

# FOR THE Elimination OF Leprosy

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



In this dramatic reenactment, local residents are cleared off the island of Culion, the Philippines, in preparation for its new role as a leprosy colony.

## A MESSAGE FROM THE GOODWILL AMBASSADOR

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### Remembering Dr. J.W. Lee

I was deeply saddened by the sudden death last month of WHO Director-General Dr. Jong-Wook Lee, a comrade in the fight against leprosy. Dr. Lee devoted his life to public health and was involved with leprosy from early in his career. He met his Japanese-born wife at a leprosy sanatorium in South Korea, where she was working as a volunteer.

Among the many diseases that the WHO tackles, Dr. Lee took a special interest in leprosy. It was Dr. Lee who appointed me as WHO Goodwill Ambassador for Leprosy Elimination. In particular, he was concerned about the issue of discrimination.

At this year's World Health Assembly in Geneva, Dr. Lee had been planning to extend my term for a further two years. In the event, I received my letter of appointment from Acting Director-General Anders Nordstrom. At the WHO's request, newly included in my mandate is the reduction of stigma and discrimination suffered by persons affected by leprosy.

My new term as goodwill ambassador has thus begun. I intend to do my utmost to honor the

wishes of the late Dr. Lee and reward the faith he showed in me.

Former WHO Director-General Dr. Halfdan Mahler, in mourning the loss of Dr. Lee, quoted words that I believe are attributable to Dr. Benjamin Mays, an American scholar and social activist.

"The tragedy of life does not lie in not reaching your goal. The tragedy lies in having no goal to reach. It is not a calamity to die with dreams unfulfilled, but it is a calamity not to dream. It is not a disaster to be unable to capture your ideal but it is a disaster to have no ideal to capture. It is not a disgrace not to reach the stars but it is a disgrace to have no stars to reach for. Not failure, but low aim is sin."

As Dr. Mahler said, Dr. Lee had very high aims for the WHO, the organization he served with love and skill. He dedicated his life to building a healthy, happy society.

Let us fulfill one of his cherished wishes, and achieve a world without leprosy.

— Yohei Sasakawa, WHO Goodwill Ambassador

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# Leprosy Control in India

A senior health official puts the elimination achievement in context

The first record of a leprosy-like disease in India appeared in the sixth century BC. It is said that leprosy was referred to as “Kusht” in Vedic writing, which is how the disease is known even to this day.

The government of India started a National Leprosy Control Program in 1955 based on Dapsone domiciliary treatment through vertical units implementing survey, education and treatment activities. The National Leprosy Eradication Program was launched in 1983 with the objective of arresting disease activity in all known cases of leprosy with the use of multidrug therapy.

In December 2005, at the end of some two decades of the fight against leprosy with MDT, India succeeded in achieving the goal of elimination of leprosy as a public health problem at the national level, reaching a prevalence rate of 0.95 per 10,000 population. Three months later, on March 31, 2006, PR was further reduced to 0.84.

India contributes nearly 70% of the global case load of leprosy and therefore this achievement will have a huge bearing on the global situation. The gradual reduction in newly detected leprosy cases since the year 2002-03 also speaks well of the strategy.

The significant achievements associated with leprosy elimination in India have been:

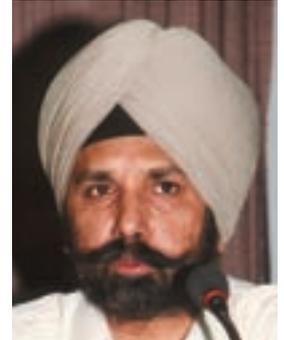
- changes in service delivery to the integrated system through the Primary Health Centers, which increased people’s accessibility to services nearer to home;
- training and retraining of a large number of

General Health Care practitioners to make them proficient in recognizing leprosy and providing health education;

- repeated mass awareness campaigns that have helped to increase public awareness of leprosy and its curability, resulting in an increase in self-reporting for diagnosis and treatment;
- the slow but sure diminishing of stigma associated with the disease in society;
- streamlining of data generation, reporting and monitoring through a Simplified Information System (SIS) introduced in 2002.

With 74% of districts having already achieved elimination and only 29 districts (5%) having a PR of more than 2, progress toward achieving subnational elimination is well under way.

