WHO GOODWILL AMBASSADOR'S NEWSLETTER

FOR THE Elimination OF Leprosy

April 2018 • Number 90

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

Lalita Devi, a resident of Sai Baba Kushth Ashram in Allahabad, UP, India, photographed in December 2017 for the exhibition "Our Lives".

MESSAGE

# Make Leprosy Part of the Conversation

In recent years, leprosy control activities have been stagnating and I have been thinking about what can be done to overcome this situation.

On a recent visit to Indonesia, I went to a small radio station in Makassar to take part in a live program about leprosy with someone from the local health department. As usual, I tried to talk about leprosy in as plain language as possible. During the program, calls came in from listeners.

"If I get leprosy when I'm pregnant, will my child also be infected?" "Is every white patch a sign of leprosy?"

I was struck by the refreshing directness of the questions, and at the same time I appreciated the importance of addressing the specifics that people want to know about.

As a matter of course, the messages I put across at every opportunity are that leprosy is curable, treatment is free and that discrimination has no place. Wherever possible, I also invite local media to accompany me on my field trips and report on the situation in their country. On such occasions, I believe there is no better form of awareness-raising than for them to see me physically interacting with persons affected by leprosy.

My experience at the radio station in Makassar, where I was able to reply on the spot to questions the public had about leprosy, suggested to me that this is a more effective approach than having experts just transmit correct knowledge. I have come to think that this style of communication will help resolve misunderstandings among people who have little contact with leprosy in their daily lives, thus creating a positive conversation about the disease. I am now actively exploring opportunities to appear on TV and radio as part of my mission.

Making leprosy part of everyday conversation via radio and television will help to dispel misperceptions about the disease, encourage people to seek treatment, and make the work of national leprosy control programs easier.

It is true that many people don't know very much about leprosy. But if we want to increase our chances of overcoming the disease—and the stigma—we need to get people talking about it more.

— Yohei Sasakawa, WHO Goodwill Ambassador

CONTENTS

# “Our Lives”

Photo exhibition documents the lives of people affected by leprosy in India.

Over the past 16 years of visiting communities of people affected by leprosy around the world, I have always been drawn to the issue of discrimination and its impact.

Last December, I travelled to four self-settled leprosy colonies in India to document the lives of people who have experienced leprosy and its stigmas.

India has around 800 such colonies. While no new colonies have formed in recent years, they bear witness to a time when the severity of discrimination was so great that some people found themselves with no alternative but to live alongside other people affected by leprosy in their own communities.

The colonies I visited were in Madhya Pradesh, Maharashtra and Uttar Pradesh. The resulting photographs feature in an exhibition, “Our Lives,” being held in New Delhi between April 20 and May 1, 2018. These images are supplemented by others that I have taken as I accompany the Goodwill Ambassador on his overseas missions.

## UPROOTED LIVES

In the colonies I visited, I met individuals affected by leprosy who have overcome discrimination with the support of their families, and others who lament how leprosy uprooted their lives and exposed them to society’s prejudices.

Unfortunately, old perceptions about leprosy are not easily erased and are further reinforced by stigmatizing language, which reduces a person to his or her disease.

“Our Lives” is intended to encourage viewers to see the world from the standpoint of people affected by leprosy and ask themselves why stigma and discrimination persist in society.

Ultimately, I want to show that people affected by leprosy are ordinary human beings, too. Leprosy doesn’t change that fact – it’s just a disease, despite what some people think.

The following images are of some of the people I met in India last December who shared their stories with me for the exhibition.

**AUTHOR:**
Natsuko Tominaga
Natsuko Tominaga is the official photographer of The Nippon Foundation.

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**Anita Bhavre, 35**

Anita Bhavre is raising two sons. When I met her I was attracted by her positive attitude and noted the proud expression on her face when she told me she worked as a housekeeper at the nearby hospital. “Do you want me to change into my uniform for the photo shoot?” she asked.

