

# FOR THE Elimination OF Leprosy

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



Ensuring that children have a healthy future is a key task (Photograph taken at Jayapura Hospital, Papua Province, Indonesia, January 2014)

## MESSAGE

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# For Our Children's Future

Visiting Timor-Leste in 2005, I was surprised to meet a 7-year-old leprosy patient. This January, when I went to Indonesia's Papua Province, I came across a 4-year-old with leprosy. Fortunately, she had been diagnosed early and was receiving treatment, and showed no signs of disability.

Leprosy is not just a medical issue. These days, much attention is being paid to the stigma and discrimination it causes. To appreciate how much of a problem this is, one only has to look at the difficulties people face even after they have completed their treatment.

In the past, the health ministry of the Indian state of Uttar Pradesh arranged for pupils at government schools to be taught about leprosy and given a body chart to take home with them. Their assignment was to conduct a skin check of their family members for signs of leprosy. This approach was a boost to the early detection of new cases, especially among children.

I would like to see health ministries everywhere adopt this approach and engage in a major effort to uncover new cases, especially child cases. This has

the added benefit of getting families to talk about leprosy. Not every child case will be diagnosed in this way, but if it became a social movement, I believe it would achieve excellent results.

Every parent wants their children to grow up healthy and free from stigma and discrimination. In that regard, the early diagnosis and treatment of child cases is one of the most important undertakings in the fight against leprosy, as preventing disability also acts as a shield against discrimination.

At 75, I grow impatient at how little time I have left to make difference, when I see the tragedies that leprosy still causes. I am also concerned by the slow progress we are making against the disease. Last year, 17 endemic countries signed the Bangkok Declaration, renewing their commitment to fight leprosy. The Nippon Foundation has made a commitment of US\$20 million over a five-year period. Let all of us redouble our efforts to achieve a world without leprosy and its consequences.

— Yohei Sasakawa, WHO Goodwill Ambassador

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# Lessons from Thailand

How to deal with leprosy and its consequences in a low-endemic context.



*Thailand eliminated leprosy as a public health problem in 1994. We asked staff of the Raj Pracha Samasai Institute of the Ministry of Public Health's Department of Disease Control to explain what the country is doing to sustain leprosy services 20 years on.*

## What were the main contributing factors in Thailand's elimination of leprosy?

The integration of leprosy control into general health services started in 1973, and by 1976 the whole country was covered. After the introduction of multi-drug therapy in 1984, 100% coverage was achieved in terms of area and registered cases, by 1989 and 1994, respectively. Other factors included the commitment of health organizations in and outside the country, the improving socio-economic levels of the population and the fact that the leprosy control program in Thailand is under royal patronage.

## What steps has Thailand taken to sustain leprosy services and continue to reduce the burden of the disease in the country?

After Thailand achieved elimination at the national level, the leprosy program was strengthened. We conducted three Leprosy Elimination Campaigns (LECs) between 1996 and 2002 to accelerate case-finding in the community, which resulted in the detection of new cases. From 1998 to 1999, we carried out Leprosy Elimination Monitoring (LEM) based on WHO guidelines in 32 provinces and implemented a

Special Action Project for the Elimination of Leprosy (SAPEL).<sup>\*</sup> We also launched Leprosy Elimination Accreditation (LEA) to ensure the quality of leprosy services. As a result, we achieved elimination at the sub-national level in 2005.

Thailand still detects a few hundred new cases a year and has around 6,000 people with leprosy-related disability. We remain committed to sustaining the program, treating new cases promptly, providing rehabilitation services to people with disability, bringing down new case numbers and reducing the proportion of Grade 2 disability in new cases.

## What do you see as the biggest challenges facing the program today?

First, the proportion of new cases with Grade 2 disability at the time of diagnosis has not declined, suggesting the continuance of diagnostic delays. Second, we are finding new cases among foreign migrants and refugees, mainly from Myanmar. And third, not all people with disability due to leprosy are accessing rehabilitation services.

## How do you retain leprosy-related knowledge and skills in a situation of low endemicity?

Under Thailand's universal healthcare system we have developed a leprosy network of 20 general/community hospitals in the country's four regions. We are building the capacity of the central and provincial leprosy coordinators and have developed screening guidelines for health officers at the peripheral level, as well as a referral system from peripheral health centers to specialized hospitals. In addition, we use LEA to assess the quality of case-finding, case-holding, disability prevention and rehabilitation.