**AUTHOR:**  
**Dr. G.P.S. Dhillon**



Dr. G.P.S. Dhillon is India’s Deputy Director General of Health Service (Leprosy), Ministry of Health and Family Welfare.

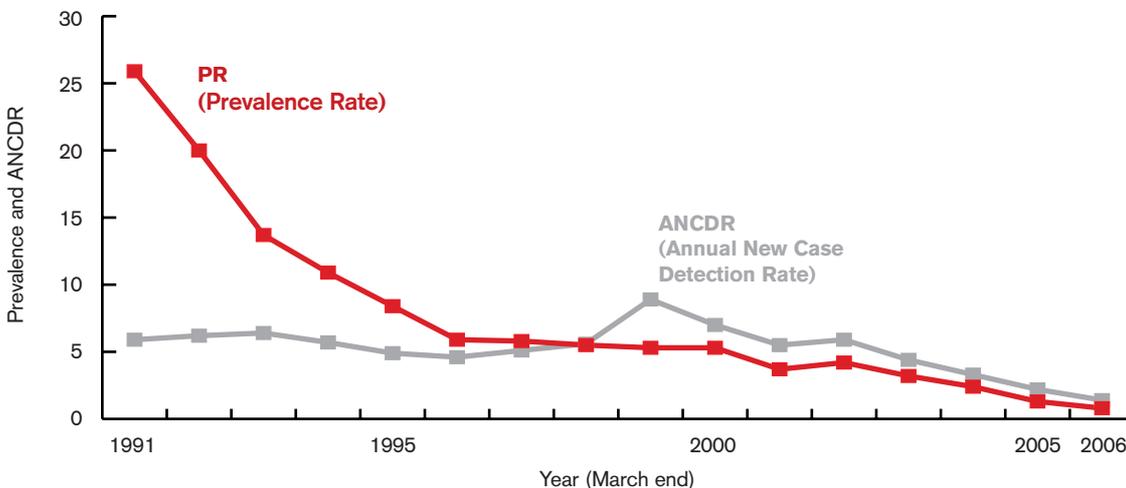
The face of leprosy in India will be hugely different from the past.

## FUTURE STRATEGIES

For a few more years, India will follow the same strategy of case diagnosis and management through integrated services, continuous capacity-building of GHC staff, focused IEC activities, improved disability prevention and medical rehabilitation, and continuous monitoring and supervision.

In the current year, activities center on the

Trend of Leprosy Prevalence & Annual New Case Detection Rates/10,000 Population



## Leprosy FACT

- India detected 161,457 new cases of leprosy during 2005, followed by Brazil (38,410), Indonesia (19,695) and the D.R. Congo (10,369) (WHO)

following:

- continue efforts to achieve elimination of leprosy through existing MDT services in the remaining states/ Union Territories;
- focus attention on :
  - endemic districts
  - endemic urban localities
  - districts showing high disability rates
  - states with a high proportion of child cases;
- continue efforts to provide quality diagnostic and treatment services for leprosy in each peripheral health institution; provide services on all working days; underscore necessity for correct diagnosis by a PHC medical officer; continue process of validation by District Nucleus/District Technical Support Team; carry out proper counseling and case follow-up for better case-holding;
- improve capability of the GHC staff in prevention and management of leprosy disability, along with increasing the number of reconstructive surgery centers; plan for a three-tier system of prevention of disability services;
- continue capacity-efforts for all categories of staff whose involvement in the program is essential, both in rural as well as urban areas;
- continue to increase awareness about leprosy among the masses with the aim of bringing about attitudinal change and removing stigma against the disease;
- draw up a special activity plan for the year 2006-07 for the 29 districts remaining with a PR of more than 2/10,000.

### LESSONS LEARNT

1. Repeated Modified Leprosy Elimination Campaigns (a total of five in eight years) with specific strategies for different areas helped detect nearly 0.99 million leprosy cases in a relatively short period of time (six days). Each successive MLEC showed detection of a much smaller number of cases, indicating that hidden cases were being flushed out and transmission potential reduced. New case detection dropped only after the 4th MLEC, which is very significant.
2. Mass awareness about leprosy was possible



As awareness of leprosy increases, stigma diminishes

only through these campaigns organized at regular intervals. Interpersonal communication at village and community level has a big advantage over other IEC methods in NLEP.

