WHO GOODWILL AMBASSADOR'S NEWSLETTER

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Elimination of Leprosy FOR THE

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

Participants in the International Leprosy Summit pose for a commemorative photo following the endorsement of the Bangkok Declaration on July 24.

MESSAGE

After the Summit

A three-day International Leprosy Summit that brought together health ministers and health ministry officials from 17 countries that annually report over 1,000 new cases of leprosy successfully concluded in Bangkok on July 26.

The summit was organized by the WHO's Southeast Asia Regional Office and The Nippon Foundation because of concern that efforts to tackle leprosy appear to be stalling and new case detection rates have remained static in recent years.

At the summit, participants made a commitment to devote further efforts to combat the disease. They recognized the urgent need to focus on the early detection of new cases in pockets of high risk such as urban slums, border regions and ethnic minority areas.

In addition, participants agreed on the goal of reducing the number of new cases with Grade 2 (visible) disability to less than 1 case per million population by 2020 and to create a mechanism in each country to monitor and evaluate the effectiveness of anti-leprosy activities. Promoting the active involvement of people affected by leprosy in the fight against the disease was also emphasized.

These and other points were adopted as part of the Bangkok Declaration, but only after delegates had engaged in full and frank debate. That they eventually agreed on a document that reflected their concerns was one of the great achievements of this summit.

Now we must plan how to realize the aims of the Bangkok Declaration without delay. In addition to pledging my own commitment, I said The Nippon Foundation will donate $20 million over the next five years to tackle leprosy.

The leprosy summit was a meeting in which participating countries, the WHO, the International Federation of Anti-Leprosy Associations, organizations of people affected by leprosy and other stakeholders agreed to contribute resources and expertise toward a leprosy-free world. I believe this summit represents a big step in that direction.

— *Yohei Sasakawa*, WHO Goodwill Ambassador

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A Big Step Forward

Bangkok summit refocuses political commitment on tackling leprosy.

Compared with public health challenges such as malaria, TB and HIV/AIDS, leprosy ranks as a relatively minor problem in most countries today—especially given the progress that has been made since the introduction of multidrug therapy (MDT) in the 1980s. With just one major country (Brazil) still to eliminate the disease as a public health problem, the challenge in countries where leprosy remains endemic is to continue to reduce the incidence and prevalence of the disease and to sustain leprosy services.

But leprosy's so-called last mile is proving a tough challenge. Having "eliminated" leprosy, many countries have been shifting their health priorities elsewhere. There are fears that a sense of complacency may undermine the efforts required to bring an end to leprosy and its consequences.

At the same time, there are still unanswered questions about the disease — a full understanding of the route of transmission, for example — and the need to develop new tools and tests that would make it possible to diagnose leprosy earlier and recognize and manage leprosy reactions more effectively.

Against this backdrop, health ministers or their representatives from 17 countries* that annually report more than 1,000 new cases of leprosy gathered in Bangkok for an International Leprosy Summit. Organized jointly by the World Health Organization and The Nippon Foundation, and hosted with the cooperation of the Thai government, the July 24-26 meeting was called to renew political commitment to tackling leprosy.

The summit duly delivered, with ministers and other partners endorsing the Bangkok Declaration towards a Leprosy-Free World (see page 4). In it they pledge to reaffirm their commitments and strengthen their involvement "in order to ensure a leprosy-free world at the earliest."

To get the wording right and produce a document that delegates felt accurately reflected the ambitions of the summit, a small group worked through lunch on the first day to revise the declaration to everyone's satisfaction, following lively exchanges on the floor. "This declaration is very important. I think it will prove to be a tipping point," said Dr. Jarbas Barbosa, Brazil's vice minister of health surveillance.

> "This declaration is very important. I think it will prove to be a tipping point."

NO ROOM FOR COMPLACENCY

At the opening session, some 100 participants heard Dr Samlee Plianbangchang, Regional Director, WHO South-East Asia, say, "Our challenge is to sustain the quality of leprosy services and to ensure that all persons affected by leprosy, wherever they live, have an equal opportunity to be diagnosed early and treated by competent health workers. While we've covered a lot of ground in reducing the disease burden in all endemic countries, there is no room for complacency. The final battle against leprosy is yet to be won."