She contracted leprosy when she was six or seven. Because she was treated in good time, she didn’t suffer any deformity. “My life would have been more difficult otherwise,” she told me.

She likes to get together and chat with other people, passing on helpful advice. Her favorite place in the colony is the temple precincts (above) where people gather. She told me she wants to stay strong so that she can motivate others and help change society.

For Anita, leprosy is just a disease. When I asked her what she would like to tell people who come to the photo exhibition, she replied: “These are not ‘leprosy-affected people,’ just normal human beings like everyone else.” (Ma Saraswati Kushth Ashram, Indore, MP)

**Babita Kishore Ajnare, 40**

Babita contracted leprosy when she was 18. She told me her great grandfather had been buried alive because of the disease. “Now it’s curable and is nothing,” she said.

Although she herself is not disabled, Babita has noticed how those with disabilities get ignored or given strange looks, and it upsets her. “There shouldn’t be any discrimination. Everyone should be treated as part of society.” (Ma Saraswati Kushth Ashram, Indore, MP)

Babita (second from right) with her daughters and grandchildren.

Above photo: Subhash with the rickshaw he inherited from his grandfather; right-hand photos, clockwise from top: Prakash and Rupali; son Shubham; Prakash flexes his muscles

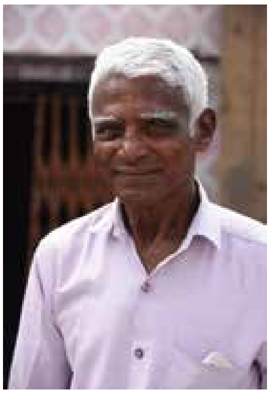
**Subhash Kailash Sen, 35**

Subhash comes across as a very decent person. He works as an accounts officer and lives with his wife, son and father. His hobby is listening to music.

When his grandfather fell ill, his company gave him time off so that he could nurse him. Following his grandfather's death, Subhash inherited a rickshaw from him. From time to time he works as a rickshaw driver in his grandfather's memory.

Although he says he hasn't experienced discrimination himself, he was aware that his grandfather had been forced to leave his village because of leprosy.

"Leprosy shouldn't be thought of as a dreadful condition. It's just a disease. Once it's treated, it isn't a disease anymore," he told me. "We are human beings too."
(Ma Saraswati Kushth Ashram, Indore, MP)



**Kailash Sen, 65**

Kailash Sen is Subhash's father. He has a warm expression that hasn't been dimmed by the indignities he has experienced in life. He came down with leprosy as a child. "Things changed after the deformity appeared," he told me. "I have felt discrimination many times, such as shopkeepers refusing to sell me anything."

"There is no need for that kind of behavior. Everyone deserves to be treated with respect. People should accept that leprosy is a disease, a curable disease."
(Ma Saraswati Kushth Ashram, Indore, MP)

**Prakash Kulkarni, 48**

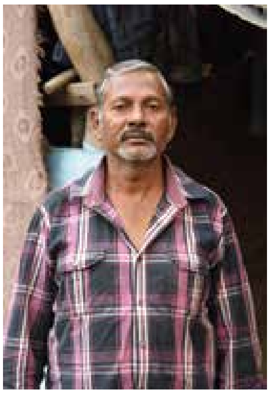
Prakash Kulkarni says that leprosy has made him a strong person—and he also keeps in very good shape. "My father always told me to take care of my body. That's why I keep muscular and fit."

Prakash had to leave school because of leprosy, but carved out a path for himself through hard work and determination. Today he works for the local municipal corporation.

He lives with his wife Rupali, their three children and his mother. The happiest moment in his life was when he asked Rupali to marry him, "even though I've had leprosy." Rupali replied, "You *had* leprosy. Our marriage will send a strong message to society."

It was obvious they are a very close-knit family. "Don't look at his face. Look at his heart and see how beautiful it is," said Rupali said of her husband.

