

# FOR THE Elimination OF Leprosy

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



Global Appeal 2017 is launched in New Delhi on January 30, endorsed by the Inter-Parliamentary Union, which has 171 national parliaments as members.

**MESSAGE**

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## A World Leprosy Day to Remember

World Leprosy Day is observed on the last Sunday in January. This year, there were messages from both the Vatican and Pope Francis. In his Sunday Angelus address on January 29, the Pope said of leprosy: "This disease, although in decline, is still among the most feared, and afflicts the poorest and most marginalized. It is important to fight this disease, but also against the discrimination that it engenders."

The following day, January 30, was Martyr's Day in India, marking the assassination of Mahatma Gandhi; it is also India's Anti-Leprosy Day. On this day, the 12th Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy was launched in New Delhi.

This year's appeal was endorsed by the Inter-Parliamentary Union. Its president, Mr. Saber Chowdhury, noted that parliaments have the power to effect change by drafting or repealing laws, allocating budgets and implementing policies. Referring to my motorcycle analogy, in which the front wheel represents efforts to eliminate leprosy and the back wheel efforts to end discrimination, he said: "That motorcycle needs a very powerful engine.

I hope parliamentarians are going to be that engine."

There was also a video message from Indian Prime Minister Narendra Modi. He said that while the goal of eliminating leprosy as a public health problem had been achieved at the national level in 2005, India still has a long way to go, noting that a special leprosy case detection campaign in 2016 had uncovered 32,000 new cases. He also said it had been Gandhi's dream that people affected by leprosy should live a life of dignity, and thus the prime minister was happy to note the role of the Global Appeal.

For those of us who have spent long years working for a world without leprosy and the discrimination it causes, the commitment of one of the world's leading faiths, of an organization representing the world's parliaments, and of the prime minister of India on the occasion of World Leprosy Day represents a tremendous show of support. Building on this momentum, let us take further steps toward our goal.

— Yohei Sasakawa, WHO Goodwill Ambassador

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# The Power of the Legislature

Parliamentarians bring a new dimension to the Global Appeal initiative.



Global Appeal 2017 is the third appeal launched from India, following those in 2006 and 2010.

Over 300 people gathered in New Delhi, India on January 30 for the launch of Global Appeal 2017 to End Stigma and Discrimination against Persons Affected by Leprosy

The 12th in the series of appeals initiated by Goodwill Ambassador Yohei Sasakawa in 2006 to draw attention to the discrimination that people affected by leprosy continue to face, Global Appeal 2017 was endorsed by the Inter-Parliamentary Union (IPU). Founded in 1889, the IPU is the world body of parliaments and currently has 171 national assemblies as members.

Protecting and promoting human rights is one of the priorities of the IPU, and its president, Saber Chowdhury, an MP from Bangladesh, said that supporting the Global Appeal was in line with these commitments. “We feel it is something very close to our hearts,” he said.

## BRANCH OF GOVERNMENT

Referencing some of the individuals and organizations that have backed previous Global Appeals, including Nobel Laureates and most



Chowdhury: what the appeal stands for is “close to our hearts.”

recently the Junior Chamber International, Chowdhury underlined what made the IPU’s support different. “This is the first time that a branch of the government is endorsing the Global Appeal, and I think that is very important. It is also the branch that is

responsible for legislation.”

With discriminatory laws still on the books in a number of countries, there is “a real battle that we have to fight, and legislation is going to be at the very top of that battle. And who are the people that are going to legislate? Parliamentarians,” he said.

The IPU president has already shown how this is done. In Bangladesh, Chowdhury was successful in bringing about the repeal of the 1898 Lepers Act through a Private Member’s Bill he tabled in Parliament. The discriminatory act included a provision for imprisonment.