3. Integration of leprosy services with the GHC system has helped patients a lot, not only because of increased accessibility but because of the confidence they gain from consulting with the Medical Officer. This creates greater acceptance and leads to more voluntary reporting.
4. The inexperience of GHC staff, the self-interest of vertical leprosy staff and lack of patient awareness of the importance of completing treatment during the prescribed period caused certain “operational factors” to develop, which initially kept the leprosy case load higher than it actually was. Leprosy Elimination Monitoring surveys were carried out during the years 2002, 2003 and 2004 through independent agencies, which helped in pointing out deficiencies in the integrated system, availability of service in all health facilities, status of community awareness and operational factors.

Once these operational factors — wrong diagnosis, re-registered cases, non-existent cases, non-release of patients from treatment even after completion, irregularity in drugs collection by patients, lack of follow-up — were identified and corrected, the results were soon apparent.

Although the goal of leprosy elimination as a public health problem at the national level has been achieved, the government will continue with its program of leprosy eradication, to bring the benefits to people living in all parts of the country. There is no place for complacency at any level. The face of leprosy in India during the next six years is expected to be hugely different from the past. ■

# Heritage Preserved

New museum is a rich repository of Culion’s past as world’s largest leprosy colony

A hundred years ago, when the American colonial authorities decided that segregation was the only answer to the Philippines’s leprosy problem, the island of Culion was designated as a leprosy colony. In May 1906, the first arrivals were brought ashore.

Today, their story and the stories of the many that followed are preserved in the Culion Museum & Archives, a fascinating repository of leprosy history newly opened during Culion’s centennial celebrations last month.

The two-story museum, located in what was the first laboratory for leprosy research in the Far East, houses a wealth of photographs, documents and clinical records relating to the days when Culion was the world’s largest leprosy colony.

It also showcases many instruments and artifacts, ranging from the syringes with which patients were injected with chaulmoogra oil to the special currency used on Culion to prevent (it was believed) the disease being transmitted elsewhere.

Despite its reputation as an “island of the living dead,” the museum shows how colony residents had a life of their own, holding elections and forming their own council. It also records the pioneering research work that was carried out on Culion by, among others, Dr. Windsor Wade, the founding editor of the *International Journal of Leprosy*.

“The museum will help the people of Culion to know themselves and their past,” says Dr. Arturo Cunanan, in charge of the island’s leprosy control and rehabilitation program. “It will help them to fill the gaps in their lives.”

It also makes a wider contribution — to the history of leprosy, of medicine, of American colonial rule. “It’s a rich collection, and our job is to provide access to scholars. There are materials here that can further their research,” says Alexandra Botelho, an expert in paper and photo conservation.

Organizing the collection has been the work of Ricardo Punzalan, assistant professor of archival studies at the University of the Philippines. The professionalism he has brought to the project is apparent at every turn, from the decisions on what items to display to how they are presented. “The majority of the time was spent on thinking about what we wanted to communicate, not on installation,” he says.

Both Punzalan and Botelho have volunteered their services and are happy to do so. “It’s not just a job of work. It’s a significant part of our heritage, and I believe internationally as well,” says Punzalan. “Our goal is to have the museum listed in UNESCO’s Memory of the World Register. This should definitely be part of human memory.” ■



Ricardo Punzalan: volunteered his services as curator

**Reference**  
 Culion Museum & Archives  
 Opening Hours:  
 9:00-12:00, 1:00-4:00  
 Closed Saturdays, Sundays, & Holidays  
 Email inquiries:  
 artculsan@yahoo.com



With its valuable collection of records and artifacts, including special currency (right, bottom), the new museum will be a boon to scholars.



# Strategy Evolves for 2006-2010

Referral system, quality of leprosy services, human rights among issues highlighted

## GLOBAL FORUM

In April, the Global Forum on Leprosy met in Aberdeen, Scotland, to discuss operational guidelines for the WHO global leprosy strategy for 2006-2010. Among the points highlighted were:

- the need for an effective referral system, now that leprosy services are being integrated into general health service worldwide
- the importance of self-reporting as a crucial component of case-detection
- the necessity to pay more attention to prevention of disability.

In particular, it was emphasized that program managers must adapt the operational guidelines to the situation in their own country.