"My father is a brave man. He looks after his family," his son Shubham added.
(Hanuman Nagar Kushta, Maharashtra)



**Bideshi, 55**

Bideshi's symptoms appeared when he was 15 and he had to leave home to protect to his family from the stigma. He came to Allahabad for treatment, and lived by the side of the road for a year, working as a rickshaw driver. He is married with two sons and two daughters.

"Leprosy is nothing, and it's a lot," he told me. "It gives no physical pain, but there is a lot of emotional pain from society."
(Nav Nirman Kushth Ashram, Allahabad, UP)

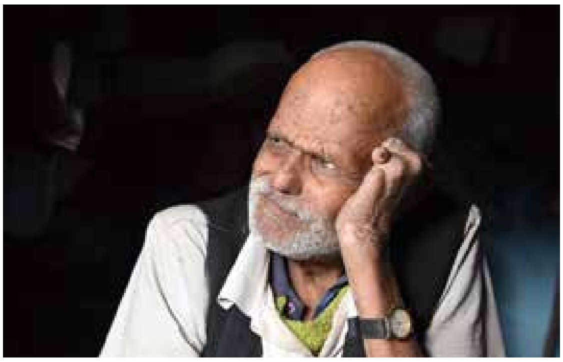
**Hari Har Nand, 60**
Hari Har worked as a cook for a government officer but had to leave his job after being diagnosed with leprosy when he was 40. "I was a skilled worker. I knew cooking, carpentry and had other skills. But I had to leave everything and ended up a beggar," he told me.

In his experience, leprosy is a disease that pushes people away. "But it's just a disease. Don't hate people. Keep together."
(Nav Nirman Kushth Ashram, Allahabad, UP)

"Leprosy made my life worse. If it wasn't for leprosy, I'd be living a normal life, just like you."

**Dharam Nath Tiwari, 80**
Nobody in Dharam Nath Tiwari's home village in Bihar knows he is still alive, other than his family. After being diagnosed with leprosy in 1978, he was treated at various locations before ending up in Allahabad because he wasn't welcome back.

Many years have passed since he last attended a function in his village. "I have to play dead so my family can live without stigma," he told me.
(Sai Baba Kushth Ashram, Allahabad, UP)



**Lala Soni, 80**
Lala worked as an ornamentalist. He contracted leprosy at the age of 35. The saddest day in his life was when he lost his foot. Now he can't stand and he can't work. He told me he has experienced numerous instances of discrimination as a result of leprosy. "Leprosy made my life worse. If it wasn't for leprosy, I'd be living a normal life, just like you."
(Sai Baba Kushth Ashram, Allahabad, UP)

**Sahtreen, 45**
Sahtreen's words left a big impression on me. "What was the happiest time in your life?" I asked her. "My youth, because it was joyful," she replied. "And the saddest time?" "My youth, because it was destroyed by leprosy."
(Sai Baba Kushth Ashram, Allahabad, UP)

**Kapil Dev, 67**
I photographed Kapil (above left) with his son and grandson. When I asked him if he had a message for people coming to see the exhibition, he replied: "Be happy! Thank you for looking at our photos."
(Sai Baba Kushth Ashram, Allahabad, UP) ■

# Learning Experience

An Indonesian journalist accompanies the Goodwill Ambassador on a recent mission.

**AUTHOR:**
Nilam Suri
Nilam Suri is a reporter for the online news portal Liputan 6.

I am the daughter of a doctor. That should have equipped me with more knowledge of leprosy than I possessed.

In fact, I knew no more about leprosy than the average Indonesian—in other words, not very much at all—and my lack of knowledge made me fearful.

In my student days, I went to a cram school in central Tangerang, a city west of the capital, Jakarta. Traveling by *angkot* (a shared minivan), I would see lots of persons with leprosy begging on the street as we drove by.

I remember feeling afraid, worried that I could get infected. I wasn't even within touching distance, but the fear was real. In the end, I asked my parents to send me to a cram school nearer home. What I didn't do was ask my mother about the disease itself.

