

FOR THE Elimination OF Leprosy

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



Children at Adarsh Kushta Ashram, a self-settled leprosy colony on the outskirts of Lucknow, India, photographed in March. (see p.7)

MESSAGE

There Must Be a Reason

The target set by the WHO to reduce the prevalence rate of leprosy to below one case per 10,000 population in each country by 2005, and so eliminate the disease as a public health problem, has yielded impressive results. The approach has not been without its critics, however. Among other things, they feared that when a country achieved 'elimination,' this would mislead people into thinking that leprosy had been consigned to history. While this criticism may be valid for some countries, it is not for others.

India, which accounted for about 54% of the world's new cases of leprosy in 2007, achieved the elimination goal several years ago yet remains committed to tackling the disease. Treatment has been integrated into the general health services and the government is strengthening rural health programs. India has a clear vision of completely eradicating the disease in the foreseeable future. By contrast, Indonesia and some African countries need to do more if they are simply to sustain the achievement.

Among the three countries yet to achieve

elimination, Nepal and Timor Leste will likely do so this year. The country facing the biggest challenge is Brazil. President Lula, more than most leaders, truly cares about the lives of people affected by leprosy. Given the interest taken by the head of state, it is all the harder to understand why Brazil lags behind in reaching elimination. There must be a reason for this.

I hope the government and other experts in Brazil examine the situation, pinpoint the causes and address them in a timely manner. While respecting Brazil's intentions, the WHO and its partners must do what they can to assist the country more vigorously than ever. I myself am willing to go there as often as required.

The day cannot come quickly enough when every country in the world has moved past the elimination milestone. By now, we should all be focused on reducing the disease burden further and setting our sights on the ultimate goal of eradicating the disease altogether.

— Yohei Sasakawa, WHO Goodwill Ambassador

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A National Forum Wish List

Northern Region conference highlights need for jobs, amenities.

India's National Forum of people affected by leprosy recently held its Northern Region Conference in the historic city of Lucknow. The conference was attended by 300 people, including the Health Minister of host state Uttar Pradesh, Shri Anant Kumar Mishra, and Goodwill Ambassador Yohei Sasakawa.

The National Forum represents 12 million leprosy-affected people throughout India. Dr. P. K. Gopal, head of the National Forum and president of IDEA India also attended the conference, along with Uday Thakar of Hind Kusht Nivaran Sanghatana, and Dr. Rashmi Shukla, a consultant for the WHO in Uttar Pradesh.

The Lucknow conference was organized for the socio-economic empowerment of those affected by leprosy in the 10 states of North India, including Uttar Pradesh. In Uttar Pradesh alone, there are 59 self-settled leprosy colonies, many located on vacant government land.

"The living conditions in these centers are most unsatisfactory," said S.K. Dutta, president of the National Forum Northern Region, and G. Venu Gopal, the Northern Region general secretary, in a report to the conference participants.

"The leprosy affected persons have no sources of income and therefore live on charity donations from the public and rather depend on begging," they added and requested the government of Uttar Pradesh to provide basic civic amenities such as water, electricity, roads and toilets.

Among the other proposals they had for the state government were:

- Allot the colonies the land they are built on.
- Provide residents with housing under the late Shri Kanshi Ram Ji urban poor housing scheme.
- Grant people affected by leprosy and their dependents a monthly allowance of 1000 Rupees per person per month along the lines of the aid offered by the Delhi authorities.
- Treat people affected by leprosy that are incapable of earning a living on account of their mental or physical condition as People Below the Poverty Line (BPL).

- Supply electricity to families affected by leprosy at no cost or at subsidized rates.
- Organize the supply of ointments, bandages, and medicines, and microcellular rubber footwear, twice a year under the Disability Prevention and Medical Rehabilitation scheme.
- Provide free education and technical training for children of people affected by leprosy.
- Provide employment in government departments under the 1995 Persons with Disabilities Act for people affected by leprosy.

Health Minister Mishra responded positively, pledging to immediately discuss the requests with the state's chief minister.

Yohei Sasakawa also promised his continued support to the National Forum goals of integration and empowerment, and spoke of the need to eliminate leprosy completely as well as the social stigma it attracts. He said, "My dream is to see a leprosy-free world. By this I mean a world not only free from leprosy, but free from social discrimination."