For his part, the Goodwill Ambassador said he was delighted to receive the IPU’s backing and looked forward to working closely with it. In a *Handbook for Parliamentarians* published for the occasion, he said that in addition to their role in amending or abolishing outdated legislation that discriminates unjustly on the grounds of leprosy, parliamentarians can also play an influential role in raising awareness of the disease and dispelling myths that allow discrimination to flourish.\*

## ‘GANDHI’S VISION’

Prime Minister Narendra Modi contributed a video message in which he spoke of Mahatma Gandhi’s enduring concern for persons affected by leprosy and noted that Gandhi’s vision was not just to treat them but to ensure they were part of mainstream society.

The prime minister said there is still a long way to go before leprosy is completely eliminated from India and that work is needed for the socio-economic upliftment of people affected by leprosy so they can make their contribution to nation-building. “We have to strive hard to ensure that these citizens of

## FOOTNOTE

\* *A Handbook for Parliamentarians: Eliminating Discrimination against Persons Affected by Leprosy and Their Families* (The Nippon Foundation, January 2017)



(Right) Video message from Prime Minister Modi; (far right) a choir of children from leprosy colonies in Delhi perform Gandhi's favorite devotional song, Vaishnav Jan.

our country lead a life with dignity that Mahatma Gandhi dreamt of," he said.

Among those attending were some 100 residents of leprosy colonies around India. They had been present the previous day for the Sasakawa-India Leprosy Foundation (S-ILF)-sponsored "Rising to Dignity" awards, which honor successful enterprises started with microfinancing from S-ILF. The awards were presented by India's Minister for Social Justice and Empowerment Thawar Chand Gehlot.

**READING OF THE APPEAL**

As dignitaries gathered on stage, including parliamentarians from India, Sri Lanka, Laos and Myanmar, two recipients of S-ILF scholarships and the IPU president took it in turns to read aloud the text.

Global Appeal 2017 condemns all forms of discrimination on the grounds that a person has or once had leprosy, recognizes and supports the 2010 UN General Assembly Resolution on Elimination of Discrimination against Persons Affected by Leprosy and Their Family Members, and urges all Parliaments "to promote and enforce non-discriminatory laws and policies to end stigma and discrimination against

persons affected by leprosy."

In the afternoon, a roundtable discussion was held to explore ways to achieve the Global Appeal's goals of a world free of stigma and discrimination. Taking part in the discussions were parliamentarians, people affected by leprosy and representatives of NGOs working in leprosy.

The IPU president, who was one of the participants, said that "we have to prove our commitment through action. We have a list of discriminatory laws; we are going to write to the speaker of each parliament asking for them to be repealed." ■



Rising to Dignity award winners, photographed on January 29.

**'THE 3 Ps'**

I shall end by referring to three powers that parliamentarians bring to the table. These are the 3 Ps.

First is the power of pronouncements. What we say makes a difference in the public discourse. What we discuss in the budget speech, in the president's speech, what we speak about in our own constituency, is important.

Second is the power of policy. Legislation does not operate in a vacuum. First you have to have a policy that articulates the political priorities of the government and then you have legislation to promote that policy.

Third is the power that I am going to refer to as

the power of the purse. Policies are only as good as the extent to which they are funded. Unless you have the resources, you cannot implement the policies.

These are the three Ps that we as parliamentarians bring to the table, and this is a commitment that is going to endure until such time that we have a world that is not just free of leprosy but in which all people are treated with the dignity and respect that they are entitled to as human beings. That is the commitment I make to you on behalf of the IPU. *(Extract from speech by IPU President Saber Chowdhury at Global Appeal 2017, 30 January 2017.)*

# Taking Aim at Disability

Chhattisgarh's state leprosy officer is on a mission to prevent Grade II deformity.



## What are the attributes of a state leprosy officer?

A state leprosy officer is a manager. But he must also be a doctor with good knowledge of how to examine a patient for leprosy, and how to analyze the data collected.

## How much of your time is spent at your desk, and how much in the field?

I spend 10 days of each month in the field or in meetings. And two to three days training NMAs (non-medical assistants).

## How big is your team?

We have a district leprosy officer (DLO) in all 27 districts, but they are all part-time DLOs. At block level we have NMAs, at sub-block level we have multipurpose workers (MPWs) and in the gram panchayat (villages) we have mitanins.