The guidelines were endorsed by the 8th WHO Technical Advisory Group, also in Aberdeen.

## SEAR NAT'L PROGRAM MANAGERS MEETING

On May 15-17, the national leprosy program managers of the WHO South-East Asian Region\* countries met in Bangkok. Also taking part were representatives from a number of NGOs.

With the exception of Nepal and Timor Leste, all countries in the region have achieved elimination and are making progress in reducing the burden of leprosy and its consequences.

In view of the declining leprosy burden, the meeting strongly recommended that the annual new case detection and cure rates be used as the primary indicators for monitoring leprosy programs. It also stressed that importance should be given to achieving high cure rates.

Large countries in the region that are aiming at subnational elimination were discouraged from pursuing this goal through case detection targets. Other recommendations included:

- according high priority to sustainability and ensuring quality of services;
- strengthening prevention, management and care of disabilities and rehabilitation, which are an essential component of leprosy services;
- bringing human rights issues related to leprosy to the attention of policy makers and opinion makers, including the judiciary, the media and civil society, and seeking the repeal of discriminatory laws that remain. ■

## Reference

\* The WHO South-East Asia Region groups together Bangladesh, Bhutan, Democratic People's Republic of Korea, India, Indonesia, Maldives, Myanmar, Nepal, Sri Lanka, Thailand and Timor Leste.

## TRIBUTE

### DR. J.W. LEE



© WHO/C. Bodenstein

It came as a great shock to learn of the sudden passing of Dr. J.W. Lee, the director-general of the WHO. He was in apparent good health, and eager to shoulder his heavy burden for the next five years after his current appointment through 2007.

My first contact with him was when he wished to go to Hawaii to do a Masters in Public Health. Dr. P. Worth, a renowned epidemiologist with whom I was acquainted, approached the Sasakawa Memorial

Health Foundation for a fellowship for a promising young Korean doctor, and we agreed to meet his request.

The young doctor turned out to be Dr. Lee, as I found out several years later when he joined the WHO's Western Pacific Regional Office in the early 1980s. He was first stationed in Fiji, and later in Manila as the regional advisor on leprosy and TB.

Thus he became a very close working partner of ours in Asia. He was particularly helpful in involving countries such as Papua New Guinea and Micronesia — countries not among our regular working partners such as the Philippines, Vietnam and China — in our foundation's activities. He and I made joint field visits several times a year for nearly 10 years, until he was promoted to a higher position in WPRO, then moved to Geneva.

Our most memorable joint work was to draw up a regional strategy to

reduce the prevalence of leprosy to less than 1/10,000 at the national level and eliminate the disease as a major public health problem by 1998. This came about as a result of a request by Dr. S.T. Han, the regional director at the time. This regional strategy led to the 1991 World Health Assembly resolution to achieve elimination on a global scale.

I had the privilege of spending one whole Sunday with Dr. Lee and his wife after he became director-general. I learned of his continued interest in and commitment to leprosy, even though his vast responsibilities for global public health issues limited his involvement personally. We have lost a dear friend and valuable supporter of world leprosy programs.

— Dr. Yo Yuasa

*The author is former executive director of the Sasakawa Memorial Health Foundation.*

# A Journey toward a New Beginning

Vietnam, India and the Philippines were among the destinations on the goodwill ambassador's itinerary in recent months.

## VIETNAM (MARCH 31)

This March found me in Vietnam to mark the 50th anniversary of the founding of Vietnam Maritime University. While there, I used the opportunity to visit a leprosy treatment center in Quacam, about 90 minutes by car from the capital, Hanoi.

I last visited Quacam in 1994. Alongside the center is a colony that is home to around 200 people who have recovered from leprosy and about 100 children. There is also a residential section for the elderly, where I met a 76-year-old woman who had spent the past 52 years in the colony, as well as another elderly woman of 96.

About 50 residents gathered in a hall to greet me. I was struck by how full of life they were, and the general atmosphere of well-being I found there.

The reason for this, I gathered, was the absence of stigma. Stigma existed in the past, but there is almost none today. The elementary school within the leprosy treatment center is also the local village school. Altogether, about 300 children attend. The treatment center also functions as a dermatological hospital. There are about 20 beds for leprosy patients.