But, he emphasized, members of the National Forum must make their voices heard, otherwise society won't change. He said: "You are the main actors in the fight! Be confident of what you can achieve. Grow strong and confront injustice. For your own sakes, and for your children's sakes, reclaim your dignity as human beings."

Sasakawa's final words to the National Forum participants were: "Today let us take another step toward realizing a leprosy-free world. We are embarked on a momentous journey, and one day we shall reach our destination."

Also present at the conference were staff of the Sasakawa-India Leprosy Foundation (SILF), including Executive Director Vineeta Shanker, who announced that SILF had approved its first 10 grants for microfinancing following a meeting of its selection committee on January 23. The grants, are for projects in three states — Madhya Pradesh, Uttarkhand and Tamil Nadu — including dairy farming, candle-making and retailing. ■

AUTHOR:
Dr. David Tharp



Health Minister Mishra (left photo) and Yohei Sasakawa address the Lucknow conference on March 1.

Thoughts on Empowerment

People affected by leprosy must be treated with the respect they are due.

AUTHOR:
Kopila Basnet



Kopila Basnet is a lawyer living in Jhapa District, Nepal.



All smiles: participants in the IDEA Nepal empowerment workshop in Jhapa District last December

On 3 December 2008, I hosted a Women's Empowerment Workshop for people affected by leprosy organized by IDEA Nepal in Jhapa District. Around a dozen women affected by leprosy from three different districts attended the program.

As the workshop progressed, the women grew more confident, asking questions and eager to learn about their rights. I found it very inspiring to see them becoming empowered to live as normal members of society.

Yet many other women did not have the opportunity to attend. For this kind of program to be truly effective and reach every person affected by leprosy in Jhapa, it must be implemented in all Village Development Committees.

A recent study has shown that in Jhapa alone, 210 people have leprosy. The real number is likely to be much higher, however, as many people hide their illness through fear of discrimination.

Let me share a personal experience. After my brother got married, he began to notice that his wife was always hiding her right hand. This continued for a few months, and eventually he discovered she had leprosy. For a while, he kept the disease a secret, afraid the family would disown them if they found out. But my brother and I are very close, and eventually he came to me for help. The night he told me, the three of us sat together and cried.

We took my sister-in-law to the Biratnagar Leprosy Center, where the doctors explained about the disease and started my sister-in-law on a course of treatment. After a few months, her skin darkened — a temporary side effect of the drugs she was taking. My mother noticed and asked

what was wrong. Only then did we tell her.

My mother is not educated, and adheres to old beliefs about leprosy. For example, she banned my sister-in-law from cooking food in the house, even though we explained there was no fear of infection. She hasn't changed her mind, even though my sister-in-law is now cured. To me, this kind of discrimination inflicted by a family member is a form of psychological violence.

Such ill-founded ideas about leprosy are common. Many people tell my brother that he is unlucky to be married to a woman who had leprosy. People look at him as though he must have committed many sins in a past life to deserve such a 'bad' wife. Actually, our whole family faces discrimination as a result.

Five or six years ago, a friend of mine came to me in tears, telling me her husband had leprosy. Terrified of society's reaction, she has kept this a secret, but at great personal cost. I have not seen my friend or her husband since. They hide in their house, afraid to attend even social events such as weddings and funerals.

I believe the government must pass legislation outlawing violence in all its forms — physical, psychological, sexual — and help ensure that people affected by leprosy are treated with respect within the community. At the same time, people affected by leprosy need to be aware of their rights. They also need the means to live, and for this they need skills in order to lead independent, productive lives.

NGOs have different agendas, but the most important must surely be to advocate against discrimination. We all have equal rights, and that includes women and men affected by leprosy. ■

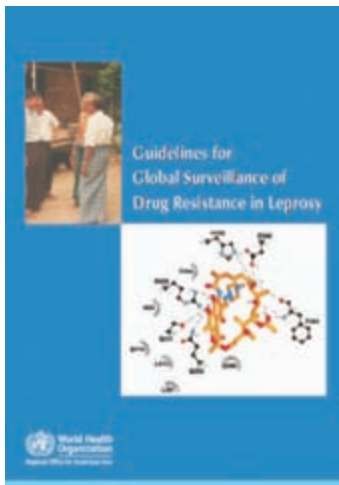
VOICES:

Women suffer more discrimination than men. They are vulnerable to psychological violence because of their position in our society. I know of a woman, Bimala, who has been rejected by her husband and his family because she was diagnosed with leprosy. Culture, tradition and lack of education make it hard for her to fight for her rights.