## Why do you think there are so many cases of leprosy in Chhattisgarh?

I have only been state leprosy officer for a couple of months, but I think the program was neglected after India achieved elimination of leprosy as a public health problem at the national level in 2005. Prior to that, it was a priority-based program; after that, slackness set in. Now we are gearing up the program, there are campaigns and new cases are coming out. We have deformity cases. We have child cases. Hidden cases have always been there. It's a problem.

## Are you finding the hidden cases in a particular part of the state?

We are finding them all over, but they are mainly in nontribal areas. In tribal areas, the standard of living may be poorer, but houses are clean and set further apart. This may be a reason for less disease prevalence.

## When you were offered the post of SLO, how did you feel about taking on this challenge?

I wanted to do this work because I saw the old

cases of Grade II deformity. There is no way back from that deformity. There is a distance between a normal, healthy person and a person affected by leprosy. People think those with the disease are cursed. One of my motivations is to prevent Grade II disability. We see people residing in colonies and we see new patients going to reside in colonies. Why? It is because of Grade II deformity. If Grade II deformity is not there, the stigma will be less.

## What is the key?

Early diagnosis. Finding the cases and starting treatment. We should be treating PB (paucibacillary) cases so that they do not turn into MB (multibacillary) cases. Already we are seeing some progress. In 2016, there were slightly more PB cases than MB cases in Chhattisgarh.

## How important are mitanins to your work?

The mitanin is a voluntary health worker appointed from within her community. We give them training. We have 60,000 mitanins. They are the main strength of the state. We are the founder state of mitanins. In other states they are known as ASHA (Accredited Social Health Activists).

I wanted to do this work because I saw the old cases of Grade II deformity.

## Do you see attitudes toward leprosy changing?

I had a conversation with a friend of mine from the education department, who asked me if there are cases of children affected by leprosy. When I answered yes, he said, 'Then the students should be removed from school!' I told him it is a child's right to have an education and they should not be removed. They can be treated and they are not infectious. He accepted my explanation.

I was examining a case of leprosy. The patient told me that he had "kushta" (skin disease), not "kodha" (leprosy with Grade II deformity).

I know of a boy who was taken to the hospital by his mother and diagnosed with leprosy when he was 14. He was treated, but when the villagers came know this they advised her to send him to a leprosy colony. She refused. Some years later, his marriage was fixed. He told the girl that he had suffered from leprosy in the past. The girl's parents didn't want her to marry him, but she did anyway. Now they have children and are doing well. ■

## PROFILE:

### Dr. M.R. Deshpande

Dr. M.R. Deshpande is the state leprosy officer for Chhattisgarh in central India. Chhattisgarh is among six of the country's 34 states and Union Territories that currently have a disease prevalence rate of above 1 case per 10,000 population.

## Visits to Indonesia and India

The Goodwill Ambassador travels to two of the three countries with the biggest burden of leprosy for an update on the progress they are making against the disease.

### INDONESIA (DECEMBER 12-18, 2016)

Late last year I visited Indonesia, which reports the third highest number of annual new cases of leprosy after India and Brazil. Since eliminating leprosy as a public health problem in 2000, the country sees between 16,000 and 19,000 new cases a year.

Of its 34 provinces, 12 have yet to achieve elimination. This is partly explained by the sprawling archipelago's complicated geography and the decentralized nature of its administration—the latter requiring the central government to gain the understanding of each governor for its policies. It is up to each province how much of its budget it allocates for anti-leprosy measures.

After a briefing at the WHO country office in Jakarta, I flew to Padang city in West Sumatra province, where I took part in a leprosy awareness meeting. I was particularly interested to hear of an initiative of the state health department to educate bike taxi drivers about leprosy and involve them in awareness-raising activities. I also learned of initiatives to spread awareness involving mosques and women's associations, and the work of an organization of people affected by leprosy promoting early case detection and offering patients advice on coping with the psychological issues they may experience following their diagnosis.