## Do people affected by leprosy play a role in leprosy services in Thailand?

They take part in leprosy-related research as interviewers and gatekeepers. We choose people who are educated and have good communication skills and train them how to interview. In our experience, interviews conducted by people affected by leprosy with others in the same situation can yield more in-depth information, because of the atmosphere of trust that develops. The role of the gatekeeper is to facilitate the process by leading the interviewee to a private spot, taking photos and preventing third parties from interrupting.

Another way they contribute is by forming Self-Help Groups (SHGs). These consist of people with leprosy-related and other disabilities, and result in better self-care practices and quality of life.

People affected by leprosy also participate in case detection, based on their own experience.



Atmosphere of trust: interviewer at work

## FOOTNOTE

<sup>\*</sup> SAPEL is an initiative aimed at finding and treating cases in difficult-to-reach areas or situations, or belonging to neglected population groups.

They are very conscious of their children's health and each year a number of new cases are brought to the attention of the health services by parents or grandparents who recognize the early symptoms.

**Thailand has a program to transform leprosy villages into normal communities. What is the thinking behind this and how successful has it been?**

The integration of leprosy villages into the general community is being carried out to improve their access to public services, promote the rights of residents and end the division between people affected by leprosy and the rest of society. It follows complaints that living conditions in the colonies lagged behind those in the wider community: roads, water and electricity were lacking; primary health care was limited in terms of the medicines and equipment available; and rights to housing and land could not be transferred to children.

So far, two of the 13 colonies have been integrated; a further eight are currently in the process. Integration only goes ahead when colony residents have been fully briefed on what will be involved and a majority of them are in favor.

**Are there any particular lessons from Thailand's post-elimination experience that you would like to share with other countries?**

For case-finding activities, it is cost-effective to have focused target areas. To identify these, we have three criteria: 1) districts in which new cases have been detected every year for the past five years; 2) districts in which new cases have been detected in children in any of the past five years; and 3) districts in which more than 10 new cases have been detected in any of the past five years.

Also, advocacy is important for keeping leprosy on the health agenda and building awareness. This includes everything from a speech by the deputy minister of public health on World Leprosy Day to establishing volunteer groups (see sidebar) and encouraging people affected by leprosy to participate in community events and interact with the general public and officials.

We have found that involving people affected by leprosy and showing what they can do promotes self-confidence and helps to change community attitudes toward the disease in a positive way.

**You are also embarked on preserving the history of leprosy. What is the purpose?**

Preserving the history of leprosy secures essential information on how the people affected, their relatives, communities, and related organizations have overcome the difficulties they faced. It provides precious lessons for the next generation — the good practices to follow and the mistakes to avoid. ■

## VOLUNTEER SPIRIT

Raj Pracha Samasai Spirit Volunteer Groups (RPS-SVGs) provide rehabilitation services to people affected by leprosy — particularly those with disabilities — and other disadvantaged individuals. Based in communities where people affected by leprosy live, they consist of health volunteers and a key community leader, such as a monk, a teacher or a village chief. The first RPS-SVG was established in Pitsanulok Province in 2010; there are now 20 such groups throughout Thailand.

RPS-SVGs are supported by the Raj Pracha Samasai Institute and Raj Pracha Samasai Foundation. The institute is a government organization under the Department of Disease Control, while the foundation is an NGO that supports leprosy activities not covered by the government. Under its president, Prof. Teera Ramasoota, the foundation is particularly focused on the rehabilitation of people affected by leprosy and provides each newly formed spirit volunteer group with initial funding of 5,000 baht.



In addition to rehabilitation activities, ranging from wound care to housing renovation, RPS-SVGs are also encouraged to carry out case-finding. Training is given to enable them to perform their tasks more effectively.

To sustain the RPS-SVGs and build relations between them, a workshop is organized at least every other year. This provides a chance for RPS-SVGs to learn from one another and share their experiences.



# Seven Things I've Learned from Leprosy

A medical anthropologist shares her insights.

