

FOR THE Elimination OF Leprosy

- Leprosy is curable
- Free treatment is available
- Social discrimination has no place



Delegates at the National Forum's eastern regional conference of people affected by leprosy in Kolkata, India, on September 7.

MESSAGE

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A Current for Social Change

India's National Forum of people affected by leprosy is now in its third year. In September, there was a regional conference in Kolkata for colony leaders from West Bengal, Orissa, Jharkhand and the northeastern states.

Invited to give a speech, I was profoundly moved as I looked out over the packed auditorium. Thanks to the efforts of all involved, the organization has come a long way in three short years.

The Forum has created a network of colony leaders. But in order to deepen the links between them and India's 700-plus self-settled colonies, and to strengthen their unity, more efforts are needed. Enhancing the functions of the headquarters and regional offices, and recruiting talented people — especially young people — are essential for the growth of the organization. Without the further development of the National Forum, an organization of and for people affected by leprosy, the various social and economic problems facing the colonies will not be solved.

In June, the UN Human Rights Council unanimously approved a resolution to eliminate stigma and discrimination against people affected by leprosy. India was one of the 47 member countries of the Council to approve it. All governments that are party to the resolution must honor the commitments they undertook in Geneva. To help them in this task, they need a responsible partner. In India, I hope the National Forum will be that partner, gaining the trust of both the central and state governments and collaborating with them closely on resolving the outstanding issues.

On this visit to India I went for the first time to the holy city of Varanasi, where I saw the sacred River Ganges. The Ganges flows from the Himalayas to the Bay of Bengal, and runs through India's past, present and future. Like the Ganges, the National Forum is made up of many tributaries. I believe it will become a mighty river and a powerful current for social change.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Kathmandu's Challenge

Nepal's leprosy program must reach the country's difficult-to-reach populations.

In the WHO-South East Asia Region, Nepal is one of two countries yet to achieve the goal of eliminating leprosy as a public health problem, the other being Timor Leste.

Annual numbers of new leprosy cases have decreased dramatically since the commencement of multidrug therapy (MDT) in 1982/83, when there were 31,527 cases on treatment. However, at the end of the Nepali calendar year 2007/2008 in June, there were 3,817 cases on treatment, making for a national prevalence rate (PR) of 1.42 per 10,000 population. The trends in PR and in the new case detection rate (NCDR) over five years show steady but slow decline, not sufficient for Nepal to have reached the elimination goal by now.

Administratively, Nepal is divided into five developmental regions. However, there are three topographically distinct regions in the country: the Mountain region (35% of the land mass), the Hilly region (42%) and the Plains or Terai region (23%). Nearly half (48.4%) of the country's population lives in the Terai region, wherein 82% of new cases were detected during 2004/2005.

At the district level, there are 42 districts with a PR of below 1 per 10,000 population and 14 where the PR is above 2, most of them in the Terai region. Detailed analysis of district-level data for the Nepali calendar year just ended will soon be available.

SIMPLIFIED APPROACH

In recent years, due to security reasons, the movement of health personnel was restricted in a number of districts in the Terai region. To address this challenge, the national program in October 2007 conducted an informal program review meeting in collaboration with partners, and agreed upon a simplified strategic approach to intensify activities in one of the highly endemic districts through the active involvement of local health staff and the community.

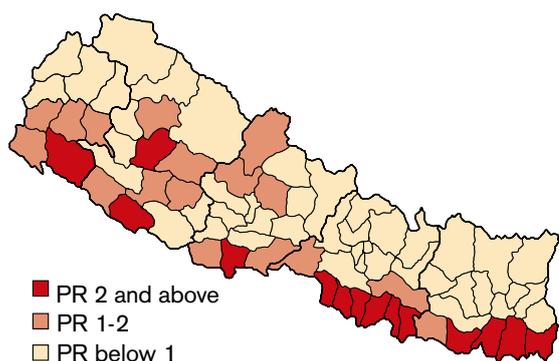


The national program was able to review the cases on treatment and update the registry for treatment completion at the health center and district levels. As a result, the registered prevalence in the area was reported to have gone down.