Self-care activities in West Sumatra

After the meeting, I departed for Padang Pariaman Regency. About 100 people affected by leprosy and health staff were waiting for me at the Enam Lingkungan health center. During my visit, I had the chance to watch people participate in self-care activities. One man I met, who had been left with poor eyesight and severely deformed fingers as a result of leprosy, told me of his delight at undergoing surgery and seeing a marked improvement in both conditions. Support for his surgery had come from Baznas, the National Alms Agency, which provides assistance to the country's needy.

Returning to Jakarta, I attended a WHO strategy meeting about a five-year plan to detect



Dr. Nila Moeloek, Indonesia's Minister of Health

and eliminate leprosy and yaws in every state of Indonesia by 2020. I said I was prepared to visit Indonesia as often as necessary if I could be of assistance in this effort.

In a meeting with Health Minister Dr. Nila Moeloek, I learned that the ministry was adopting both a community-based approach and a family-based one in the 12 provinces that had yet to eliminate leprosy. I said I hoped that the ministry would involve PerMaTa, the country's main organization of people affected by leprosy, in these activities. I also repeated my offer to visit Indonesia any number of times in support of its goals. Hearing this, the minister promised to accompany me on a visit to a leprosy-endemic area next time.

While in Jakarta, I called on the offices of Muhammadiyah, a major Islamic NGO that operates the nation's largest private school network. It has over 1,000 schools, ranging from kindergarten through university, and reaches 30 million people. I requested that Muhammadiyah spread awareness of leprosy among its network, and Dr. Sudibyo Markus, senior vice president for international relations, said he would be delighted to oblige.

Subang Regency has one of the heavier caseloads



PerMaTa training session in Central Java



(Far left) Addressing residents of Ganga Kusta Colony in Raipur; (left) mitanin: these female community health volunteers perform a vital role

of leprosy in West Java province. During my stay in Indonesia I paid a visit to see the situation for myself. The health director told me that their efforts to tackle the disease were hampered by insufficient staff and funds. I was able to meet with a number of people affected, including a youth called Yudi. He told me that after he contracted leprosy, he had lost confidence and became afraid to talk to people. Now he was coming out of his shell and was using his experience to support others affected by the disease.

On my last day I flew to Solo (Surakarta) in Central Java, where PerMaTa had organized a training session. Leaders of 27 branches from three states had assembled to exchange information and ideas on awareness-raising, economic self-reliance and education. PerMaTa has 3,000 members throughout the country and with many young leaders emerging, it is actively engaged in its work.

I am committed to seeing Indonesia make further strides against leprosy. Consequently, I am planning to make a number of visits in 2017 to follow its progress and encourage all involved in their efforts.

### INDIA (JANUARY 28 – FEBRUARY 5)

Chhattisgarh is one of India's high-burden states for leprosy, but it is making concerted efforts to tackle the disease, as I found on a recent visit following the successful launch of Global Appeal 2017 in New Delhi.

Located in central India, Chhattisgarh was formed in 2000 from part of Madhya Pradesh. In my meeting with Health & Family Welfare Minister Ajay Chandrakar, he told me that Chhattisgarh does not have a good track record historically speaking regarding leprosy, but that this was changing and leprosy was being made a priority.

As I learned during my stay, this has involved a change in strategy, seen in the shift from a top-down, government-led approach to a community participation model, with the involvement of gram panchayats, or local self-governing bodies in villages.

The health authorities are running skin camps, which they discuss in advance with the gram panchayat. By not calling them "leprosy camps" they are able to attract and screen more people.

They have also identified one or more "leprosy

champions" in every village. These are people who previously had leprosy and were treated and cured, who are prepared to stand before the community and talk about their experiences. These "champions" encourage people to see a doctor if they suspect a problem; their stories also convince people that leprosy is curable.

Another key player is the mitanin. These are female community health volunteers chosen by their communities. The word is Chhattisgarhi for "a female friend" and they are exactly that—female friends to their communities who improve awareness of health issues and provide relief for common health problems. The mitanin system has been replicated in other states, where these health workers are known as ASHA, or Accredited Social Health Activists.