Since then, I hadn't given leprosy much thought until I was assigned to cover a mission to Sulawesi by the WHO Goodwill Ambassador for Leprosy Elimination. I hadn't been aware such an ambassador existed, and had never heard of Yohei Sasakawa.

## PINK SOCKS

When we met, I was struck by the fact he was wearing bright pink socks. This fact intrigued me. When I finally got the chance to ask him about this, he said the bright pink color lifted his spirits because it symbolizes youthfulness for him.

> When he spoke, he said something that changed my whole understanding of leprosy.

The first place we visited was a primary health center in Gowa, which forms part of Makassar in South Sulawesi. Elaborate preparations had been made for Mr. Sasakawa's visit and he was warmly received, almost as if he were an old friend.

When it was his turn to speak, he said something that changed my whole understanding of leprosy. "I have met thousands of people affected by leprosy, and to this day I have never developed the disease." I recalled my previous fears, and felt confused.

Later that morning, we visited a household where several members were undergoing treatment for leprosy. I watched Mr. Sasakawa kneel down and casually begin chatting with them, taking them by the hand and offering words of encouragement.

Nilam (left) interviews a member of PerMaTa in Makassar

The Goodwill Ambassador offering words of encouragement

Listening to what he said and seeing what he did made me realize that I had it all wrong about leprosy. What's more, I believe most Indonesians have got it all wrong—about how contagious it is, and whether or not it is curable—and that our ignorance is responsible for the stigma that surrounds leprosy.

During the rest of the mission to South and Central Sulawesi, I sought to learn as much as I could about the disease, talking with patients under treatment and others who have been cured. Listening to their stories and the struggles they had faced was humbling.

Particularly inspiring were those who have become advocates for others facing the challenges of leprosy, helping them to access treatment and speaking out against discrimination. It was almost as if being a person affected by leprosy was a badge they wore proudly because their experiences have made them stronger.

Take the case of Rahma. She was diagnosed with leprosy when she was quite young. Her parents banished her from the house because they thought she was cursed. Later her engagement was broken off when her in-laws to be found out that she had once had leprosy.

But Rahma did not let the disease affect her further. She has since joined PerMatTa, an organization of people affected by leprosy, where she speaks out to spread awareness and dispel stigma.

## VALUABLE JOURNEY

My assignment stopped being merely a work trip and became a valuable journey that taught me many wonderful things. Seeing Mr. Sasakawa in action, and witnessing his compassion and conviction, brought home to me that no matter who or where you are, you can make a difference if you decide to.

And after meeting and talking with members of PerMaTa, I learned that nothing can crush you, unless you let it. I have become passionate about sharing what I now know about leprosy—and for that I am grateful. ■

# Awareness-raising in Sulawesi

The Goodwill Ambassador pays another visit to Indonesia to meet with local decision makers and carry out more media work.

**INDONESIA** (March 15-22)

In March I made a return visit to Indonesia. It reports the third highest number of leprosy cases after India and Brazil, and is a country I have been focusing on of late.

Since Indonesia's provinces and districts are relatively autonomous, I believe it is important to meet with local decision makers and impress upon them that in a world of competing health priorities, they cannot afford to overlook leprosy.

With that in mind I flew back to the island of Sulawesi, following my mission to Gorontalo Province last November. This time I travelled to the provinces of South Sulawesi and Central Sulawesi. They are among 12 of Indonesia's 34 provinces yet to eliminate leprosy as a public health problem.

Arriving in Makassar, the provincial capital of South Sulawesi, the first item on my agenda was a visit to Kanjilo Health Center in Gowa District. There I was briefed by staff and local officials on the work they are doing to detect and treat leprosy.

> “I have many bitter memories and scars on my body,” Ermawati said. But she also shed tears of joy.

One of the speakers said he had seen clips of me on YouTube “shaking hands with patients and treating leprosy as just another disease, and this inspires us to do the same.”