In the 19th century, surgeon Jonathan Hutchinson wrote, "The problem of leprosy is not for the idle-minded. It is full of intricacy and difficulty." He also described leprosy as "a sort of aristocrat amongst diseases," with a history that is "interwoven with that of civilization itself."

Leprosy touches all aspects of life: the physical body, personal and community relationships, education, employment, citizenship and spirituality, to name but a few. Also, leprosy doesn't just teach you things about life; leprosy changes your life.

Here are seven insights I have gained while conducting research on leprosy as a medical anthropologist in Portugal and Brazil.

## 1) The value of touch for social relations and what it means to be acknowledged as human.

We tend to think of touch as the most subjective and unreliable of the five senses. When I started my research at Portugal's last leprosarium, Hospital Rovisco Pais, however, I discovered that the simple gesture of greeting someone with a handshake or a kiss on the cheek is full of meaning. It allows you to surmount historical barriers that separate people with leprosy from the rest of society.

There is a remarkable fund of knowledge to be found in lay sectors of society.

Leprosy showed me that to inhabit an untouchable body (the most radical form of social exclusion) is to be made by society less human, or even inhuman — without the same civil, political, social and human rights as everyone else. It taught me that touch is central to mutual recognition, which is the first step toward social



The value of touch: the Goodwill Ambassador in Russia

inclusion. Touch revealed itself to be a valuable language in the daily struggle for human rights.

## 2) The body is a biosocial phenomenon reflecting politics, economics and culture.

Leprosy was classified as a pathology with biological causes in the late 19th century, but its causes are not restricted to the bacillus *Mycobacterium leprae*. Social injustice plays a determinant role in leprosy's incidence, transmission and outcome.

From both an epidemiological perspective and the personal testimonies of those affected by leprosy, it is clear that the private body interacts with public dialectics of citizenship and marginalization, as well as with social processes such as gender inequality, lack of access to education and/or dignified work. Another factor is the commodification of global health, which explains why leprosy is a neglected disease suffering from underinvestment in scientific research.

The conclusion? To overcome the medical challenges posed by leprosy, social justice is as important as access to drugs.

## 3) Pragmatic cooperation between scientific and lay knowledge produces the most effective results for health promotion.

My work with leprosy organizations taught me that there is a remarkable fund of knowledge to be found in lay sectors of society, from women and men who have gained outstanding wisdom through experience. Such knowledge is seldom acknowledged by the State in the design of public health policies or by science in the planning of research. Unlike science or State management, lay knowledge doesn't separate life into different spheres. Instead, it can create a synthesis between history, society, culture, etiology and disease. As such, it is particularly helpful in producing new and needed medical geographies — i.e., the effects of locale and climate on health — that could map the complex intersection between leprosy and social factors.

## 4) The passage of leprosy from private memory to public history shapes the social, political and medical conditions of people today.

A Yoruba proverb says, "Until the lion tells his side of the story, the hunt will only be seen through the eyes of the hunter." By comparing the opposite policies of Portugal and Brazil on memory of the past compulsory internment of people affected by leprosy, I learned how the

### AUTHOR:

Alice Cruz



Alice Cruz is currently working as a researcher on *ALICE: Strange mirrors, unsuspected lessons: leading Europe to a new way of sharing the world experiences*, a project under the auspices of the Centre for Social Studies, University of Coimbra.



Social struggle involves many hardships and sacrifices.

forgetting of leprosy becomes an important factor for the persistence of stigma and discrimination. Furthermore, the public act of remembering must be done by people affected by leprosy themselves.

Unlike Portugal, which still harbors what might be called an institutional stigma, Brazil renewed the public imagery of leprosy through the struggle of those who came out into public space claiming equal rights and reshaping the social representation of leprosy as Hansen's disease — a disease like any other. Human rights aren't merely an individual attribute; they also possess a collective dimension. The dispute for memory and history has important consequences for society at large.

### **5) The personal impact of collective struggle and the collective benefit of personal empowerment.**

In Brazil, I witnessed the power of people coming together at meetings involving MORHAN.\* By coming together, those affected by leprosy are able to rebuild a positive identity and thus fight self-stigmatization by enhancing their self-esteem.

People feel stronger when they are together. They also feel more inclined to claim their own agency in fighting stigma and discrimination. The impact of this is huge, since one of the most effective strategies for eliminating stigma is close interaction at the micro level.