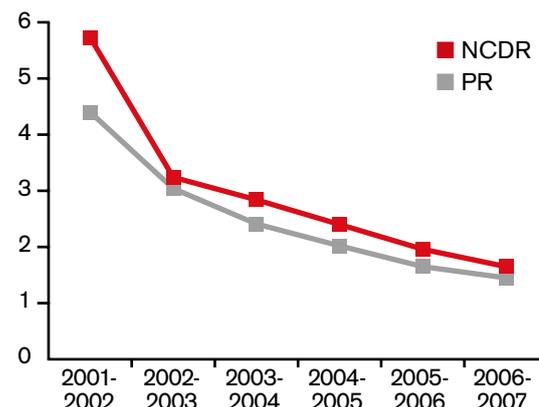
With recent political developments and improved mobility of health personnel, the national program has decided to replicate the approach in six more hyper-endemic districts. This will be done in collaboration with the WHO Nepal Country Office with a view to reaching the difficult-to-reach populations of the remote communities.

The WHO Representative to Nepal has indicated that three teams will be formed, each responsible for two districts. The local health staff and the community will work together, after a brief training stint, in reviewing the cases on treatment and updating the registry for treatment completion at the health center and the district levels. The WHO country representative invited the Global Leprosy Program and the South-East Asia Region staff to accompany the local health team to the areas and provide direct technical support as and when necessary. Gradually, the national program, in collaboration with the WHO and other partners, expects to expand the approach to other parts of the country with a view to reaching elimination. Nepal is exerting concerted effort to achieve the elimination target, in spite of the existing situation. ■

Prevalence rate by district



Trends in prevalence rate/new case detection rate



‘Sustained Action’ Is Key

India needs to consolidate its achievements, says Dr. P.L. Joshi.

India eliminated leprosy as a public health problem in December 2005, but still accounts for some 70% of the world’s new cases. What are the challenges it faces in the “post-elimination era,” and how is it addressing them? For some answers, we turned to Dr. P.L. Joshi, the deputy director general (leprosy) at India’s Ministry of Health and Family Welfare.

What are your priorities?

India is a leprosy-endemic country. We need sustained action for the coming two to three decades in order to consolidate the achievements we have made so far. This should be across the country, and throughout the year. We should not consider one area as having more burden of the disease than another.

What is the status of the National Leprosy Eradication Program within the ministry?

It is not a high-priority program compared with other programs for epidemic-prone diseases we are facing, such as HIV/AIDS. Leprosy is not a public health problem at the national level. But the government realizes that we have to sustain the program, and political commitment is very high.

How is this commitment expressed?

The government is offering 100% central assistance to states, in addition to funds provided under the National Rural Health Mission. The budget for health has increased from 0.9% of GDP to 1.5%, and in coming years will increase to 3%.

What is the rural health mission’s role?

The mission was launched in 2005. Its objective is to provide quality health services to the people of this country. One of the key concepts of the mission is to provide every village with a trained female community health activist, known as an ASHA. Selected from the village itself, she acts as an interface between the community and the public health system. We are training them in leprosy work, and the ASHA will be paid Rs. 100 for every case of leprosy she finds once it is confirmed at a primary health center. After the patient has completed treatment, the ASHA receives a further Rs. 200 in a case of PB leprosy, and Rs. 400 in a case of MB leprosy.

In what other ways is the NRHM contributing to the leprosy program?

There is a lot of emphasis on community participation. At the village level, there is a seven- or eight-member village health and sanitation committee, consisting of members of civil society and health workers. They decide what health



services to offer and are provided with Rs. 10,000 annually in untied funds. We are sensitizing members to the issue of stigma and discrimination. At the health subcenter level, which covers a population of 3,000 to 5,000, there are two female health workers and one male worker. Subcenters each receive Rs. 10,000 to be spent on what is needed. This is a good opportunity for all programs, not just leprosy. At the district level, every district has to determine what kind of support it requires for all programs, including leprosy. For example, if there are 10 people in the district with insensitive feet, it becomes a priority to obtain MCR* footwear.

How else is the program evolving?

In the post-elimination era, the program has broadened in scope to take up many other issues that had been left out before. We are working with other ministries such as rural development, social justice and empowerment, and law and justice, to provide help for the socio-economic rehabilitation of people affected by leprosy. We are also providing financial incentives to people affected by leprosy to encourage them to come forward for reconstructive surgery. They receive Rs. 5,000, while the hospital receives Rs. 5,000 to offset the cost of operations.

Your program is called the National Leprosy Eradication Program. What do you understand eradication to mean?

Our goal, our vision is eradication. But I am not talking as a scientist, I am talking as a program manager, and program managers have to have a vision. It is the vision of the country that ultimately we have to make India leprosy free. ■

Reference

* Micro-cellular rubber protective footwear is widely used by persons affected by leprosy with anaesthetic feet.

