

FOR THE
Elimination
 OF **Leprosy**

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



The Goodwill Ambassador with Sinknesh at the symposium on leprosy and human rights in Addis Ababa, Ethiopia, on September 18.

MESSAGE

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Encouraging Words from Ethiopia

Recently I travelled to Addis Ababa to attend a symposium on leprosy and human rights. Jointly hosted by The Nippon Foundation and Ethiopia's Ministry of Health, it drew some 200 delegates, including representatives of governments, international organizations, NGOs, organizations of people affected by leprosy and human rights experts. Of the 13 countries represented, eight were from Africa: Angola, Congo, Ethiopia, Ghana, Mali, Niger, South Africa and Tanzania.

The purpose of the symposium was to raise awareness of the U.N. resolution adopted in 2010 on the elimination of discrimination against persons affected by leprosy and their families and to promote the implementation of its accompanying principles and guidelines. The Nippon Foundation is organizing a series of five symposia in different regions of the world; this was the third, following ones in Brazil and India.

The conference opened with a speech by Ethiopian Prime Minister Hailemariam Desalegn, who is also chair of the African Union. In an address that gave hope and inspiration to all

participants, he pledged his government's firm support for the resolution and guidelines.

The Ethiopian National Association of Persons Affected by Leprosy (ENAPAL) was well represented at the symposium. This organization is actively working to eliminate stigma and discrimination and embodies what the principles and guidelines are all about.

Among its members was Sinknesh, a 28-year-old woman who had been diagnosed with leprosy at the age of 12 and suffered severe discrimination from her family. She was kicked out of home and had to beg on the street. Thanks to ENAPAL's support she now works as an embroiderer and her life is full of hope. This is the kind of grassroots activism that I hope will spread across Africa.

To ensure that the U.N. resolution doesn't end up as mere words on paper, we have to keep working to see that the principles and guidelines are put into practice. Let us go forward together, hand in hand, and make this happen.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Expert Gathering

18th International Leprosy Congress convenes in Brussels to tackle “hidden challenges”.



Brazil as No. 1: the largest number of delegates to the 18th Congress came from Brazil, followed by India.

Over 840 delegates from 83 countries converged on Brussels for the 18th International Leprosy Congress, held from September 16 to 19. Hosted by the Damien Foundation, the Belgium-based NGO that celebrates its 50th anniversary next year, the congress takes place every five years and is the main scientific meeting in the field of leprosy.

With “Hidden Challenges” as its theme, the 18th Congress came at a significant juncture in the history of leprosy control. Although good progress has been made against the disease since the introduction of multidrug therapy in the 1980s, in recent years there has been noticeable stagnation in case detection. Globally, annual new case numbers hover around 200,000 to 250,000 — or just where they were at the time of the previous congress in Hyderabad in 2008. Concern that the situation had become static is what prompted The Nippon Foundation and the WHO to organize an International Leprosy Summit in Bangkok in July to reinvigorate commitment at the political level.

But political commitment alone is not enough. With fewer cases of leprosy, it becomes more difficult technically for countries to manage their leprosy programs. “The challenge now is for the scientific community to come up with innovations and this is an opportunity to see what they have in the way of new ideas,” said Professor Cairns Smith, in charge of the Scientific Program, at the outset of the congress.

One particular intervention that received a lot of attention was chemoprophylaxis: a one-drug treatment given to household contacts of people diagnosed with leprosy. Trials over the last few years have shown this can reduce the risk of developing leprosy by about 50-60%. A

special session hosted by the Novartis Foundation for Sustainable Development made the case for chemoprophylaxis as part of a contact-centered strategy that could bring new case numbers down. It was apparent, however, that not all delegates were ready to give their endorsement.

At the cutting edge of genome research, Professor Steward Cole of UPCOL noted the “fantastic technological progress” that has been made in understanding more about the *m.leprae* bacillus. There is “a need to exploit this for the benefit of patients,” he said, including by targeting pre-clinical cases of leprosy.