— Kopila Basnet

Monitoring Drug Resistance

Aim is to ensure the effectiveness of MDT for years to come.



Multidrug therapy (MDT) is the cornerstone of leprosy treatment. Thanks to MDT, the global burden of leprosy has been substantially reduced over the past two decades. Disease prevalence has

declined significantly, especially in countries where leprosy has been highly endemic for decades, and along with the decline in prevalence, annual new case detection has also started to fall in some countries.

To ensure that the achievements made as a result of MDT are sustained and that it continues to be an effective treatment for many years to come, the WHO is setting up a system to monitor drug resistance in leprosy.

“Although the problem of drug resistance is presently not acute, it is important that we collect data more systematically and monitor the trend carefully so that effective measures to combat this problem can be developed,” writes Dr. V. Pannikar in the Foreword to the recently published Guidelines for Global Surveillance of Drug Resistance in Leprosy.

The emergence of drug resistance poses a threat to any infectious disease intervention. Leprosy control has already experienced this in the form of dapsone resistance, dating back to the time when the drug was used as a monotherapy treatment for leprosy.

This is what led the WHO to develop multidrug therapy in 1981, working on the assumption that a combination of three drugs, taken regularly, would prevent drug resistance.

MDT uses rifampicin, clofazimine and dapsone for treatment of multibacillary (MB) leprosy. Recent reports have indicated instances of rifampicin resistance in several endemic areas. Resistance to dapsone has been known since the late 1960s, but so far no convincing data on clofazimine resistance has been reported.

“The establishment of a network of global surveillance for drug resistance in leprosy is primarily to keep a close vigil on the drug resistance scenario at many vulnerable settings,” writes Dr. Pannikar, who is the team leader of WHO’s Global Leprosy Program.

TWO-PRONGED APPROACH

In order to address the threat, the WHO has planned the following two-pronged strategy:

1. To closely monitor trends in the occurrence of relapses* among patients after completing a full course of treatment with MDT due to drug resistance, particularly to rifampicin, which is the most important component of leprosy control, and
2. To promote research on developing new drug regimens to treat patients who harbor *M. leprae* strains that are resistant to standard MDT drugs or patients who cannot be treated by the standard MDT regimens due to contraindications or other reasons.

To put in place the global surveillance system, health facilities will be identified as sentinel sites in selected endemic countries that have the necessary clinical, field and laboratory support systems.

“It is important that we collect data more systematically and monitor the trend carefully.”

Tissue samples will be systematically collected at these sites before being transported to designated referral laboratories where tests for drug resistance will be carried out.

Surveillance will be coordinated by the WHO’s Global Leprosy Program with the support and collaboration of national programs and major research institutes around the world. The institutes have agreed to provide free-of-cost testing of samples sent to them from the sentinel sites in the endemic countries.

The initiative is expected to be conducted on a routine basis and the results will be published annually in the WHO’s Weekly Epidemiological Record.

Underlining the importance of containing drug resistance, the guidelines conclude: “The global burden of leprosy in many endemic countries has declined and many patients are leading normal and productive lives as a result of MDT treatment. It is important that the achievements made with MDT over the past two decades be sustained so that the disease burden is further reduced and leprosy ceases to be a dreaded disease in the community.” ■

Footnote

* A relapse is defined as the recurrence of the disease at any time after the completion of a full course of treatment with WHO-recommended MDT.

Mumbai's Place in Leprosy Control

Acworth Leprosy Museum provides a legacy for future generations.

A bust of Harry Arbuthnot Acworth greets visitors to the leprosy museum and hospital that bear his name. Acworth founded "The Homeless Leper Asylum" for vagrants and beggars in Bombay in 1890 when he was municipal commissioner. In recognition of his efforts, it was renamed the "Acworth Leper Asylum" in 1904, later undergoing further name changes before becoming the "Acworth Municipal Hospital for Leprosy" in 1992.