Stigma is not a natural consequence of leprosy; it is socially produced, revealing itself in different spheres of society, from institutions to work relations. In many cases, it is multilayered and associated with discrimination based on gender, race and/or class. By feeling more positive about themselves people with leprosy become powerful agents for communicating

information about the disease and changing its social representation.

### **6) The power of spirituality and empathy in a political struggle.**

Social struggle from below involves many hardships, and activists make enormous personal sacrifices, as I have seen in Brazil. The energy that sustains them comes not only from ideological commitment but also from the unique empathy between people who come together as kindred spirits to fight political and social battles. In a collective struggle, spirituality is not out of place. It plays a role through the sharing of beliefs and the strengthening of resilience with faith. Grassroots movements nourish their struggles daily with the spiritual bond between activists and with a broader notion of social justice that reconnects human dignity and the human soul.

### **7) Who defines the cure and what this means for medical care.**

Many people affected by leprosy say that the bacteriological cure with multidrug therapy (MDT) did not make them feel healed. Such statements should not be dismissed as examples of the so-called inability of lay people to grasp medical procedures and knowledge. Healing comes with the full restoration of health. For people affected by leprosy, access to MDT alone may not be enough.

The outcome of medical intervention is mediated by institutional barriers to health such as dysfunctional access to medical care, delays in the diagnosis of leprosy or of leprosy reaction, or by extra-institutional barriers such as the type of work you do. Lay people provide a powerful insight into the link between leprosy and social justice. They also suggest something highly meaningful about the power to define the disease and the cure.

For a person being treated for leprosy reaction or who has developed disability, leprosy still threatens. A high level of medical care may be required, even if the case is no longer relevant to the epidemiological goal of stopping transmission.

The gap between curing and healing highlights the importance of involving people affected by leprosy in public health policies and medical services, since by evaluating the outcome of medical intervention using the evidence of their own bodies, they contribute a form of knowledge that is beyond the reach of scientific inquiry. It also teaches us that social justice depends on cognitive justice. ■

#### **FOOTNOTE**

\* The Movement for the Reintegration of People Affected by Hansen's Disease

# A Tale of Two Birthdays

There's a profound reason why 11 May 2001 means so much to Masako Ueno.



Masako Ueno has two birthdays: the day she was born, and the day she resumed using her real name after more than 60 years as Yaeko Suyama, patient number 1801 at National Sanatorium Hoshizuka Keiaien.\*

Now 87, Masako was born on 18 April 1927 in Ishigaki City in Japan's southernmost prefecture, Okinawa. In 1940, when she was 13, her father took her to Hoshizuka Keiaien, where she was diagnosed with leprosy.

She thought she would be returning home, but awoke the next morning to find her father had gone. Devasted, she only learned decades later of the pain it had caused him to leave her there, as required by Japan's Leprosy Prevention Law.

Her disappearance caused difficulties for those back home. Even though she assumed a false name at the sanatorium to protect her family's reputation, rumor spread that eating something from their shop would result in a terrible disease. As a result, the business nearly went bankrupt.

Masako grew up and married a fellow patient, dreaming that one day they would leave and start a

family. What she had not known was that Kiyoshi had been sterilized as a precondition for living with her in the sanatorium's married quarters. The truth emerged when she saw his bloodied undergarments, and came as a terrible shock.

The story of her husband's enforced vasectomy was included in the testimony she gave as one of the original 13 plaintiffs who sued the government for depriving people affected by leprosy of their human rights through its isolation policy.

They filed suit for compensation in 1998, two years after the Leprosy Prevention Law had been abolished. On the morning of the court ruling, 11 May 2001, she wrote a will. "If we lose, I will die. Please scatter my ashes in the seas off Okinawa, my home."

But the plaintiffs won, and from that day on, Masako began using the name her parents had given her. "I consider it my birthday. It had been so painful to live under a pseudonym," she says.

Masako has spent 74 years in Hoshizuka Keiaien. Accounts of her life have been published and she travels throughout Japan, bearing witness to the injustices she and others like her have borne and speaking out for a world without prejudice and discrimination. Once she dreamed of being a teacher; now she addresses students of all ages, passing on the lessons of her life and stressing the preciousness of existence. ■



Masako Ueno loves to make sweets, including a type of donut special to Okinawa called *sata andagi*.