They also heard Nippon Foundation Chairman and WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa announce that his foundation would donate $20 million over the next five years toward the fight against the disease. He cautioned that the remaining challenges were becoming more difficult and complex, while urging governments to "reaffirm your strong determination to achieve a leprosy-free world."

During the summit, program managers gave overviews of the situation in their countries, while experts looked at the remaining technical and operational challenges. The meeting also featured a brainstorming session led by Professor Cairns Smith, chairman of the International Federation of Anti-Leprosy Associations (ILEP) Technical Commission, on what should be the goal of the

WHO Regional Director for Southeast Asia Dr. Samlee: "The final battle against leprosy is yet to be won."

(L-R) Myanmar Health Minister Dr. Pe Thet Khin with the WHO's Dr. Sumana Barua and Dr. Hiroki Nakatani.

FOOTNOTE

* Angola, Bangladesh, Brazil, China, DR Congo, Ethiopia, Indonesia, Madagascar, Mozambique, Myanmar, Nepal, Nigeria, Philippines, South Sudan, Sri Lanka, Sudan and Tanzania.

The Goodwill Ambassador pledges his commitment.

WHO's next five-year global strategy for leprosy, which is due to come into effect in 2016.

TASKS AHEAD

The summit noted that the challenges facing the high-burden countries include reducing Grade 2 disabilities in new cases through early case detection, access to equitable and quality health care, and promoting leprosy, wherever appropriate, as an integral part of neglected tropical diseases.

The summit also acknowledged the commitment and contribution of partners and the need to strengthen partnerships further; the importance of involving communities of people affected by leprosy in anti-leprosy activities, including efforts to reduce stigma and discrimination; the need for adequate resources to support program implementation; and also the need to support research in leprosy.

In a statement from one of the partner organizations present, ILEP President Rene Staheli said, "Leprosy is not the worst killer disease in these countries; leprosy is not the main challenge on the health agendas; but it is a political decision whether to set the agenda to finish leprosy, or not."

With the issuing of the Bangkok Declaration, it is to be hoped this decision has now been taken and all involved will indeed move forward to achieve their publicly-stated goal "at the earliest." ■

A PROGRAM MANAGER'S VIEW

One man who was happy to attend the recent International Leprosy Summit was Tanzania's National TB/Leprosy Program Manager Dr. Blasdus F. Njako. It's not often that a leprosy program manager gets much "face time" with his country's health minister, so to be able to spend three days in Bangkok with Minister of Health and Social Welfare Dr. Hussein Ali Hassan Mwinyi was for Dr. Njako a rare privilege.

"It makes my job much easier," he said following the end of the summit. "Normally I come to conferences by myself and report back to the minister after I return home. But having the minister alongside me and having him exposed directly to the problems and challenges in leprosy that were discussed at the meeting makes a real difference. He could ask me questions and I could explain things to him, or seek his views on certain issues."

He admitted it was unusual for him to get direct access to the minister. "In the normal procedure, the program manager only gets as far as the permanent secretary, so this was a fantastic opportunity," he said.

Dr. Njako had praise for the Bangkok Declaration, saying, "It is a very important document. All the challenges are there." As he told his fellow program managers at the conference, "We have been given our marching orders."

For his part, Dr. Njako's boss acknowledged the significance of the three-day gathering. "Ministers have noted the significant contribution of their countries to the global leprosy burden and acknowledged the crucial importance of renewed political commitment in future leprosy control," Dr. Hussein said in the closing address. The summit, he told participants, represented "a crucial milestone in the fight against leprosy in the world."

A Clear Statement of Intent

Text of "Bangkok Declaration Towards a Leprosy-free World".