Keeping an Eye on Progress

Journeys to Niger, the DR Congo and India provide an update on leprosy control efforts in three countries where many challenges remain.

NIGER (AUGUST 7-10)

In August I made my first visit to the Republic of Niger. Two-thirds desert, Niger has a population of 13.5 million and shares its borders with seven other countries. According to the UNDP's Human Development Index rankings, it is among the poorest nations in the world.

Notwithstanding the many difficulties the country faces, Niger achieved the WHO's goal of eliminating leprosy as a public health problem in 2002. Last year, it reported 610 new cases of the disease, and had a leprosy prevalence rate (PR) of 0.39 per 10,000 population. At the sub-national level, the disease prevalence rate has fallen below one in all but two of its 42 provinces.

In recent years, however, Niger has not drawn up a new plan to sustain these achievements and further reduce the disease burden, and has not been taking advantage of the free MDT available from the WHO, relying instead on an NGO to supply the drugs. Therefore, the purpose of my visit was to refocus attention on leprosy and encourage the government to move forward and tackle the remaining challenges.

Calling at the health ministry the day following my arrival, I thanked Minister Issa Lamine for what Niger had achieved so far, and urged him to make it the first country in Africa to wipe out leprosy altogether. The minister indicated his willingness to aim for this goal, and vowed to step up activities to combat the disease in the two provinces where efforts are lagging behind.

My next appointment was with Minister of Population and Social Reform Zila Manane Bookani. I underlined the necessity of ending stigma and discrimination against people affected by leprosy, and briefed her on the resolution to this effect that was unanimously approved by the Human Rights Council in June. For her part, she told me that people affected by leprosy in Niger are among the poorest members of society, and that the ministry is working with various NGOs to address their many needs. She added that Niger conducts nationwide events and radio campaigns on World Leprosy Day to promote public awareness of the disease.

In the afternoon, I met with a couple of NGOs — Raoul Follereau Niger and Serving in Mission. Our discussions left me with the distinct impression that without the efforts of these organizations — which provide skills training,

literacy programs, agricultural support, and microfinancing — the social rehabilitation of people affected by the disease would be very difficult.

On the third day, I met with people affected by leprosy themselves. First I called at the National Center for Dermatology and Leprosy. Built in 1981, it initially specialized in leprosy, but now treats other skin diseases as well. Then I traveled to Koira Tegui, a village of 215 households of people affected by leprosy and other persons with disabilities on the outskirts of the capital, Niamey.

The villagers gave me a wonderful welcome. They sang and danced, and the young men of the community treated me to a demonstration of local wrestling. I was happy that these scenes were being recorded by a TV crew as I believe such positive images go a long way to lessening the stigma and discrimination attached to the disease.

I believe such positive images go a long way to lessening stigma and discrimination.

The same day, I was invited to the private residence of Prime Minister Seyni Oumarou. He was surprised to see me dressed in traditional Niger attire and said it sent the message that “you are thinking about Niger's problems with us.” The prime minister voiced support for eradicating leprosy from Niger completely, and promised to redouble efforts to that end.

My visit concluded with a press conference, where I was joined by the health minister and the population minister as well as some village



Niger's Minister of Public Health Issa Lamine



Beating out a welcome at Koira Tegui village in the outskirts of Niamey



Villagers gather on the shore of Lake Tanganyika for the arrival of the Goodwill Ambassador

leaders from Koira Tegui whom I had invited to attend. The health minister reiterated the commitment he gave me to tackle the disease, and said that the government would be liaising closely with the WHO on a number of issues, including strategy, drug supply and the deployment of human resources. I am hopeful that my visit has succeeded in galvanizing the government to engage more fully with leprosy, and I look forward to seeing how these intentions are translated into actions on the ground.

**DEMOCRATIC REPUBLIC OF CONGO
(AUGUST 12-16)**

From Niger I traveled to the Democratic Republic of Congo, which I was visiting for the third time. The DR Congo achieved the WHO’s leprosy elimination goal at the end of last year, when the disease prevalence rate dropped to 0.97 cases per 10,000 population.