In Acworth's time, the solution to the problem posed by leprosy was to segregate people with the disease from the general population. However, Acworth was not unsympathetic to their plight and declared he would do all he could to make their time comfortable.

"The inmates of the asylum are, without having committed any crime, prisoners for life, and (I) feel it to be my clear and sacred duty to provide, as far as (I) can, for all their legitimate requirements . . ."

The hospital was tolerant of relations between the sexes, and of the caste and religious affiliations of the inmates. A Hindu Temple, a Mosque and a Roman Catholic Church were all erected on the grounds.



(Top) External view of the museum; (above) the refurbished interior

LEPROSY RESEARCH

In 1970, hospital staff established the Acworth Leprosy Hospital Society for Research, Rehabilitation, and Education in Leprosy (ALH RRE), with the aim of facilitating the rehabilitation of people affected by leprosy, encouraging research studies and carrying out health education in leprosy. The Acworth Leprosy Museum is an extension of these activities in collaboration with Acworth Municipal Hospital for Leprosy.

Founded in 2003, the museum is housed in a former ward of the hospital and is divided into various modules: The Disease, History of Treatment, Official Reports, Legal and Social Perspectives, Institutions, Philanthropic Efforts and Approaches, Literature and Leprosy, Archival Records and Health Education.

In addition to documenting the story of the hospital, the museum's broader aim is to serve as a leprosy archival center for all of India, by making available important historical documents, reports, photographs and other records that together constitute both a medical and social history of leprosy. This work is taking on more significance as incidence of the disease declines and leprosy organizations diversify into other areas.

Visitors to the museum will doubtless see the parallel between historical social responses to leprosy and the current attitude toward other stigmatizing diseases. Among the documents held in Acworth's growing archives are those that show that the idea of a "good pious death" by suicide for those with then-incurable leprosy was espoused by ancient Indian scriptures.

"We want people to take away with them the lesson that what happened in leprosy should not happen in any other disease," said Mrs. Prathibha Kathe, the ALH RRE Society's project coordinator.

Included in the exhibits is a wooden partition once used to keep patients and doctors apart during consultations in the days when it was not known how the disease was transmitted. Also on display are posters designed by art students for a health poster competition. One reads, "Leprosy attacks the body, prejudice attacks the mind, one caused by virus, one caused by ignorance."

In recent months the museum has undergone extensive refurbishment and has been digitizing its archive of documents and books, which are available in the museum's library cum reference center. It also has an online presence. For students of medical history, and anyone with a social conscience, a visit to Acworth Museum will be richly rewarded. <http://www.theacworthleprosymuseum.org> ■

Death of a Human Rights Champion

Remembering Bernard Ka'owakaokalani Punikai'a and his 'Quest for Dignity'

Bernard K. Punikai'a, human rights advocate, musician, composer, Vice-President of the Coalition for Specialized Housing, recipient of one of the first Wellesley Bailey Awards, and IDEA's President for International Advocacy from 1997-2007, passed away in Honolulu, Hawaii, on February 25, 2009. He was buried at Kalaupapa on March 11 — IDEA's International Day of Dignity and Respect, a day he helped establish in 1999 as an occasion to reaffirm the dignity inherent in every individual.

Bernard was born in Honolulu in 1930. At the age of 6, he was taken from his mother because he had leprosy and sent to Kalihi Hospital. In 1942, at the age of 11, he was sent to the Kalaupapa peninsula where he would go on to hold many leadership roles. In Hawaii, he is best known for his efforts to resist the closure of Hale Mohalu, the Honolulu-based treatment facility that provided an alternative to Kalaupapa. As a result of these efforts, a specialized housing complex was built at Hale Mohalu which now provides affordable housing for close to 300 senior citizens and people with disabilities.

"Quest for Dignity" — words that have been translated into numerous languages — came from an interview given by Bernard in 1985. At the United Nations, Bernard's words not only launched an exhibit, but an international social movement. Quest for Dignity was a vehicle for challenging old attitudes and promoting the inclusion of the voices of individuals affected by leprosy in planning and policy-making as well as in their own history.