His research in the United States has also raised the possibility that leprosy is a zoonosis. “There is strong evidence to suggest that exposure to infected armadillos could lead to leprosy,” he told the congress.

Meanwhile, Dr. Julie Jacobson of the Bill and Melinda Gates Foundation looked at another important area for leprosy programs moving forward: opportunities to improve leprosy control within the context of neglected tropical diseases and potential synergies with other NTD programs.

MULTIDISCIPLINARY FLAVOR

Leprosy is not only a medical condition. It also has long-term physical and social consequences. These aspects too were given a thorough airing in Brussels, with sessions on everything from prevention of disability to stigma reduction and leprosy and human rights.

Indeed, one of the remarkable aspects of the congress, which is proud of its tradition as a scientific forum dating back to 1897, is the wide range of subject matter it now covers. Hence

delegates could hear a paper on the effect of tactile sensors in detecting the pressure threshold of anesthetic hands as well as one on the diversity and richness of patient literature in Japan.

While few in number, delegates included people affected by leprosy, and there were discussions on what role they can play in leprosy control activities. “But this talk of greater participation must go beyond tokenism,” warned Kay Yamaguchi of Sasakawa Memorial Health Foundation in a pre-Congress workshop on community-based approaches to patient detection and improving services.

In a welcome development for researchers and historians alike, International Leprosy Association (ILA) President Dr. Marcos Virmond announced that every issue of the *International Journal of Leprosy and Other Mycobacterial Diseases*, which was published between 1933 and 2005, has been digitized and that “this wonderful body of knowledge” can be

accessed online from the ILA website.

In a break with past precedent, the ILA decided to hold its next congress in three years’ time, in order to “keep up with the fast pace of change.” The 19th Congress will be held in China in 2016 and the 20th Congress in the Philippines in 2019.

Dr. Virmond, who is a reconstructive surgeon from Brazil, was elected to serve a further term as ILA president. Speaking on the final day of the congress, he said he had been hoping for some more answers from scientists on how they were going to assist programs in the field, particularly in the area of rapid diagnostic tests. “We could not get a clear position on that,” he said.

Nonetheless, he felt delegates would be going home reinvigorated by the congress. In any case, he confidently predicted, scientists will continue to study leprosy long after it no longer poses a problem, “because there is still so much to understand about this intriguing disease.” ■

LEPROSY RESEARCH INITIATIVE

A FUNDING BOOST FOR LEPROSY

What better venue than the field’s main scientific gathering to unveil a major new funding initiative for leprosy research? Four NGOs took to the floor at the 18th International Leprosy Congress to announce they will contribute 6 million euros (approximately 8 million dollars) over the next five years to fund international studies into addressing leprosy’s remaining challenges.

Netherlands Leprosy Relief, American Leprosy Missions, German Leprosy and Tuberculosis Relief and The Leprosy Mission Canada pointed to the need for further research given that leprosy transmission is still continuing and many people released from treatment struggle with the physical or social consequences of the disease.

“In a way, the success of the Global Leprosy Program over the past two to three decades has seen funds for leprosy research decline quite substantially,” said NLR director Jan van Berkel. “Frequently, researchers have moved into other fields because funding may have been more easily available. Therefore, we do not only

join our funds under one policy, but we are also committed to making investments to attract more external funding toward the area of leprosy-related research.”

The Leprosy Research Initiative has identified five priority areas for funding: preventing delay in diagnosis; early detection and treatment of nerve function impairment and reactions; “inclusion research” for people with leprosy-related and other disabilities; integration of prevention of disability in national programs; and the roll-out of chemoprophylaxis.

All research supported by the LRI will be reviewed, selected and monitored by an independent Scientific Research Committee.

“The LRI is unique because its members have established joint research policies and priorities and have given the LRI’s independent scientific committee the authority to disperse their combined funds,” said Bill Simmons, president and CEO of ALM. “The founding partners have agreed that this is the best way to insure sustainable funding for excellent, scientifically rigorous projects.”

