issue. As reported in the last issue, Yohei Sasakawa met with Acting UN High Commissioner for Human Rights Bertrand Ramcharan on July 2nd in Geneva to discuss the problem of discrimination against people affected with leprosy. Mr. Ramcharan agreed that the issue must be dealt with as a human rights issue. At his suggestion, a briefing meeting was organized by The Nippon Foundation and Sasakawa Memorial Health Foundation at the 55th Session of the UN Human Rights Sub-Commission on August 4, 2003. This was the very first meeting in the history of the UN Human Rights Commission to take up the issue of leprosy as a human rights issue.

During the period of the Sub-Commission meetings, an exhibit was arranged with 18 photo panels displaying messages from leprosy affected people calling for better awareness of the strong social stigma they continue to experience worldwide.

The briefing was chaired by Dr. Kenzo Kiikuni, Chairperson, Sasakawa Memorial Health Foundation. Presentations were made by Yohei Sasakawa; Arturo C. Cunanan, Jr., Head, Culion Leprosy Control Project, Culion Sanitarium, Culion, Philippines; Birke Nigatu, Chairperson, Ethiopian National Association of Ex-leprosy Patients; Jose

Ramirez, Jr., Advanced Clinical Practitioner, Department Director for Network and Transportation, IDEA (International Association for Integration, Dignity, and Economic Advancement), Texas, USA; Magdalena Ramirez, Social Work Program Manager (VA Hospital, Texas); and P. K. Gopal, President, IDEA, India.

Each speaker reported the history of the difficult lives people affected with leprosy have had and the current situation in which there is still strong social discrimination and stigma against them. There were voices of surprise from the audience who, for the first time in their lives, heard about what people affected with leprosy continue to endure.

This was a very significant step forward in the fight for the elimination of leprosy as a human rights issue. This was the first opportunity provided for people affected by leprosy to speak at the UN Human Rights Sub-Commission, and it generated very positive reactions from the people concerned. It was agreed that further efforts need to be continued toward creating more occasions to convey this issue to a world audience.

The following are condensed versions of speeches given at the meeting.



Yohei Sasakawa

We who are working for the elimination of leprosy have set elimination (as a public health problem) by the year 2005 as our target. Since 1985, thanks to the introduction of MDT, well over 100 countries have achieved the elimination goal but there remain about ten countries that still have high prevalence rates. The goal of eliminating leprosy as a public health problem is clearly in sight. Now, however, it is time to seriously consider how we are going to tackle the difficult social issues associated with leprosy; the discrimination that arises from prejudice and social stigma.

Since the dawn of recorded history, there have been

numerous references to leprosy. Accounts of it can be found in the Old and New Testaments, the ancient documents of China, and Indian classics from the sixth century B.C. All of these show that, from time immemorial, the individual with leprosy has been treated with all of the fear that dwells deep within the hearts of people.

In Japan, there existed a law justifying the segregation of sufferers until seven years ago. Recently, however, those who had been expelled from society sought compensation from the government for the loss of their rights and in May 2001, they won their case. Immediately after this victory, one of the plaintiffs described his feelings by saying, "Human rights are like air. I feel that today is the first time that I can breathe freely."

The history of leprosy is the history of men, women and families whose lives have been completely determined by this particular disease. There are tens of millions of people who are still suffering from unnecessary discrimination and resulting injustice.



Arturo C. Cunanan, Jr.

I represent people affected with leprosy in the Philippines. I am among the third generation of the original patients who were sent to Culion. I became a medical doctor, and have experienced discrimination, even though I have never contracted the disease myself.

Culion at the present time persists in suffering the effects of stigmatization. There is still a myth that Culion is synonymous with leprosy and that all inhabitants have the disease. Culion is still basically considered an island of the living dead, and leprosy is still often considered to be a disease that is highly contagious and hereditary.

The effect of this is that, at present, we still do not experience equal employment opportunities, Culion students are often made to feel inferior, descendants of Culion live as outcasts, hiding their identities, and on the economic side, it is difficult to market Culion products, as people will not purchase products — especially food products — from Culion.

The people of Culion wish that the world would be free of leprosy, and especially that we had a world free of the complications of prejudice and stigmatization, and they hope that all people will work together to live in harmony and peace with mutual respect and human rights.



Birke Nigatu

Many leprosy-affected people in Ethiopia have developed visible disabilities and are classified as the poorest part of society. Disability and poverty are the results of segregation, feelings of inferiority and improper treatment.