Of all the presentations, the most moving was by a young lady called Ermawati, who was reduced to tears as she gave an account of the stigma she had faced after being diagnosed with leprosy. Her testimony was so affecting that my interpreter began to cry.

Posing with Chia, an ambassador for TB and leprosy awareness, in South Sulawesi

“I have many bitter memories and scars on my body,” Ermawati said. But she also shed tears of joy as she recalled making friends with other patients and encountering the people's organization, PerMaTa, of which she is now a proud member. “I am so grateful to PerMaTa,” Ermawati said. “They told me I should not feel ashamed.”

Next I called on two households to offer encouragement to family members currently being treated for leprosy with multidrug therapy (MDT). I found them in good spirits and told them that they were on track to make a complete recovery because they had been diagnosed early.

Later in the day I made the first of four live TV and radio appearances I had scheduled during my stay, continuing the media work I did on my previous visit to Indonesia. This was on TVRI Makassar, where I was joined by a local health official and PerMaTa Vice President Al Qadri for an hour-long discussion about leprosy.

The following morning found me at a local radio station, Gamasi 105.9, where I was again one of three guests, including Al Qadri. He told listeners about his experience of leprosy and said: “My wife

Ermawati tells her story at Kanjilo Health Center

Far left: Appearing in a live TV broadcast in Palu; left: taking part in a radio phone-in show in Makassar

With members of Commission IX and other health representatives at a meeting in Jakarta

is also a person affected by leprosy. We have two children and they are perfectly fine."

To learn more about PerMaTa's activities, I visited one of its branches in South Sulawesi; in total, it has 29 branches in four Indonesian provinces. Among their activities, members make home visits, accompany patients to hospital and promote self care.

Before leaving South Sulawesi I attended a stakeholders' meeting in Gowa. I appreciate these meetings because they bring together representatives of different government agencies. This is important, because only through the cooperation of many sectors will it be possible to beat leprosy and its stigmas.

In Central Sulawesi, I first visited Sigi District, a mountainous district with many remote communities. "People talk about Papua Province as having areas that are difficult to access, but the same is true of Sigi," Mayor Moh Irwan Lapatta told me. He said he would draw up a strategy involving different departments to better tackle leprosy in the district. "It's all about synergy," the mayor said, a message he repeated later in the morning when we visited Biromaru Health Center together.

The presentations at the health center illustrated the challenges to leprosy control in the area. These included the difficulty of keeping track of patients; low living standards; severe stigma; lack of awareness in the community; hard-to- reach areas; and inability to retain staff.

Among those invited to speak was Paulus Manek, the president of PerMaTa, who expressed the hope that the new strategy the mayor was planning would involve the input of a person affected by the disease. "Please use us," he said.

I had two more media appearances scheduled. The first was on TVRI Palu, where I shared the stage with a health official and a local man who spoke about his experiences with leprosy. I also featured in a discussion about leprosy on RRI Radio. Appearing with me was Paulus Manek: "Leprosy is not the problem," he told listeners. "It is lack of awareness that's the problem."

While in Central Sulawesi, I appreciated the opportunity to call on Governor Longki Djanggola. I requested that he use his position to convey to local legislators, educators and other persons of influence that leprosy is curable and treatment is available free of charge.

I also recorded a short video message on leprosy to be used for awareness-raising purposes as part of the People's Healthy Lifestyle Movement (Germas). The initiative promotes community health via different means, including video clips shown in public places such as shopping centers, restaurants and even aboard ferries. I hope my message plays its part.

Before leaving Indonesia, I had a meeting in Jakarta with a group of parliamentarians who are members of Commission IX, a cross-party body whose responsibilities include health. They took a real interest in leprosy and suggested creating "local ambassadors" to engage in awareness building.