HOW TO GET FINANCIAL SUPPORT FOR YOUR RESEARCH?
Tuesday, 17 September 2013, 13:30-14:00

Sponsored announcement
The Leprosy Research Initiative (LRI) is a unique partnership between four NGOs: Netherlands Leprosy Relief (NLR), American Leprosy Missions (ALM), German Leprosy and Tuberculosis Relief (GLTR), and The Leprosy Mission Canada (LMC). The LRI will fund research into addressing leprosy's remaining challenges. The LRI will contribute 6 million euros (approximately 8 million dollars) over the next five years to fund international studies into addressing leprosy's remaining challenges.

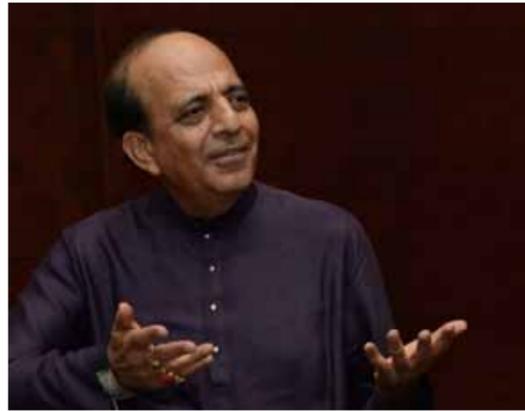
Sponsors
Netherlands Leprosy Relief (NLR), American Leprosy Missions (ALM), German Leprosy and Tuberculosis Relief (GLTR), and The Leprosy Mission Canada (LMC).

Added van Berkel: “It is only by working together and funding relevant, highly-qualified research that we can develop, in the end, the control programs and disability programs that we need that will one day bring leprosy and its consequences under control.”

For more information, visit www.leprosyresearch.org

Leading from the Top

India's parliamentarians look to address the age-old stigma of leprosy.



How and why did you become involved in this initiative to tackle leprosy and related human rights issues?

At last year's symposium in Delhi on leprosy and human rights organized by The Nippon Foundation, to which I was invited as chief guest, there were quite a few people affected by leprosy present. As I interacted with them, I felt that we needed to do something at the highest level of democracy, which is the Parliament of India. I felt there could be some laws we need to initiate, and some laws we need to repeal. I thought we must form a forum of parliamentarians. I was fortunate to work with Mother Teresa in Kolkata when I was a young student. When you see something as a young man, it leaves a deep impression.

How did you motivate other parliamentarians to join?

Everywhere in the world, people are looking for an opportunity to be part of something that is good. When they realized I was initiating this forum, everyone wanted to be a part of it. That shows there is a lot of hope and people want to participate and contribute in anything that is done for humanity. All we need is good leadership, and we have been fortunate to get that from Mr. Sasakawa. He goes into the field; he doesn't just sit in an air-conditioned room. I was with him to visit leprosy colonies in Asansol, West Bengal, yesterday and I could see people were so happy by his visit.

How many members make up the parliamentarians forum?

We have 52 members. They are from all parties and all regions of India.

What activities do you have in mind as a forum collectively, and what do you expect parliamentarians to do individually?

The biggest thing is awareness. There is a lot of

stigma attached to leprosy. Many people have no idea about the disease. So the first thing is to understand the disease ourselves, acknowledging that we are not experts. We need to have seminars, talk to experts and take their opinion. We need to go to colonies of people affected by leprosy, talk to them, encourage them and tell them they are not alone. We will make sure that they are brought into the mainstream. The minimum a human being needs is dignity. They need to be treated with respect.

You mentioned the possibility of a new law.

It is very important that there is a law that will make discrimination an offence. Let's say someone who has had leprosy wants to go to school and is refused admission. That's wrong. That should be declared illegal. And we need to make sure that laws that infringe human rights are repealed.

What else do you have in mind?

There are human rights societies and human rights commissions, which are government structures. We need to make them participants, because this is a human rights issue. Whenever anything happens in the world that enhances the dignity of human beings, India is always in the forefront. This is the land of Mahatma Gandhi. We need to follow his teachings. He always talked about humanity. Our philosophy in India is humanity.