We, the Ministers of Health from the 17 high-burden leprosy countries in all WHO regions, with relevant stakeholders, and the WHO;

Appreciating the enormous strides made in the reduction of the global burden of leprosy over the past 25 years, including the attainment of the global goal of elimination of leprosy as a public health problem as defined in the World Health Assembly resolution WHA44.9 (in 1991), to reduce the prevalence of leprosy to less than 1 case per 10 000 population;

Acknowledging the huge reduction of disease burden through the widespread implementation of multidrug therapy (MDT) among other prevention and control and care approaches;

Further acknowledging the contribution of all partners involved in leprosy work;

Believing that the long experience of the leprosy control programme in achieving the goal of elimination of leprosy as a public health problem globally will be used to improve the interventions against other neglected tropical diseases;

Concerned, however, with the continuing occurrence of new leprosy cases annually in significant numbers in various countries and also with the continued existence of hyperendemic areas within countries that have led to the consequent stagnation of the leprosy situation over recent years;

Noting with concern the rising complacency consequent to perceiving the leprosy problem as relatively small, and that such complacency results in reduced political commitment, relegated priority, and decreased resources towards dealing effectively with this public health problem;

Recognizing the set target in the current enhanced global strategy for further reducing the disease burden due to leprosy (2011–2015), following the recommendations of the WHO Expert Committee on Leprosy in its eighth report, and *considering* the World Health Assembly resolution WHA66.12 (2013) on Neglected Tropical Diseases, which includes leprosy, and that urges Member States to implement the WHO roadmap for accelerating the work to overcome the global impact of such diseases;

We, the Ministers of Health from the 17 high-burden leprosy countries in all WHO regions, with relevant stakeholders, and the WHO;

1. Declare that it is time for the leprosy-endemic countries, as well as their international and national partners, to reaffirm their commitments and reinforce their participation towards addressing leprosy in order to ensure a leprosy-free world at the earliest;

2. Urge governments and all interested parties to accord higher priority for activities towards a leprosy-free world and allocate increased resources in the coming years, in a sustainable manner, and in doing so:
a: aim to reduce the burden of leprosy and ultimately move towards a leprosy-free world;
b: apply special focus on high-endemic geographic areas within countries through vigorous and innovative approaches towards timely case detection and treatment completion aiming to achieve leprosy elimination as a public health problem at subnational levels;
c: achieve the global target of reducing the occurrence of new cases with visible deformity (grade 2 disability) to less than one case per million population by the year 2020;
d: prevent occurrence of disability through early detection as well as limiting disabilities among already disabled persons;
e: involve communities and the forums of persons affected by leprosy in the process of strategy formulation and implementation of leprosy care, including physical, social and economic rehabilitation and social integration, as per WHO guidelines;*
f: promote empowerment of persons affected by leprosy and ensure effective implementation of United Nations resolutions A/RES/65/215, Elimination of Discrimination against Persons Affected by Leprosy and their Family Members, and A/HRC/15/30, Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and their Family Members.
g: monitor the progress towards attainment of targets through a mechanism at the national level with technical support from WHO and other relevant partners;

3. Reaffirm our political commitment and guidance towards a world free of leprosy.

Bangkok, 24 July 2013 ■

FOOTNOTE

* Guidelines for strengthening participation of persons affected by leprosy in leprosy services.New Delhi, World Health Organization, 2011.

Travels in Central Asia

Accompanied by Dr. Romana Drabik, the Goodwill Ambassador visits Uzbekistan and Tajikistan to learn more about leprosy in these two countries.

In front of Muynak's dermatology outpatient clinic

UZBEKISTAN (JULY 3-6)

In June last year I met several leprologists from Central Asia at a conference in Russia. The event had been organized by Dr. Victor Duyko, director of the Institute of Leprosy Training and Research in Astrakhan, and by Dr. Romana Drabik, a German doctor who has made it her personal mission to assist anti-leprosy activities in countries of the former Soviet Union.

Keen to learn more, I arranged a follow-up visit to two of the countries represented at the conference: Uzbekistan, where the autonomous republic of Karakalpakstan has contributed the bulk of that country's leprosy cases over the years; and Tajikistan, where I had been told that patients from neighboring Afghanistan cross the border for treatment. Accompanying me on my travels was the indefatigable Dr. Drabik.

After a brief stay in the Uzbek capital, Tashkent, where I called on WHO country representative Dr. Asmus Hammerich and Minister of Health Alimov Anvar Valiyevich, I flew to Nukus, the capital of Karakalpakstan. Situated in the northwest of Uzbekistan, Karakalpakstan literally means "the country of black hats."