The results of these initiatives are beginning to be seen in increased case numbers. From reporting around 8,000 cases per annum for the reporting years 2013-2014, 2014-2015, and 2015-16, Chhattisgarh had recorded over 10,500 new cases between April and December 2016, and was expecting a figure of around 12,000 by the end of March. This is a good sign as it means hidden cases are being uncovered. The current year is the first that Chhattisgarh has seen more PB cases than MB cases.

In addition to Health Minister Chandrakar, I also had meetings with Sonmoni Borah, secretary of the social welfare department, and Social Welfare Minister Ramshila Sahu and other partners in the fight against leprosy, including India's national program manager, Dr. Anil Kumar (see sidebar).

Among the points we discussed were the idea of



APAL state leader for Chhattisgarh Ghasiram Bhoi introduces the Goodwill Ambassador to his mother.



Ghasiram Bhoi speaks at a gathering of residents of Indra Dharam Dham Kusta Colony in Raipur.

forming a coordination committee that would cut across departments and agencies and make it easier for various issues relating to leprosy to be discussed under the same roof. I am pleased to say that the health department has put itself forward to be the “nodal department” for leprosy.

We also discussed skills training and a maintenance allowance for people affected by leprosy, one that takes account of the social disability they shoulder as a result of the stigma attached to the disease.

During my stay I traveled from the capital Raipur to the district of Masahamund where I had a chance to meet with some mitanin and talk to a number of people under treatment.

Among those accompanying me during my stay in Chhattisgarh were the leaders of the Association of People Affected by Leprosy (APAL), Vagavathali Narsappa and Guntreddy Venugopal, and APAL’s state leaders Ghashiram Bhoi and Vijay Masih.

Mr. Bhoi’s colony is located in Raipur. Of its 150 residents, 80 are people affected by leprosy—and all 80 beg for a living. However, a resident I spoke with there said he did not want his son to do the same and I believe this holds true of all parents. With ramped up efforts to control the disease, provisions to provide skills training and allowances to overcome social disability, I am confident that one day such a situation will be a thing of the past. ■

## MAKING UP FOR LOST TIME



During my stay in Chhattisgarh I attended a partners’ meeting at which Dr. Anil Kumar, the deputy director general (leprosy) for India’s Ministry of Health & Family Welfare gave a presentation on the situation in the country as a whole. He assumed his post in September 2015, following which there have been some positive developments.

India achieved the elimination of leprosy as a public health problem at the end of 2005. Since then, 34 out of the 36 states and Union Territories have achieved elimination “at some point” although four have subsequently relapsed. Chhattisgarh is one of the two states yet to achieve elimination.

What troubles Dr. Kumar is that since national-level elimination was achieved and leprosy services have been integrated into the general health services, the new

case detection rate has remained almost static while the rate of Grade II (visible) disability has started to go up. “After 2005, we did not detect hidden cases. We allowed GII disability to occur for the last 10 years. This is very unfortunate,” he said. “We have to take action to reverse this.”

One of the mistakes of the past was to have assessed the program based only on the number of cases and prevalence of leprosy, he said. To illustrate his point, he displayed two maps of India. The first showed states with a high rate of prevalence, the second showed states with high rates of GII disability. What is apparent is that GII disability is higher in many of the low prevalence states. “We must not concentrate only on states where the prevalence rate is high,” he said. “We have to concentrate on other states also, because ultimately these are the states where the program is not being implemented effectively and so prevalence could again rise and they become problem states.”

To address the challenges, Dr. Kumar has introduced a three-pronged strategy: leprosy case detection campaigns (LCDCs), focused campaigns in hotspots, and special plans for hard-to-reach areas. The LCDCs that were

conducted last year uncovered 32,000 new cases and he expects thousands of cases of GII disability to be averted as a result.