Bernard attended four International Leprosy Congresses, beginning in 1984. In 1998, his presentation in Beijing outlined the process that led from discrimination to acceptance and participation.

"Twenty years ago I was denied service in a restaurant because I had Hansen's disease. Fifteen years ago I was arrested for attempting to have

a voice in decisions concerning my future. Ten years ago I was appointed to the Hawaii State Board of Health. Last year I spoke at the United Nations and was elected IDEA's President for International Advocacy. The process that has led from discrimination and rejection to acceptance and participation provides practical solutions for eliminating society's fear . . .

"When injustices accumulate over a long period of time, the human spirit can no longer accept such conditions, and three things occur.

First, individuals realize that they have to assert themselves and speak out publicly in order to be seen as people, not a disease. Second, they realize that one cannot fight discrimination alone, so they network with others who have had Hansen's disease. And, third, they reach out to caring people in the community to become partners in overcoming restrictive policies, archaic attitudes and discriminatory actions.

"It's ultimately about empowering yourself. You have been put in a box — that little box whose walls are people's misconceptions about us, about what we can and cannot do. Unless

you speak out, unless you let your feelings be known, people will not know you. They will not see into your heart."

Within a few hours of Bernard's death, messages started coming in from around the world, from Japan, Brazil, South Korea, P.R. China, Mali, Nigeria, the mainland U.S., India and Nepal. Miyoji Morimoto wrote: "I first met you at the IDEA exhibit held at the United Nations Headquarters in New York in 1997. You have been with me ever since. You have left un-erasable footprints in the quest for world peace and human happiness. You have united people who had Hansen's disease. You were the pride of IDEA. You were the hope of IDEA. Now you have so many of us who are following your path with the same determination you had." ■

It is appropriate that we begin our united campaign against fear and ignorance at the United Nations, a place where world leaders come together to resolve world problems. It is our expectation that this Exhibition will help dispel ignorance, reaffirm our humanity and unite us in partnership with others . . . We want to be a part of the process, to be in a position to help others as well as ourselves . . . A Quest for Dignity.

— Bernard K. Punikai'a



AUTHOR:

Anwei Skinsnes Law
Anwei Skinsnes Law is International Coordinator for IDEA — the International Association for Integration, Dignity and Economic Advancement.

Caption

Bernard Punikai'a educates young students at the Quest for Dignity Exhibit, Honolulu City Hall, 1998. Photo by Pamela Parlapiano

A Visit to Uttar Pradesh

The Goodwill Ambassador attends a conference of people affected by leprosy in Lucknow, India, and tours a nearby colony where most residents make a living from begging.

INDIA (FEBRUARY 28 – MARCH 2)

At the beginning of March I attended a regional conference in Lucknow, Uttar Pradesh, of India's National Forum of persons affected by leprosy. The Forum had its origins in a conversation I had back in 2005 with Dr. P.K. Gopal, the president of IDEA India and also now the head of the National Forum. We agreed that if people wanted to recover their rights and improve their circumstances in life, then they would have to stand up and act. So long as they continued to live in colonies beyond the social mainstream, begging for a living, then the outside world's attitude toward them wouldn't change, and discrimination wouldn't go away.

Since its founding in 2005, the National Forum has developed nationwide, nurturing leaders in each of India's more than 700 self-settled colonies, connecting them at state level, and working for the integration and empowerment of people affected by the disease. The conference in Lucknow, which was held on March 1, was the third regional gathering to date, and attended by over 300 colony representatives in India's 10 northern states.

The chief guest was Uttar Pradesh's health minister, Shri Anant Kumar Mishra. He told the audience, "Tomorrow I have a meeting with the chief minister of UP, so if you have any requests, then give them to me during the course of today." (For more details, see page 2.)

Common to all delegates was the desire not only to better their own situation but to ensure there are good prospects for the next generation and the generation after that. "It's not charity we want, but opportunity," best sums up their outlook, I feel.