According to Uzbekistan's chief leprologist, Dr. Eshboyev Egamberdi Khusanovich, who traveled with me to Nukus, Uzbekistan has recorded 28 new cases of leprosy since 1991, the year it became an independent nation. Of these, 17 were from Karakalpakstan. Moreover, nearly 300 of the 328 people registered in Uzbekistan as having had leprosy are also from Karakalpakstan.

Over a welcome dinner hosted by Dr. Khamraev Atajan Karimovich, the Vice Chairman of the Council of Ministers of Karakalpakstan, I was fascinated to hear from Dr. Eshboyev that four or five Japanese soldiers taken prisoner during World War II and held in Uzbekistan had been diagnosed with leprosy. Their records remain in the health ministry archives, including such details as their shoe size. All eventually returned to Japan.

Rusting boats that used to ply the Aral Sea

On July 5, I traveled 220 kilometers north of Nukus to Muynak. This used to be a town of 70,000 people on the southern shore of the Aral Sea, once one of the largest lakes in the world. But two rivers that fed the lake, the Amu Darya and the Syr Darya, were diverted in Soviet times to irrigate land for food crops and cotton. The result is one of the great ecological disasters of modern times. In three decades, the Aral Sea has shrunk to a fraction of its former area. Left behind is a desert landscape that throws up a dust of salt and chemical residues that is said to be the cause of a growing number >> page 6

The head of the clinic with a cabinet of over 400 patient records from Muynak (far left); a huge boiler to warm residential accommodation at Krantau Leprosarium

of health problems among people living in the area.

I had come to see the site of the former leprosarium and visit a clinic where the town's 49 people affected by leprosy are treated for ulcers and other conditions. Like the Aral Sea, there is little trace of the leprosarium today, but the eight ladies I met at the clinic painted a picture of life in Muynak in the old days.

They reminisced about swimming in the sea as children, working in the town's cannery, which produced 20 million cans of seafood a year, and how lively Muynak was at night with all the vacationers it attracted. "It was so noisy you couldn't sleep sometimes," one lady told me. The leprosarium may be gone, but the clinic stores the yellowing medical records of over 400 leprosy patients dating back 80 years to when the leprosarium opened in 1933.

The only leprosarium remaining in Uzbekistan today is in Krantau, 40 kilometers south of Nukus. It moved to its current location in 1952. It was at its busiest in the 1950s, home to some 700 patients. Today are there are just 35 residents and over twice that many staff. The residents live in one-story cottages, divided between two households. Prominent in each cottage is a floor-to-ceiling boiler, indicative of the fact that temperatures in Krantau fall to minus 10C in winter.

> One lady I met entered the sanatorium at age nine and has spent 67 years there.

Most of the elderly residents have lived in Krantau for decades, but were able to marry and start families — in stark contrast to the situation in my own country, Japan. Among those I met was a lady who entered the sanatorium aged nine and has spent 67 years there. She has children, grandchildren and great grandchildren living nearby, and greeted me with a warm smile. Another lady wiped back tears as she proudly told me that her daughter, a university student, is a champion of the Russian martial art known as Sambo.

Because of growing water shortages and frequent power cuts, there are plans to relocate the leprosarium to an outpatient clinic closer to Nukus. I was taken there on my way back to the city. I looked on as Dr. Khamraev, who used to be Karakalpakstan's minister of health, explained the plan to some of the outpatients. He told them they could look forward to better services once the facility was built, although I had the impression that some further explanations would be necessary. Be that as it may, it seems likely that, within a year of my visit, there will be no one at the Krantau facility.