I am very glad to have made this contact. With the support of Commission IX, I think there could be fresh impetus against leprosy. ■

Right: Sharing a light-hearted moment at the home of a patient in Gowa District, South Sulawesi; far right: Central Sulawesi Governor Longki Djanggola

# WHO Guidelines on Leprosy

Conditional use of chemoprophylaxis recommended as preventive treatment.

The WHO is about to release recommendations on the diagnosis, treatment and prevention of leprosy. An executive summary is now available online and the full recommendations will be published in the coming weeks.

On diagnosis, the guidelines recommend no additional tests beyond the standard methods of testing for patches on the skin with no sensation; thickened or enlarged peripheral nerves; or the presence of acid-fast bacilli in a slit-skin smear.

On treatment, the guidelines recommend a three-drug regimen of rifampicin, dapsone and clofazimine for all leprosy patients, with a duration of treatment of six months for patients with paucibacilliary (PB) leprosy and 12 months for those with multibacilliary (MB) leprosy.

This represents a change from the current standard two-drug treatment for PB leprosy using rifampicin and dapsone for six months, "due to some evidence indicating better clinical outcomes" with a three-drug regimen. Meanwhile, evidence on the potential benefits and harms of a shorter, six-month three-drug regimen for MB leprosy was "limited and inconclusive," hence the guidelines do not recommend shortening the treatment duration for MB leprosy.

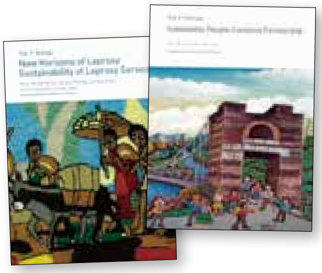
On prevention of leprosy through chemoprophylaxis, the use of single-dose rifampicin (SDR) as treatment is recommended for adult and child contacts of leprosy patients. Use of SDR in controlled trials is associated with a 57% reduction in leprosy in contacts over two years and 30% after five to six years.

However, SDR is only recommended if programs are able to "adequately identify and manage contacts" and only if the index case consents to disclose his/her disease to others, given the highly stigmatizing nature of leprosy.

For more information: www.searo.who.int/entity/global_leprosy_programme/en/

## ROLE OF PEOPLE'S ORGANIZATIONS

Two retreats on leprosy organized by Sasakawa Memorial Health Foundation in Gotemba, Japan, in 2015 and New Delhi, India, in 2018 examined the role and prospects for people's organizations in a changing leprosy landscape. The learnings from these two retreats have now been published in booklet form and are available from the foundation.



*New Horizons of Leprosy: Sustainability of Leprosy Services—Wider Involvement of Persons Affected, and New Actors* addresses ways of strengthening the participation of persons affected by leprosy in leprosy services and on building partnerships with other individuals and organizations, including those from the non-leprosy sector.

*Sustainable People-Centered Partnership* covers strategies for increasing the sustainability of people's organizations and strengthening partnerships, and why the active involvement of such organizations is essential to addressing the outstanding challenges that remain as leprosy becomes less prioritized in public health services.

Thirty-five participants from 11 countries took part in the first retreat, and five organizations of persons affected—from India, Brazil, Indonesia, China and the Philippines—attended the second. ■

## FROM THE EDITOR

### 'MAKE MORE NOISE'

Interviewed during a visit to the secretariat of the new Global Partnership for Zero Leprosy, Dr. Ann Aerts of Novartis Foundation speaks of the need to "make much more noise" about leprosy.

Several items in this issue of the newsletter cover efforts to make more noise—from the Goodwill Ambassador's recent forays into television and radio studios in Indonesia to talk about leprosy; to a report on a photo exhibition in New Delhi that aims to put a human face on the disease; and the account of an Indonesian journalist who covered the Goodwill Ambassador's visit and is now passionate about sharing her new-found knowledge.

From individuals who have personally experienced the disease to organizations that are committed to ending it, there are people "making a noise" about leprosy to keep it on the health and human rights agenda and ensure that it is not forgotten. By working in concert, they can surely make their voices heard.

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