With regard to that, I am hopeful that the Sasakawa-India Leprosy Foundation will



Stopping to chat with colony residents



Colony leader Om Prakash with family members

make a difference. The foundation, which formally began operations last year, took the opportunity of the conference to announce that it has approved its first 10 grants of financial aid to people affected by leprosy for business development. Next it plans to award scholarships for higher education and vocational training.

While in Lucknow, I visited the Adarsh Kushta Ashram, a self-settled leprosy colony about 40 minutes' drive from the city, not far from the airport. This colony, established in 1974, is home to Om Prakash, leader of the nearly 60 colonies found in Uttar Pradesh. The colony consists of 52 households, or about 250 people, of whom some 90 are persons affected by leprosy. Around 100 children go to mission-run boarding schools in Varanasi and elsewhere.

The colony is built on public land, with residents living in concrete tenements around the perimeter of the colony, leaving the central area open. I was told that 90% of the residents making a living from begging outside temples, restaurants and shops.

I learned that they each carry a certificate to show that they are residents of the colony, so distinguishing them from other beggars found on the streets. The residents earn an average 50 Rupees a day. They pool their earnings and distribute them among the community.

Overall, this is a well-organized colony. It is clean and tidy, and has its own water supply. But the fact is, most residents beg for a living, and many children are going to mission schools rather than public schools. It shows the challenges that remain before these residents and others like them can become part of the social mainstream. ■

Asia-Pacific CBR Congress Held

Post-congress workshop looks at strengthening linkage between CBR and leprosy.



Opening ceremony of the Asia-Pacific CBR conference in Bangkok

The First Asia-Pacific Community-Based Rehabilitation Congress was held in Bangkok, Thailand, from February 18 to 20. Around 700 participants attended from over 50 countries in the region, including representatives from central and local governments, NGOs, disabled people's organizations, and regional and international organizations. The involvement of people with disabilities was extremely high both as presenters and participants.

The congress, the largest gathering of community-based rehabilitation (CBR) practitioners to date, highlighted evidence of innovative

initiatives under way in the region as well as the popularity of CBR in the Asia-Pacific.

A post-congress workshop on CBR and Leprosy was held on February 21 and 22. The main objectives were the strengthening of the linkage between CBR and leprosy programs; the promotion of the WHO/IILEP Technical Guide on CBR and Leprosy and leprosy programs to embrace CBR; and the inclusion of people affected by leprosy in a CBR program and in society. A total of 86 participants from 20 countries took part.

At the end of the workshop it was unanimously decided that more such workshops are needed to bring these two sectors closer so as to promote quality of life of people affected by leprosy, to enhance their inclusion in society and to ensure that people affected by leprosy enjoy the same rights and opportunities as any other disabled as well as non-disabled person.

For further information regarding the Asia-Pacific congress, please visit <http://www.cbr-asiapacific.org/> and for the post-congress workshop on CBR and leprosy, go to the AIFO website: <http://www.aifo.it/english> ■

FROM THE EDITORS

WORDS TO LIVE BY

Anwei Law's remembrance of Bernard Punikai'a, who died earlier this year, lets Bernard's own words serve as the best tribute to a man whose "Quest for Dignity" inspired an international social movement for the empowerment of people affected by leprosy. A 1998 presentation he made in Beijing (quoted on page 6), which described his journey from discrimination to acceptance and participation, showed how far he had come and why he served as such an inspiration to others.

Inspiring people affected by leprosy in India to take charge of their lives is the role of the National Forum, which held its latest regional conference in Lucknow in March (page 2). The Forum is committed to the goals of integration and empowerment, and is building up a network of leaders among the country's self-settled colonies and generating momentum for change. Yet the

conference was also an occasion to confront the reality on the ground: many delegates lead a hard existence, and wonder whether prospects will be any better for their children.

Empowerment is on the mind of Kopila Basnet, a lawyer in Nepal's Jhapa District (page 3). Kopila was the emcee of an IDEA Nepal workshop for women affected by leprosy held last December. She describes being inspired by the transformation that came over the participants, but notes that so many more women who would also have benefited from the event did not have the opportunity to attend. This too is the reality on the ground, even at the local level.

For many people affected by leprosy, opportunities for empowerment remain far off. But if every person who makes the transition can blaze a trail for others to follow, progress will surely be made.

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