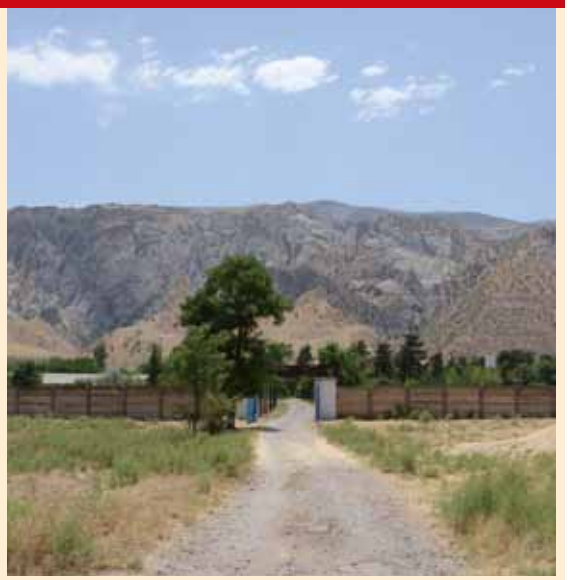
TAJIKISTAN (JULY 8-10)

Although the distance from Tashkent to Dushanbe, the capital of Tajikistan, is only around 300 kilometers as the crow flies, it proved easier to fly via Istanbul — 3,000 kilometers to the west — to get there. Arriving early in the morning, I was met at the airport by Dr. Azizullo Kosimov, the head of the Republican Center of Venereal and Skin Diseases, whom I had met the previous year in Astrakhan. He was especially pleased to see Dr. Drabik again.

Following the breakup of the Soviet Union, the country was plunged into a civil war that lasted until 1997 and claimed 50,000 lives. It was in the midst of this tragic conflict that Dr. Drabik and her late husband made their first perilous visit to Tajikistan and met Dr. Kosimov. As a result, they are very close, and a picture of the Drabiks sits on Dr. Kosimov's desk "so Romana is always looking over what I do."

On my first day in Dushanbe, I had lunch with the WHO country representative, Dr. Pavel Ursu, and called on Deputy Health Minister Dr. Rahmonov S.B. As I had been hoping to fly to Khorog near the border with Afghanistan to see the situation there for myself, I was disappointed to hear the ministry advise against this.

Regarding the border situation, Dr. Rahmonov told me that in 2012 over 1,000 Afghans had received treatment for various diseases in hospitals inside Tajikistan. As for a proposal to build a leprosy



Visiting with residents of Honaka Leprosarium (right); the approach to the leprosarium (far right)

clinic to treat patients from Afghanistan, he said this would be something to discuss when ministry officials next meet their Afghan counterparts. He pointed out that Tajikistan enjoys a close relationship with its neighbor and said that many Tajiks live in Afghanistan: "It is a brother country to us."

On July 9, I visited the country's only leprosarium. It is home to 15 of the 49 people currently on the leprosy register in Tajikistan, although all have been released from treatment.

Honaka Leprosarium is in Gissar district, about 90 minutes by car from Dushanbe. It was relocated from the capital as the city grew and stands on 50 hectares of land close to the splendid Kofarnigan River. Although somewhat isolated, the setting is very pleasant.

As I had found in Uzbekistan, many of the residents raised large families. One couple who met and married in Honaka and have lived there for 50 years, told me they have five children and 13 grandchildren. Under the policy in place in Soviet times, the children were sent away to boarding school to prevent them getting the disease, although they were allowed to visit their parents. Four of the couple's five children went to university, and one now works in television.

"We keep up with what's going on in the world," they told me. "When we hear about the incessant conflicts, we are truly grateful for the peace that we enjoy here."

Another resident I spoke with told me he had qualified as a science teacher before being diagnosed with leprosy in 1961. He has lived in Honaka for 40 years, where he raises poultry and sheep. "I studied very hard when I was a student, and this is the fate that awaited me," he said.

According to Dr. Kosimov, the last person to be treated for leprosy in Tajikistan was diagnosed in 2001 as the result of a survey, although he hesitates to say there have been no cases since. "We really need to carry out another large-scale survey, but financial constraints have prevented us." He is particularly concerned about the mountainous Pamir region, where 80% of the residents of Honaka Leprosarium originated.

On my last day, I visited Dr. Kosimov's center in Dushanbe, where 100 dermatologists and ophthalmologists had gathered for a conference he had organized. I spoke about my work as Goodwill Ambassador and Dr. Drabik gave a lecture on diagnosing leprosy. As the next day was her birthday, she was treated to a rousing chorus of "Happy Birthday."