Frankly speaking, I did not think that the DR Congo would be capable of passing this milestone so quickly. Parts of the country are still at war, its infrastructure needs building up, and diagnosing and treating the hunter-gather tribes that live in the extensive tropical rain forests of the Congo River basin presents a real challenge. The fact that it was able to achieve the elimination goal is a

great credit to all involved in leprosy work

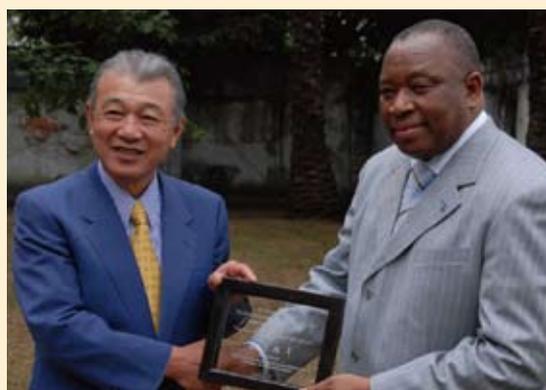
However, as with other countries that have achieved the elimination goal at the national level, the DR Congo still has pockets of high endemicity. It is therefore essential that there is no slackening of effort to control the disease. With this in mind, the purpose of my visit was both to mark the achievement of elimination with those responsible, and see for myself an area where the prevalence rate remains troublingly high.

My destination was Moba district in Katanga Province, one of four provinces where the disease is still at the level of a public health problem. Accompanied by Health Minister Dr. Victor Makwenge Kaput and the WHO country representative, I flew to the provincial capital of Lubumbashi, some 2,000 kilometers southeast of Kinshasa. From there we transferred to a 16-seater propeller plane for the 600-kilometer flight north to Moba. As we approached the dirt airstrip, I could see crowds lining the runway awaiting our arrival.

Alighting from the plane, we were met by a group of women who sang and danced for us. There must have been upward of 1,000 people who turned out to meet us.

After spending the night in a former Belgian mission, we journeyed by boat along the shore of Lake Tanganyika to the village of Mulunguzi, whose population of some 1,900 includes many people affected by leprosy. Hundreds of villagers had gathered to meet us. Stepping ashore, we were escorted to the Mulunguzi health center, walking in a huge cloud of dust thrown up by the crowds accompanying us.

The health center serves around 14,000 people. Last year, 110 new cases of leprosy were detected. It is something of a mystery why the prevalence rate remains so high, and I was told that the health ministry, NGOs, and a group of American researchers have plans to look into this. >>



Presenting a plaque to mark the achievement of elimination to DR Congo Health Minister Kaput.

Next we called at the 150-bed Moba hospital. For the occasion of my visit, the hospital had arranged for a group of leprosy outpatients to meet me. They had come with their wives and children and chatted to me in an easy-going manner. I learned that several families of affected persons lived in an area not far from the hospital. Even after being cured, they are unable to go back to their villages because of discrimination.

At the end of the day we returned to Lubumbashi for an official declaration of leprosy elimination. Planned to coincide with my visit, the event was attended by a great many media people. A lot of the questions they posed were fairly rudimentary, but I was happy to answer them all, since spreading correct information about the disease is vital to reducing stigma.

At a function that evening to mark the achievement of elimination, I toasted the DR Congo's success, promising the health minister I would return next year to help the country build on the achievement.

INDIA (SEPTEMBER 1-8)



With auxiliary health workers and ASHAs in Varanasi

I am no stranger to India, and over many visits I have seen discernable progress in the fight against leprosy. As I remarked during a courtesy call on the Ministry of Health and Family Welfare in September, I remember when the map of India on the office wall of the deputy director general (leprosy) presented a very different picture of disease prevalence.

Dr. P.L. Joshi, the current DDG, assured me that the level of political commitment is very high, and is for the long-term. He also told me about a number of new initiatives to improve health coverage at the grassroots level, including the appointment of female health volunteers known as accredited social health activists, or ASHAs, who are rewarded for each new case of leprosy they find. Hopefully, this will lead to a

lot of awareness-generation that should further assist in reducing the disease burden. There is no room for complacency: although India achieved elimination at the end of 2005, it still has the largest number of new cases of the disease in the world — some 139,000 in 2007 — so its efforts at disease control must continue.

My purpose in visiting in India this time was two-fold: to attend a seminar in Delhi to brief Indian media and partners on the Human Rights Council resolution in June, and to take part in a meeting in Kolkata of the National Forum of people affected by leprosy. Among the speakers at the human rights seminar was the charismatic Swami Agnivesh, who noted, “India takes pride in being the most religious country in the world, yet we practice the worst forms of discrimination.”