As is common in most countries, our society — including ex-patients — has developed misconceptions about the disease. Due to a lack of knowledge of leprosy, the disease is referred to as a curse, hereditary, from God, or caused by some supernatural power. Such misunderstandings about the disease have led to victims hiding themselves or being driven from their homes and separated from their families. Most victims don't even know that leprosy is curable. As a result, they end up with disabilities.

Since society has developed an exaggerated fear of the disease, no one is interested in making social contact with leprosy-affected people. Employment is also hard to find. In general, leprosy has made the lives of those affected miserable and caused the denial of their rights as human beings.



Jose Ramirez, Jr.

One person's family history may not be very significant, except to his/her immediate family. However, when family history is taken away, that individual ceases to exist in the eyes of society. Collectively, when the identity is stripped away from millions of individuals diagnosed with leprosy, the end result is that stigma and prejudice takes the place of their existence.

When I was told that I had leprosy in 1968 — "the curse of mankind" — I felt the frightening sensation of drowning.

Following my diagnosis, I was placed in isolation at the local hospital, where people were only allowed to enter my room if shrouded in a hospital gown, cap and gloves. Adding to this indignity, I was transported 750 miles in a hearse to the only leprosarium in the continental US.

My diagnosis, and seven years of institutionalization, placed me in a position to experience the extreme depression, suicide ideation, physical and emotional scarring, and unrelenting pain and ostracism felt by millions of my brothers and sisters diagnosed prior to 1968.

It is important that this commission not maintain the "Law of Silence" regarding leprosy, as people affected by leprosy oftentimes do not believe that they possess rights. You can help in reversing this belief.



Magdalena Ramirez

I am married to Jose Ramirez, Jr., who had Hansen's disease.

Jose and our family have suffered many insults, prejudice, and discrimination. With the closure of the Hansen's Disease Center, and the opening of community health clinics for the treatment of Hansen's disease, we are once again seeing a pattern of

(Continued on Page 8)

stigmatization of Hansen's disease.

On our way to Geneva, from Houston, Texas, a woman at the airport asked us what we were carrying in the big box we were taking with us. Jose told her that they were displays on leprosy for the United Nations in Geneva. "Leprosy?" she said, "I thought it was non-existent, and that it was cured a long time ago."

That's the kind of response that is specifically the problem we face today — that the general public thinks that Hansen's disease is non-existent, and therefore dismiss it as not a very important or significant health or human rights issue.



P. K. Gopal

The leprosy started in my body when I was twelve years old. My father took me to a government hospital, but it was not diagnosed. Even if it had been diagnosed, there was no specific cure at that time.

Seven years passed, and when I was studying at college, there was a medical check-up at the college. The doctor diagnosed me as having leprosy. This was a big shock to me and my family. I continued to pursue my studies however, even with physical disabilities. Fortunately, my family loved and supported me, and so I could persevere.

In most cases, people affected with leprosy were abandoned by their families and communities. When there was a leprosy patient in a family, the entire family was socially and economically affected. People refused to marry a woman from that family. When the person had visible deformities, it was very difficult for the family to find a house they could rent to live in. Thus the family was socially boycotted by the community. Husbands could easily abandon their leprosy-afflicted wives, and parents often disowned their children with leprosy. So

the disease played havoc with the social fabric of the families of people with leprosy.

The people who completely lost their social and economic positions, and were driven away to the streets due to leprosy, were forced to beg for a living. These people began to live together in places away from the community and these places were called leprosy colonies or leprosy villages. There are 300 leprosy colonies in India.

Being cured of the disease alone does not restore normal socioeconomic status to those affected. Fear and wrong notions about leprosy still prevail in the minds of people. As a result, discrimination of people affected by leprosy still continues in many ways.

It is necessary to make those affected by leprosy conscious of human rights and to sensitize them to identify the violations, reporting the incidents to concerned authorities in order to solve the problems. □

Ambassador Meetings

Ambassador Yohei Sasakawa met the following people during the month of August 2003:

August 5th — Visit to LEPRO (British Leprosy Relief Association) in Colchester, including meeting with Terry Vasey, President.

August 5th — Visit to the University of Essex to exchange views on leprosy and human rights issues with Professor Paul Hunt, Special Rapporteur for the UN Human Rights Commission.

August 27th — Meeting with ILEP (the International Federation of Anti-Leprosy Associations) Coordinating Bureau, Dominique Martineau-Needham, General Secretary, and Trevor Durston, of the Steering Committee.

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