Regarding Afghanistan, I heard later that a German NGO reported 38 new cases of leprosy in five districts there in December 2012 alone. If that is the situation, then this suggests there must be more undiagnosed cases. Whatever the reason, it is a tragedy when people who require treatment are unable to receive it. I hope peace will return to that country soon.

TURKEY (JULY 11)

On my way back to Japan, I had a morning in Istanbul and took the opportunity to revisit what had previously been Turkey's only leprosy hospital. In 2007, I had met Professor Turkan Saylan, her country's leading leprologist and the director of the hospital until 2002. Following her death in 2009, the health ministry had moved to shut the hospital down.

But supporters took the ministry to court to have it reopened — in part because they felt this specialist facility is needed, but also to preserve the memory of Professor Saylan. The legal action eventually succeeded and the hospital reopened — but as a leprosy, dermatology and venereal diseases hospital.

Dr. Ummuhan Kaya, a dermatologist and protégé of Dr. Saylan, told me that Turkey has recently been seeing some new cases of the disease — 13 in the last two years. "Doctors in Turkey don't know too much about leprosy. There is often misdiagnosis. Even my friends who are doctors ask me if leprosy still exists. I feel we are facing a leprosy problem again and we need to look into this more deeply." ■

Summer Fun at Tama Zenshoen

Japanese sanatorium welcomes local community to annual summer festival.

National Sanatorium Tama Zenshoen in the suburbs of Tokyo held its summer festival on August 8. Residents were joined by over a thousand people from the surrounding community, including many children, for an evening of dancing, fireworks, food and fun.

Up until 20 years ago, the sanatorium was largely cut off from the outside world, with only those living and working there taking part in the festivities. Now, jokes Michihiro Ko, head of the national association of sanatoria residents, it's hard to spot anyone from Tama Zenshoen among the crowds.

The fireworks are paid for by the Tama Zenshoen residents' association as part of its community outreach activities. Some of the money has been left for this purpose by residents in their wills or else donated by their relatives. Come 8 p.m., the skies light up above Tama Zenshoen, delighting onlookers and celebrating the memory of those who once lived there. ■

FROM THE EDITORS

A DECLARATION'S 'SHELF LIFE'

Leprosy is a disease that has fascinated many people and seen them devote decades of their lives to tackling it. One of the veterans of the fight for a leprosy-free world is Dr. S.K. Noordeen, the former director of the WHO's action program to eliminate leprosy and now chairman of the Leprosy Elimination Alliance. Speaking on the sidelines of the recent International Leprosy Summit in Thailand, he underlined the significance of the Bangkok Declaration that was endorsed by health ministers and their representatives.

"It is important to make a noise," he said. "People are paying attention. Program managers, NGOs and others can use the declaration. It's a political commitment. They can say to ministers, 'You agreed to it.'"

But he also sounded a note of caution: "Political commitment has a shelf life. It only lasts a few years." Making the most of the opportunity is therefore crucial.

The challenge, he said, is to persuade health ministers to devote limited resources to a relatively small problem. "You want them to focus on high-endemic areas, but as politicians they may want to spread the resources equally, or where they can find political support." Countries must also have the infrastructure in place if things are to happen, he said. "Without the right infrastructure, resources won't reach where they need to go."

Dr. Noordeen has a fund of tales about calling on ministers to ask them to place a higher priority on leprosy. The health minister of one African country told him, "You are the third person I have seen this morning: first malaria, then TB, now leprosy. What am I supposed to do?" When Dr. Noordeen mentioned that a neighboring country had already eliminated leprosy as a public health problem, the minister was suddenly interested.

Then there is the story about the shock experienced by Indira Gandhi, India's late prime minister, when a visiting Middle Eastern diplomat asked her how she could talk about India's development when the streets of Delhi were full of people suffering from leprosy. From her official vehicle, the prime minister never saw these sights. The next day she called the health minister to ask, 'What are you doing about leprosy?' The situation changed overnight. "Sometimes politicians have to be embarrassed into action," Dr. Noordeen said.

On this occasion, we believe, ministers have endorsed the Bangkok Declaration, not out of embarrassment, but because they know it is the right thing to do. The last mile is in sight, and there is a job to finish.

FOR THE ELIMINATION OF LEPROSY
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