## MUSEUM PIECE

### "SPECIAL WARD" PADLOCK

Under Japan's past policy to isolate persons with leprosy, those diagnosed with the disease were taken from their homes and placed in sanatoriums. If they tried to escape or otherwise resist authority, each sanatorium had a place to confine patients deemed troublemakers.

The facility at National Sanatorium Kuriu-Rakusen in Kusatsu, Gunma Prefecture, was especially severe. Known euphemistically as a "special ward," it offered nothing in the way of treatment, only hardship and misery.

It was built in 1938 and used until 1947. During that period, a total of 93 people were placed in detention, of whom 23 are said to have died.

The decision to lock someone up rested with the chief of each sanatorium, who had the authority to discipline a patient on the pretext of maintaining good order within the leprosarium. There was no such thing as a trial, and people

were incarcerated without any regard to their human rights.

Kusatsu had a fearsome reputation among sanatorium inmates and people were sent there from all over the country. Conditions in the "special ward" were harsh, with temperatures in the eight individual cells dropping well below freezing in winter.

Today, all that remains of the original structure are its foundations. But a replica has been built at the instigation of sanatorium residents. It opened earlier this year to show how state authorities violated their human rights.

During excavation work in 2013 that preceded construction, various items were uncovered. Among them was this padlock, one of several that were found. It symbolizes the oppressive nature of a facility whose inmates' only "crime" was to contract a disease for which they were despised and stigmatized.



## FOOTNOTE

\* Founded in 1935, the sanatorium is located in Kagoshima Prefecture, Japan.



# My Meeting with Mr. Modi

The Goodwill Ambassador discusses leprosy with Prime Minister of India Narendra Modi during the latter's recent visit to Japan.

## JAPAN (September 2)

Recently I had the pleasure of meeting Indian Prime Minister Narendra Modi, who made time during his official visit to Japan to see me. India has the highest number of leprosy cases in the world, so any opportunity to discuss the disease with the prime minister is to be welcomed.

It was our first encounter, so I introduced my role as the WHO Goodwill Ambassador for Leprosy Elimination and my foundation's involvement with India, a country that in 2013 reported around 127,000 new cases of leprosy, or about 59% of the global caseload.

The Nippon Foundation has contributed some US\$100 million to India's leprosy control activities to date. We also launched the Sasakawa-India Leprosy Foundation (SILF) in 2006 with an endowment of US\$10 million. SILF provides grant loans to fund microenterprises run by people affected by leprosy, arranges educational opportunities and engages in awareness-building and advocacy.

In addition, we support the Association of People Affected by Leprosy (APAL). Based in Hyderabad, it serves as a nationwide networking organization for residents of India's 850 leprosy colonies as well as others affected by the disease.

India achieved the goal of eliminating leprosy as a public health problem at the national level in 2005. At the time, this was hailed as a remarkable achievement. Since then, however, it has proved more difficult to make further progress at the state and district levels, where it is necessary to strengthen efforts for the early detection and treatment of leprosy at the grassroots level.

## The prime minister wanted to know how I became involved in leprosy work.

I told Prime Minister Modi I appreciated that India has many pressing public health concerns; nevertheless, I hoped that it would make leprosy a high priority.

The prime minister was curious to know how I became involved in leprosy work. I told him I was following the lead of my father, one of whose early acts against the disease was to help



With Prime Minister Modi in Tokyo in September

fund a leprosy hospital in Agra, Uttar Pradesh, in the 1960s.

Mr. Modi talked of Mahatma Gandhi and his commitment to helping people with leprosy. Gandhi was born in Gujarat, the state in western India that Mr. Modi served as chief minister from 2001 until his election as prime minister of India earlier this year.

My next visit to India is scheduled for November. Mr. Modi asked to be kept informed of my plans and I very much hope it will be possible to continue our conversation. I would appreciate the opportunity to introduce him to the leadership of APAL so that he may hear directly from the people affected about the issues they face.

India still faces many challenges where leprosy is concerned, both in terms of diagnosing and treating new cases and in combating the discrimination leprosy continues to attract. Ensuring that everyone knows that leprosy is curable, treatment is free and discrimination has no place is essential. To hear such a message coming from the Indian prime minister would have tremendous impact. I look to Mr. Modi to lead the way. ■

# WHO Issues Annual Leprosy Update

Fourteen countries accounted for 96% of new leprosy cases in 2013.