The LCDCs are being supplemented by chemoprophylaxis, with a single dose of rifampicin being administered to all contacts of confirmed cases, to help reduce community-level transmission. In hard-to-reach areas, local communities are being empowered with training and supplies of drugs so they can implement the program and detect cases.

Dr. Kumar said that all GII cases around the country detected during 2016-2017 will be investigated, the data entered in a computer and analyzed, and based on this analysis, activities will be implemented to prevent GII disability.

He said he is aiming to achieve zero GII disability among children and less than 1 case per million among the general population by 2019, one year ahead of the target set by the WHO in its current five-year strategy.

“If we work hard, if we detect cases early, if we are honest in our efforts, we will definitely be able to achieve this,” he said. Listening to the determination in Dr. Kumar’s voice, I believe that he will.

# Another Step Forward

Draft final report on Principles and Guidelines adopted by UNHRC Advisory Committee.

The Human Rights Council Advisory Committee concluded its 18th session in Geneva on February 24, adopting the draft final report on the implementation of the Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members.

With the report concluding that various forms of discrimination against those affected by leprosy continue to exist in many parts of the world, one of its key recommendations is to establish a specific and dedicated mechanism within existing U.N. human rights machinery to follow up, monitor and report on progress made at the national level on implementing the Principles and Guidelines.

The Nippon Foundation, which facilitated the drafting committee's research, thanked its members for their efforts following two years of intensive investigations into the state of discrimination against persons affected by leprosy and also the extent to which the Principles and Guidelines have been implemented.

In a written statement submitted to the session, the foundation said: "We support the final report's recommendation calling for the creation of a special procedure under the auspices of the Human Rights

Council for the purpose of following up, monitoring and reporting on progress made and measures taken by States for the effective implementation of the Principles and Guidelines. In addition, we welcome the part that recommends that the Human Rights Council encourage the OHCHR to organize seminars, conferences and side events on leprosy-related discrimination in cooperation with States and relevant organizations such as the WHO as well as concerned NGOs."

The session also received feedback from the International Federation of Anti-Leprosy Associations (ILEP), which cited findings from a survey carried out by an ILEP panel of people affected by leprosy that underline the need for a monitoring mechanism. Based on 265 responses from 20 countries, the survey found that discriminatory language and practices are still part of the experience of people affected by leprosy; there is little evidence of state involvement in reduction of stigma and discrimination; and many persons affected by leprosy are not able to participate in the elaboration of policies that affect them.

The report will now be finalized and submitted to the Human Rights Council at its 35th session in June this year. ■

## FOR THE ELIMINATION OF LEPROSY

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## FROM THE EDITORS

### EYES FILLED WITH HOPE

When India's nation leprosy program manager gave a PowerPoint presentation in Chhattisgarh recently, he made a point of commenting on the image he had used on the title page. It showed a young girl looking out of the doorway of her home; on the door, written in chalk, was information concerning the household recorded as part of a massive leprosy case detection campaign conducted last year. What Dr. Anil Kumar wanted to draw his listeners' attention to were the eyes of the girl, "eyes filled with hope," he said.

Dr. Kumar, the deputy director general (leprosy), takes his responsibilities extremely seriously, as is clear from the Goodwill Ambassador's account of his presentation on page 7. In a separate conversation, he said that when one has seen a 13-year-old girl with disabilities as a result of leprosy, and contemplated how this is going to affect the rest of her life, including her marriage prospects, it is impossible not to want to prevent this happening to other people. From his words and deeds, it is apparent that Dr. Kumar is on a mission to make up for lost time after



rates of disability were allowed to creep up.

Vagavathali Narsappa, the president of India's Association of People Affected by Leprosy, was a boy when he contracted leprosy. He lost parts of his fingers due to the disease and faced rejection and stigma. This happened to Mr. Narsappa 40 years ago. "This should not still be happening to children today," he said.

Steps are being taken to address this issue at the global level as part of the WHO's current five-year strategy for leprosy and in India under the National Leprosy Eradication Programme piloted by Dr. Kumar. Eyes filled with hope are watching.