In Kolkata, I told the packed gathering of people affected by leprosy that they must take the initiative to change society. “You are the main actors,” I said, while pledging my full support for their quest for integration and empowerment.

En route to Kolkata, I made my first visit to the holy city of Varanasi, where I visited a couple of colonies as well as two primary health centers. Kashi Vishvanath Kusthya Rogi Seva Samiti was the smaller of the two colonies, home to about 80 residents, 40 of whom were people affected by leprosy. I was interested to learn that this colony has a policy of having children move out when they marry, so that the second generation doesn't become entrenched there. I was also greatly impressed by the musicians who performed for me. Not only did they play with great skill, despite their disabilities, but the expressions on their faces spoke of the redemptive power of music and its ability to nourish the soul.

Varanasi district has a population of 314,927. It is served by six primary health centers, four community health centers, 22 additional primary health centers and 253 subcenters. I visited two of these PHCs. At the first I met around 30 auxiliary midwives and ASHAs, thanking them for the important work they were doing in delivering health care services at the grassroots level, and asked them to focus not only on medical issues but the social aspects also. Both at this PHC and at the second center, I met patients on MDT who, thanks to early diagnosis and the prompt start of treatment, displayed no deformity. This is having an important impact on reducing stigma, and I am sure the work of the ASHAs and auxiliary health workers will help to strengthen this trend. ■

'No More Begging!'

Kolkata conference airs hopes and needs of people affected by leprosy.

Around 350 delegates attended the National Forum's Eastern Regional Conference on Social Integration and Empowerment of Persons Affected by Leprosy on September 7 in Kolkata, India.

Set up in 2005 to create a network among India's 700-plus self-settled leprosy colonies, the National Forum held two nationwide conferences in 2005 and 2006 before switching to a regional format from 2007.

Represented in Kolkata were colonies in West Bengal, Jharkhand, Orissa, and India's northeastern states, whose leaders provided a snapshot of the key concerns for leprosy-affected persons. Among these were children's education, job creation, ending reliance on begging, and land ownership issues.

To loud applause, V.V. Ramana from Orissa said that children of people affected by leprosy have a responsibility to ensure that their parents do not beg, "since it reflects on their dignity too." He also railed against the misuse of funds by unscrupulous individuals, saying, "It gives a bad name to all leprosy-affected persons."

Chief guest at the conference was West Bengal's finance minister, Dr. Ashim Dashgupta, who was joined on the dais by member of parliament

Basudeb Acharia, West Bengal's director of social welfare, K.P. Sinha, and Goodwill Ambassador Yohei Sasakawa among others.

Delegates were encouraged to hear both the finance minister and social welfare director say that resources



Orissa's V.V. Ramana

were available to help people affected by leprosy in West Bengal, and that the state government was willing to do more. Said Dr. Dashgupta, "As an economist, I believe you have to empower people. As soon as they are empowered, people pay them respect."

National Forum President Dr. P.K. Gopal said that in states where colony leaders have done good work, colonies have been the beneficiaries of government programs. "Where there is a strong leader, his people will prosper," he told delegates. "If he is not capable, then you should change him." ■

TRIBUTE

PROFESSOR V.S. UPADHYAY



Professor V.S. Upadhyay, who died in July, was a good friend to people affected by leprosy, and to those who worked on their behalf, writes Dr. P.K. Gopal.

I first met Professor Upadhyay in 1988 when it was suggested that I do a PhD based on my work rehabilitating leprosy-affected persons, and that he supervise my studies. I registered at Ranchi University, where he was a professor of anthropology, and gained my social science degree in 1992. Without his guidance, I would not have been able to complete my studies. He was especially happy to see a person affected by leprosy get a PhD.

We kept in touch, and when IDEA

India was started in 1997, he became involved. He thought that IDEA India would be useful to help leprosy-affected persons in Ranchi. In fact, he proposed many projects for the welfare of leprosy-affected persons living in colonies.

He told me that his friends from the university discouraged his association with leprosy-affected persons, but he did not listen to them. In time, he became the IDEA India representative for the eastern part of the country. After he retired, his involvement expanded and he opened an office in his house.

I started to invite him to many workshops and conferences in various parts of India, as I appreciated the way he encouraged people to speak out and the contribution he made. He participated in the nationwide survey of leprosy colonies, and was very helpful in the formation of the National Forum, becoming an important member of the

core committee.