I was told that at present there are some 1,200 registered cases of leprosy in Vietnam: 15% have disabilities, and 10% are children.

While in Vietnam, I also had an opportunity to have dinner with Le Tien Thanh, vice minister of Labor, Invalids and Social Affairs. I recalled that on my last visit in 1994, I proposed at a WHO gathering to provide a five-year free supply of MDT all over the world, and this was



Residents of a leprosy colony in Quacam

unanimously accepted.

The vice minister said this has played a huge part in changing people's perceptions of leprosy, and led to the disappearance of stigma toward persons affected by the disease. I was also very pleased to hear from him that social rehabilitation is making progress.

## INDIA (APRIL 26-28)

The chief purpose of my third visit to India this year was to lay the groundwork for establishing a foundation for the social rehabilitation of persons affected by leprosy, and to meet with senior figures in the Indian business world to explain the foundation's objectives with a view to raising funds.

My other mission was to deliver a message of congratulations to the Indian government and the WHO upon India's achieving the elimination goal at the end of last year.

I first called on the Ministry of Health and Family Welfare to meet with Joint Secretary Rita Teotia and Deputy Director General (Leprosy) Dr. G.P.S. Dhillon. Both told me that the fight was not over, and that India's next goal was subnational elimination. I told them that I hoped to visit the nine states/Union Territories yet to reach the elimination target and encourage them in their efforts.

To discuss the proposed foundation, I called on both the Confederation of Indian Industries and the PHD Chamber of Commerce and Industry. Also, through the good offices of Dr. Rajiv Kumar, the director of the Indian Council for Research on International Economic Relations, one evening I was able to meet up with leading figures in the worlds of business, academia, the media and other fields.

Everyone present showed a good grasp of the issues surrounding leprosy, and expressed their strong support for stamping out discrimination and creating opportunities for social rehabilitation. They also gave their backing to the foundation idea.

Concerning funding, The Nippon Foundation will donate an initial \$10 million but I am hoping that between them India's industrialists will be making a similar contribution. I am now working through an Indian law firm on setting up the foundation, and hope it will begin operations within the next six months.

### Leprosy FACT

- The Philippines achieved elimination of leprosy as a public health problem in 1998.



Yohei Sasakawa gives a speech during his visit to Culion. Beyond him is a monument marking the landing site of the first leprosy patients brought to the island on May 27, 1906.

**PHILIPPINES (MAY 5-8)**

In early May I was delighted to take part in a remarkable event: the centenary celebration of the founding of a leprosy colony on Culion island in the Philippines.

Culion lies about 200 kilometers southwest of Manila, and at one time was the world's largest leprosy colony.

The first batch of leprosy patients arrived on Culion on May 27, 1906, where they were met by an American doctor, four French sisters of St. Paul de Chartres and a Spanish Jesuit priest. This was the subject of a poignant reenactment that I attended on May 6. The "lepers" were all played by persons affected by leprosy living on Culion.

to the world on how to overcome deep-rooted stigma and discrimination.

Following the reenactment, I took part in the formal opening of the Culion Museum & Archives. Funded by the Sasakawa Memorial Health Foundation, this is a beautifully curated project that takes visitors through Culion's history as a leprosy colony and provides an excellent introduction to the topic. In the words of Dr. Arturo Cunanan, head of the Culion Leprosy Control & Rehabilitation Program and himself born on Culion, "The museum is a repository of our heritage. We open it with pride."

Toward the end of the day, I attended a service of remembrance at Culion's cemetery for leprosy patients. Even in death, persons with leprosy were segregated.

Noting how far Culion has come since 1906, Rommel Howard Iway, the president of the St. Ignatius College Alumni Association, referred to those buried there as "sacrificial lambs." Describing Culion today as a "paradise," he added, "If they are looking at us from heaven, they might be saying, 'This is our gift to you from us.'"



Dr. Arturo Cunanan: a Culion native and main organizer of the centennial celebrations



Posing with sisters of the Order of St. Paul de Chartres.

This was followed by the unveiling of a marker at the landing site, and the release of 100 doves and balloons. Many speeches were made, and in my own remarks I heralded Culion's transformation from an island of despair to a place of hope.