"This is the land of Mahatma Gandhi. We need to follow his teachings."

Do you see this as a long-term commitment?

I can guarantee you that this is going to be a continuous effort. All the parliamentarians, including the honorable speaker of the Lok Sabha (House of the People) are excited. The chairman of the Rajya Sabha (Council of States), who is the vice president of India, is eager to interact with us and visit colonies of leprosy-affected people. I am very excited by the idea that people affected by leprosy will all be in the mainstream — youngsters will get an education, clean water and above all dignity. These are our own people — our brothers, our sisters, our mothers, our fathers. They cannot be discarded from society. The stigma has to go. In the 21st century, it is just not acceptable. ■

PROFILE:

Dinesh Trivedi

Dinesh Trivedi is a Member of Parliament from the All India Trinamool Congress Party, representing Barrackpore, West Bengal. He is the former Union Minister for Railways and the former Union Minister of State for Health and Family Welfare. He is the convener of the Forum of Parliamentarians to Free India of Leprosy.

Building Momentum

The Goodwill Ambassador maintains his unrelenting schedule, with two visits to India either side of appearances at the 18th International Leprosy Congress in Belgium and a human rights symposium in Ethiopia.

INDIA (AUGUST 28-30)

The recent International Leprosy Summit in Bangkok served to renew political commitment for a leprosy-free world among countries with a high burden of the disease. It was unfortunate, however, that no one from the central government of India — the country accounting for the most new cases of leprosy — had been able to attend.

Building on the momentum generated by the summit, I was keen to travel to India at the earliest opportunity and brief the Ministry of Health and Family Welfare on the outcome. My visit at the end of August, though short, was very productive.

I met with Health Secretary Keshav Desiraju, who assured me that India was firmly committed to leprosy control. He also promised the ministry's cooperation over upcoming visits I had planned to West Bengal and Uttar Pradesh, two high-burden states. Among others attending the meeting were Dr. Nata Menabde, WHO representative to India, Dr. Sumana Barua of the WHO's Global Leprosy Program and Dr. C.M. Agrawal, the DDG-Leprosy at the ministry. It was an important gathering.

After my meeting at the ministry, I called at the National Human Rights Commission. Next January's Global Appeal to end stigma and discrimination against people affected by leprosy is being supported by national human rights institutes and I wanted to seek the commission's endorsement in person.

I also attended a get-together of the recently inaugurated Forum of Parliamentarians to Free India of Leprosy, hosted by Dinesh Trivedi, formerly Union Minister for Railways and Union Minister of State for Health and Family Welfare. (See Interview on page 4.) It is very encouraging to have such influential figures engaged in tackling leprosy and I have high hopes for the contribution they can make.



Meeting with Health Secretary Desiraju and colleagues

Lastly, I took part in the board meeting of the Sasakawa-India Leprosy Foundation. I am happy to see the progress it is making in working with colonies to provide residents with alternatives to begging, and I look forward to further positive reports.

BELGIUM (SEPTEMBER 15-16)



Speaking at the opening ceremony of the congress

In September I flew to Brussels to attend the opening ceremony of the 18th International Leprosy Congress, which was held in the presence of HRH Princess Astrid of Belgium.

Following on from the International Leprosy Summit in Bangkok in July, it was another opportunity to focus attention on the challenges that remain in leprosy, of which there are many.

The priority of leprosy in government health agendas is declining; clinical expertise is shrinking; and stigma and discrimination in society continue to inflict pain and suffering on people affected by leprosy and their families.

Securing renewed political commitment from high-endemic countries in Bangkok was critical, but this alone cannot directly prevent further transmission of leprosy, nor can it directly change the lives of patients or those affected by leprosy. That requires the efforts of all those gathered at the congress, I told delegates. "Each of us has a vital role to play; each of us is an agent for change."

Most importantly, I said, "it is vital to sustain a platform such as this congress, where experts from various fields can come together to share their findings, build networks and learn from each other to find innovative solutions for our common challenges."

I hope that the congress will have been successful in this respect.