In its annual roundup of the global leprosy situation, the WHO's *Weekly epidemiological record* for September 5, 2014, revealed that 215,656 new cases of leprosy were reported in 2013, down from 232,857 in 2012.

Of the total, India contributed 126,913 cases, Brazil 31,044 cases and Indonesia 16,856 cases. Between them, these three countries made up 81% of all new cases of leprosy.

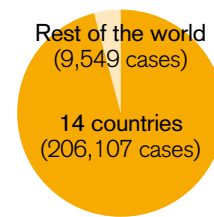
A further 11 countries reported a thousand or more new cases. They were: Ethiopia (4,374), DR Congo (3,744), Nigeria (3,385), Nepal (3,225), Bangladesh (3,141), Myanmar (2,950), Tanzania (2,005), Sri Lanka (1,990), Philippines (1,729), Madagascar (1,569) and Ivory Coast (1,169).

The top 14 reporting countries together accounted for 96% of total leprosy cases in 2013.

In an editorial note, the *WER* noted that new

cases have plateaued in the range of 245,000 to 215,000 between 2009 and 2013, and that "greater and more focused attention to the problem by all stakeholders is warranted."

It also stated that of new cases, 13,289 had Grade 2 disabilities, "which reflects low awareness about leprosy in the community and sub-optimal capacity of health systems to detect the disease early." Furthermore, 9.2% of new cases were in children, indicating continuing transmission of the disease. The target envisaged by the current global strategy for leprosy 2011-2015, that of reducing the rate of Grade 2 disabilities in new cases to 35% of that in 2010, "does not yet seem to be within sight," it said.



Distribution of cases

## APAL WEBSITE



The Association of People Affected by Leprosy (APAL) has launched a new website. Formerly known as the National Forum India, APAL works for the socio-economic empowerment of people affected by leprosy in India, especially those living in self-settled leprosy colonies and leprosy homes.

To read more about APAL's activities, its achievements to date and how it is giving a voice to people affected by leprosy in India, visit [www.apalindia.org](http://www.apalindia.org) ■

## FOR THE ELIMINATION OF LEPROSY

### Publisher

Yohei Sasakawa

### Executive Editor

Tatsuya Tanami

### Editor

Jonathan Lloyd-Owen

### Associate Editor

James Huffman

### Layout

Eiko Nishida

### Photographer

Natsuko Tominaga

### Editorial Office

5th Floor, Nippon

Foundation Building,

1-2-2 Akasaka, Minato-ku,

Tokyo 107-8404

Tel: +81-3-6229-5601

Fax: +81-3-6229-5388

[smhf@tnfb.jp](mailto:smhf@tnfb.jp)

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[www.nippon-foundation.or.jp/en/](http://www.nippon-foundation.or.jp/en/)

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## FROM THE EDITORS

### TWEET BY TWEET

Congratulations to The Leprosy Mission, which is celebrating its 140th anniversary and which marked the milestone with a global forum in Delhi on Healing, Inclusion, Dignity at the end of September. Kudos, too, for the stream of informative tweets that came out of the conference. They provided a fascinating insight into some of the key themes in leprosy today and were a mix of hard facts, home truths and hopes for the future.

We were told that the current trend in new case detection in leprosy is static and there is a need to implement new approaches. Early detection is crucial and contact examination has an important role to play. Defeating leprosy is possible, but will depend on a major new commitment from all partners. Collaborating with other neglected tropical diseases is part of the strategy.

Traditional healers — the first port of call for health treatment for thousands — should receive training in leprosy. Traditional birth attendants might be a way to reach women with leprosy messages. Women affected by leprosy are doubly disadvantaged.

Healing is not just physical; to be fully restored requires tackling emotional issues too. Dignity and rights are only possible through empowerment. One educated person affected by leprosy can do much to change the lives of others affected by the disease.

There was this rallying cry, too: It's time for people affected to come out, tell the world they have had the disease and de-stigmatize leprosy. Given prevailing social stigma, that takes courage. But, as various tweets from Delhi showed, there were inspirational speakers at the forum who are doing just that.