He used to share with me the experiences he had gained as an anthropologist. His father had taught anthropology before him, and together they had visited many famous temples and historic places. He was extremely knowledgeable about Indian culture, and a master of many subjects. Time spent in his company was invariably fascinating.

Professor Upadhyay always had a smile on his face, and I never recall him getting angry. At my request, he took part in a Government of India workshop in June 2008 on Disability Prevention and Medical Rehabilitation. He was liked by all the participants and his suggestions warmed him to the government officials.

He died of a heart attack on July 15. Doing our work in a better way for the people he loved most will be the best way to respect and remember him.

Global Leprosy Situation Improves

New cases continue to decline from 2001 peak, according to WHO figures.

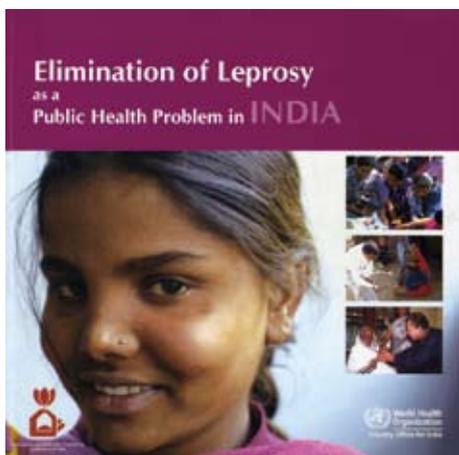
The number of new cases of leprosy detected globally continued to decline during 2007, down 11,100 cases or 4% from a year earlier, according to figures published by the WHO in the August 15 Weekly Epidemiological Record.

At the beginning of 2008, the registered prevalence of leprosy was 212,802 and the number of new cases detected during 2007 was 254,525. Annual detection is down from a peak of 763,000 in 2001.

Elimination of leprosy at the country level has been attained in all countries in the world except Brazil and Nepal. In addition, there are four countries with an extremely small number of cases or a small population where the prevalence rate is over 1 per 10,000 — Timor Leste, Micronesia, Marshall Islands and Kiribati.

In all, there are 30 countries with more than 500 new cases each year and they account for 97% of the global leprosy problem.

DOCUMENTING INDIA'S ACHIEVEMENT



India's elimination of leprosy as a public health problem by December 2005 was a significant milestone. A new publication issued in July 2008 by the WHO's country office for India tells the story of how this was done.

The 86-page booklet sketches the history of leprosy, lays out the medical and scientific facts, describes the inauguration of India's first leprosy control program in 1955 and the launch of the National Leprosy Eradication Program in 1983-84.

Dr. R.K. Srivastava, India's director general of health services, writes in the Foreword: "I am sure this publication will come in handy as a ready reference regarding the fight against the disease in the country, for the future generation of health workers and others involved in leprosy work." ■

FOR THE ELIMINATION OF LEPROSY

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With support from:

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Health Foundation,

The Nippon Foundation

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FROM THE EDITORS

JUGGLING PRIORITIES

Urging governments to remain politically committed to leprosy control activities in the post-elimination era is one of the tasks of the Goodwill Ambassador. In a world in which major public health problems clamor for attention, the pressure on the decision makers to divert resources to other diseases can be intense.

In a recent conversation with this newsletter, Dr. V. J. Pannikar, the thoughtful team leader of the WHO's global leprosy program in Delhi, said that around the world, governments are being criticized for not doing enough to combat HIV/AIDS, TB and malaria. As a result, they are looking to the leprosy infrastructure, and to key leprosy personnel, to help them out in these other areas. "They see young people dying of diseases; they have to set their own priorities," he said.

Leprosy can't compete in terms of priorities, but continued dialogue can ensure that it remains a focus of attention, said Dr. Pannikar. "There

is a moral aspect to government, and I think countries are willing to keep leprosy on the agenda. Nobody wants to have leprosy in their country."

Translating that moral commitment into a monetary commitment is harder, however. Very few national governments put resources into leprosy, he said, not because they don't want to but because they don't have them to give. One one country strengthening its effort is India. "Ever since I have known the program, the budget has only gone up. It has never stabilized or gone down. This year, in fact, the amount has doubled," said Dr. Pannikar.

His comments are echoed by the Indian government's leprosy point man, Dr. P.L. Joshi (see page 3), who assures that political commitment to tackling leprosy is high, and is being translated into new initiatives. India, for one, sees the return in investing in leprosy.