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Participants in the African Regional Symposium on Leprosy and Human Rights

ETHIOPIA (SEPTEMBER 17-21)

From Belgium I moved on to Ethiopia to attend the African Regional Symposium on Leprosy and Human Rights on September 18. This was the third in a series of five regional symposia. The Nippon Foundation is organizing to familiarize governments and policy makers with the U.N. resolution on eliminating stigma against people affected by leprosy and to guide them on how to implement its accompanying principles and guidelines.

In my speech at the conference, I said that many of the problems facing people affected by leprosy today stem from society's misperceptions and ignorance about leprosy. I gave the example of Sinknesh, a 28-year-old woman born in the western region of Ethiopia. When she was 12, she began to develop symptoms of leprosy. Sinknesh was lucky to meet leprosy workers in town who took her to Addis Ababa to be treated. With a year of treatment, she was completely cured, but her family disowned her all the same. They burned all of her belongings, told her that she was a curse and a disgrace to her family, and that she was never to return home. Being abandoned, and with no skills, she had to resort to begging on the streets.

Within a year of treatment she was completely cured, but her family disowned her all the same.

Sinknesh was fortunate to find support from the Ethiopian National Association of Persons Affected by Leprosy (ENAPAL). ENAPAL is dedicated to empowering people affected by the disease by providing opportunities for education, skills training and microfunding. It also engages in nationwide campaigns to raise public awareness

about leprosy. Now, Sinknesh no longer begs, she has found work at her church doing embroidery, and she has even returned to school. But even after many years of being cured, she still lives in a community of leprosy-affected people and, except for her brother, she has not reunited with her other family members.

It is imperative that governments work with NGOs, civil societies and media to formulate policies and plans of action to raise awareness in society and to foster respect for the human rights and dignity of persons affected by leprosy and their families. This is the most difficult task and the most time consuming. But if governments can make a commitment toward this end, I am convinced that we will be able to make an impact that is far-reaching. The more people understand what leprosy really is, the fewer stories we will have of ones like Sinknesh.

INDIA (SEPTEMBER 22-24)

From Ethiopia I flew to India for the second time in a month. My destination this time was West Bengal. After Uttar Pradesh, Maharashtra and Bihar, West Bengal annually reports the most number of new cases — 11,683 cases in 2012. A particular concern is the high rate of visible disability at time of diagnosis, which is a clear sign that cases are being diagnosed late. In particular, the state capital Kolkata reports 10% of new cases with Grade II disability, compared with a national average of 3%. Perhaps this should come as no surprise when one learns that more than half the districts in West Bengal have no leprosy officer.

On September 23, I set off from Kolkata in a convoy of six vehicles for two leprosy colonies in the Asansol sub division of Burdwan District, about 230 kilometers away. My party included Dr. A.K. Puri, from the Central Leprosy Division of the Ministry of Health and Family Welfare; Dr.



Visting Kankar Danga Leprosy Colony in West Bengal

Saurabh Jain, the focal person for leprosy at the WHO's country office for India; Dr. Pradip Kumar Mandal, the state leprosy officer for West Bengal; and last but not least, Dinesh Trivedi, whose constituency is in West Bengal.

When we arrived at Rahmat Nagar Danda Leprosy Colony around four hours later, we were met by Malay Ghatak, a member of the West Bengal legislative assembly and also state agriculture minister, and Tapas Bannerjee, the mayor of Asansol.

The colony consisted of 65 households and approximately 180 people. The dwellings were in a poor state and packed closely together; some looked like they might collapse at any moment. Like many people living in colonies, the inhabitants mostly have to beg for a living. The second generation ekes out a small income as day-laborers or garbage collectors to support their parents, many of whom are disabled.

The second colony we visited was about 20 minutes' drive away. Kankar Danga Leprosy Colony presented a rather different picture. For a start, it was bigger: 90 households and a population of 254 people. Sixty homes had been built with government grants for low income housing. Electricity and water were in good



Dinesh Trivedi chats with a colony resident

supply. Children went to the nearby public school. In general, people seemed a lot happier.