From being an isolated leprosy colony 100 years ago, Culion achieved status as a municipality in 1995, and is now seeking to make its way like any other community. Many living on the island today are the children and grandchildren of leprosy patients and of the doctors and staff of the original sanatorium facilities.

I believe Culion sends a very positive message

**SWITZERLAND (MAY 24-26)**

Toward the end of May, I was in Geneva for the World Health Assembly, an event overshadowed by the sudden and untimely death of WHO Director-General Dr. J. W. Lee (see page 5).

I had the opportunity to meet with health ministers from India, Madagascar, Tanzania, Angola, Myanmar and Nepal, as well as health ministry representatives from Indonesia, the Democratic Republic of Congo and Mozambique.

I also had the pleasure of attending the award ceremony for the 22nd Sasakawa Health Prize, which was presented to the International Leprosy Union and accepted by its president, Dr. S.D. Gokhale, for its services to leprosy work. Congratulations! ■

# ILU Wins Sasakawa Health Prize

Dr. Gokhale acknowledges Mahatma Gandhi as role model in fight against leprosy



The International Leprosy Union, represented by its president Dr. S.D. Gokhale, was one of two recipients of the 22nd Sasakawa Health Prize awarded at the World Health Assembly in Geneva on May 25.

The prize is presented annually to outstanding individuals and organizations working to improve primary health care in both the medical and social fields.

Launched in 1986, the ILU was a pioneer in the fight to protect the human rights of people affected by leprosy in India. For 20 years it has worked to correct public perceptions of the disease, empower those affected by it and help in their social reintegration.

In his speech of acceptance, Dr. Gokhale began by paying tribute to Mahatma Gandhi, saying, "Gandhi was a great visionary, and his mission was not only to treat but to eliminate and eradicate leprosy. He inspired hundreds of leprosy workers to take up this cause. ILU and myself are humble partners in this crusade."

Noting that "the battle against *M. Leprae* is more or less over," thanks to the introduction of multidrug therapy, Dr. Gokhale said that "the battle against stigma has still to be won." Even after being cured, people affected by leprosy continue to be "stigmatized, alienated and not accepted by their families and society," he said.

Based on his time as the superintendent of a leprosy home, where an elderly woman resident asked not to be introduced to a visiting official because the man was her son and believed his mother was dead, Dr. Gokhale came to see that suffering due to leprosy was not merely physical. "It is the existence of stigma that hurts leprosy patients the most," he said. ■

## Leprosy LEXICON

### ● *M. leprae*

Leprosy is a chronic infectious disease caused by a bacterium, *Mycobacterium leprae*.

This slow-growing bacterium is related to *M. tuberculosis*, the organism that causes TB. *M. leprae* was discovered in 1873 by a Norwegian physician, Gerhard Henrick Armauer Hansen. Because of the negative associations attached to the word leprosy, the disease is known by many today as Hansen's disease.

## FOR THE ELIMINATION OF LEPROSY

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## FROM THE EDITORS

### LEPROSY AND HIV/AIDS

Two recent statements on HIV/AIDS could easily have been referring to leprosy.

At a civil society hearing at the end of May in connection with a UN General Assembly high-level meeting on HIV/AIDS, Secretary-General Kofi Annan said that the only way to win the fight against HIV/AIDS is if civil society is at the heart of those efforts.

"One of the absolute musts in this effort is greater and more meaningful involvement of people living with HIV.

"Their perspectives are needed to make sense of programs, planning and policy-making for HIV prevention, care and treatment. Their engagement is the key to stamping out stigma and discrimination. Their voice is the surest way to sustain the passion and compassion we need to win against the pandemic.

"Yet, so far, HIV-positive people have not been involved nearly enough. The international community has not made full use of their

expertise and insight. Too often, attempts to engage them have looked like tokenism," he said.

"We must do better. That means that governments, the UN system and civil society at large need to develop more effective partnerships with people living with HIV."

A few days earlier, on the opening day of the World Health Assembly in Geneva, delegates were introduced to an HIV/AIDS activist from Kenya, Johnson Mwakazi.

Mwakazi, who is HIV positive, spoke of his experiences through this poem:

### Underneath the Veil

This one thing has destroyed families,  
This one thing has destroyed marriages,  
This one thing has killed men.

It is not HIV

It is not AIDS

...It is stigmatization.

I say STIGMATIZATION.