The next morning I called in at the West Bengal State Human Rights Commission, where I met Justice Asok Kumar Ganguly. Because of my schedule, I could only stay a short time, but Justice Ganguly invited my companions to stay longer. Thus did Radhavallav Panda, the president of National Forum India's state forum in West Bengal, and four other people affected by leprosy explain to him in detail the challenges they face.

In the afternoon I visited the West Bengal Ministry of Health and Family Welfare, where I met Minister of State Smt Chandrima Bhattacharya. Since the diagnosis and treatment of new cases is at the heart of the leprosy control program, I urged the minister to fill the many vacancies in the program with the appropriate personnel. The minister assured me she would do so.

The next item on my agenda was a stakeholders' summit. Among those taking part were the director of Health Services, the mission director of the National Rural Health Mission, district leprosy officers and representatives of NGOs active in West Bengal — 35 people in all. I think such stakeholders' summits in India's high-burden states are a good way to form a common front in the fight against the disease and I shall be organizing more in the months ahead, beginning with Uttar Pradesh.

I rounded off my stay in West Bengal by getting together with members of the NFI's state forum and colony leaders. Twenty one came from all corners of the state to meet with me. They face many issues, including: improving the quality of life in the colonies, securing an increase in the state pension and ensuring their children have access to education. I hope my visit will have helped to move their efforts in the right direction. ■

Showing the “The Way Home”

Newly launched website features online museum about Sungai Buloh leprosarium.



The Way Home is the title of a book of stories about children seeking to be reunited with their biological parents — parents they were separated from because of a diagnosis of leprosy.

It is also now the name of a new website that continues where the book ended. The objective is to encourage descendants of Malaysia's Sungai Buloh leprosy settlement “to get to know the emotional world of their parents and also to see the beauty of the history of where they came from.”

The book's authors Eanee Tan and Joshua Wong hope that the website will serve as a

common platform for families who have been torn apart by leprosy to share their memories, photos and videos. “By doing this,” they state, “we hope to encourage more descendants to come back and trace their roots while their parents are still alive. Our mission is to reunite the former leprosy patients and their descendants through all possible channels. In the end, we hope to empower them with knowledge and courage to preserve their own family history.”

The website includes many moving stories and testimonials from parents and the children they were separated from, oral history videos and plenty of photographs. In addition, there is an online museum relating the history of the Sungai Buloh leprosy settlement, which was once the second largest leprosarium in the world and the site of important medical research into the disease.

On display are garments made by Sungai Buloh residents, handicrafts, documents, research equipment, artifacts and old photographs that provide a rich portrait of life at the settlement in times past.

Visit the website at www.thewayhome.my ■

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FROM THE EDITORS

LEPROSY AS METAPHOR — AGAIN

Earlier this year, Pope Francis denounced careerism in the Vatican's diplomatic corps as a leprosy. Concerned that this would reinforce the strong negative associations with the disease, the Goodwill Ambassador wrote to His Holiness to ask that he refrain from such usage in future. In reply, he received a courteous letter from the Vatican assuring that the Church was committed to caring for people affected by leprosy and working to end the discrimination that they face.

"Courteous" would not be the word to describe the vast majority of the comments that appeared online when the story of the Goodwill Ambassador's "dismay" at the Pope's use of terminology was picked up by the media. Many who posted their thoughts apparently found it difficult to see what the problem was (or why, for that matter, there

was a need for a Goodwill Ambassador for leprosy elimination).

Once again, the Pope has turned to leprosy to make a point about something he wishes to reform, this time describing the papal court as the "leprosy of the papacy." Once more, the Goodwill Ambassador has written to Rome — this time out of the public spotlight — in hopes of encouraging Pope Francis to avoid using the disease as a symbol of something rotten or corrupt.

Leprosy still stigmatizes. Legislation that discriminates against people on the grounds of leprosy still exists in some countries. Marriages break up; healthy children are turned away from school because a parent has the disease. As we work to end the stigma and discrimination, using leprosy as a label — even with the best of intentions — makes that process much harder.