# Elimination of Leprosy

April 2017 • Number 85

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



Residents of Rama Krishna Pally leprosy colony in Bhubaneswar, Odisha state, India, visited by the Goodwill Ambassador in March 2017.

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# **Neglected Tropical Diseases**

On April 19, a Global Partners Meeting on Neglected Tropical Diseases was held in Geneva, presided over by WHO Director-General Dr. Margaret Chan.

Some 1 billion people are affected by NTDs, especially those living in poverty. From the perspective of people living with these diseases day and night, the label "neglected" must sound disheartening. But progress is being made.

Based on the slogan "Leave no one behind" underpinning the 2030 Sustainable Development Goals, the Bill & Melinda Gates Foundation, the U.K. and Belgian governments, pharmaceutical companies and others pledged large sums and drugs to fight NTDs. An excellent framework of support has been created. The question is: how to make it work?

At the conference I had the chance to share some of my four decades of experience in working against leprosy. As with actions against leprosy in particular, actions against NTDs in general require both medical interventions against disease and social interventions against stigma and discrimination. The three things I consider essential are: 1) securing the political commitment

of leaders; 2) enlisting the cooperation of media to disseminate information about disease and encourage people to seek treatment; and 3) forming sustainable initiatives bringing together all stakeholders, including pharmaceutical companies and people affected.

To this I would add the necessity to expand the role of people affected as the main actors in awareness-raising, case-finding and rehabilitation initiatives. They are the people who know best about their diseases. In that sense, it was a shame there were not more people affected by NTDs at the NTD summit of which this meeting was a part.

I would like the leprosy community to share with other NTDs all the experiences it has gained through its activities against the disease. Finally, we must not forget what was said at the summit, namely, "We care for people" and "See the faces behind the numbers." Addressing not just NTDs but engaging with the people who suffer from them is very important.

— Yohei Sasakawa, WHO Goodwill Ambassador

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REPORT FTEL Apr 17 ● No. 85

# **Moving Forward**

NTD Summit highlights progress made—and the challenges that remain.



(L to R) Former UN Secretary General Kofi Annan, Dr. Margaret Chan and Bill Gates attend the Global Partners Meeting in Geneva on April 19.

The World Health Organization, Uniting to Combat NTDs and the Neglected Tropical Disease (NTD) community hosted an NTD Summit in Geneva, Switzerland from April 19 to 22.

NTDs affect 1 billion people, many of them living in the poorest parts of the world. They are a cause of constant suffering and perpetuate a cycle of poverty and inequity.

The summit marked 10 years of multistakeholder collaboration, the fifth anniversary of the WHO's roadmap on NTDs, which outlined targets for the control, elimination or eradication of 17 NTDs by 2020\*, and the fifth anniversary of the London Declaration issued by partners in the fight to treat and prevent these diseases.

A WHO report released on the first day of the summit, *Integrating Neglected Tropical Diseases in Global Health and Development*, noted the impressive achievements made against NTDs including lymphatic filariasis and trachoma since 2007, thanks to political support, generous drug donations and improvements in living conditions.

But it also highlighted the need for further action, saying, "NTD programs continue to struggle with limited financial resources, inadequate capacity including capacity to implement effective surveillance, disruptive conflicts and important barriers to accessing needed health services that range from poverty to stigmatization."

Renewed commitments were made to accelerate progress at a Global Partners Meeting on April 19, attended by some 400 people including health ministers, pharmaceutical industry executives, philanthropists and NGO heads. Among those attending was Bill Gates, co-chair of the Bill & Melinda Gates Foundation, which has pledged US\$335 million in grants over the next four years.

"Thanks to this partnership, these neglected diseases are now getting the attention they deserve so fewer people have to suffer from these treatable conditions," Gates said. "There have been many successes in the past five years, but the job is not done yet."

#### PROXY FOR POVERTY

With advances against NTDs tied to progress toward achieving the 2030 Sustainable Development Goals—which include "no poverty," "zero hunger" and "clean water and sanitation"—Dr. Anarfi Asamoa-Baah, the deputy director-general of the WHO, noted that NTDs were symptoms of a bigger problem that needed to be addressed. Speaking of the one in six people who live with one or more NTD, he said, "In many cases, they are neglected by their own governments. They have no roads, no water, and no electricity. If all we do is take care of the symptoms—the diseases—and we do not advocate for good water, for good housing, good roads, then really we will not be helping them in the way we need to help them."

There were two workshops on leprosy during the conference. "Leprosy: Putting the Person at the Center of Disease Control: Lessons for and from Leprosy" and "Leprosy, NTDs and Mental Health."

Among the speakers, David Addiss of the Task Force for Global Health suggested that one of the successes of the leprosy community has been to see beyond the statistics to the individuals affected.

It is important to recognize there are consequences that go beyond the disease period.

"In global health work, we necessarily focus on numbers, on macro interventions that have impact at population level, so we focus on numbers and less on faces. We focus on justice, but we don't talk as much about compassion. We deal with human rights, less with relationships. We talk about policy rather than engaging in dialogue; ethical principles rather than the ethics of care. One of the things that the leprosy community brings to the NTD community is a fairer balance between the relational on the one side and the population on the other."

Dr. Wim van Brakel of Netherlands Leprosy Relief said it was necessary to ensure that people didn't disappear from view again once they were released from treatment. "It is important to recognize there are consequences that go beyond the disease period, and we have been struggling with that in leprosy."

"People are deducted from the statistics as soon as they complete their treatment and then they become invisible. We need to find a way—and that could be done across NTDs—to make the case for visualizing all these people," he said. "They all have faces, and there are a lot of them. They have mental health needs and other needs. If we could make them part of an official group that needs attention, that would be great."

#### QUOTE

"In April 2017, partners from all over the world...came together in an unprecedented gathering to unite around the common goal of ending the suffering caused by NTDs. This effort is an essential stepping stone in the global movement towards an economically, socially and environmentally sustainable future for the planet and for present and future generations." (From The Geneva Commitment)

#### **FOOTNOTE**

\* The WHO recognized an 18th NTD, mycetoma, in 2016. FTEL Apr 17 • No. 85

# Where Do We Go From Here?

The conversation continues on the merits of preserving leprosy heritage.



Looking to the future: participants at the 5<sup>th</sup> international symposium

The 5th International Symposium on Leprosy as Heritage of Humanity was held in the Japanese city of Setouchi, Okayama Prefecture from April 22 to 24.

Organized by Sasakawa Memorial Health Foundation and co-hosted by the western Japan municipality, it drew participants from 16 countries to discuss the progress of efforts to preserve leprosy history in different parts of the world and to explore ways of securing this legacy for future generations, including possible World Heritage listing.

Shinji Nakao, who is head of the residents' association of National Sanatorium Nagashima Aiseien, one of three Japanese sanatoria working on a joint bid for World Heritage registration, spoke for those at the heart of this history when he said: "The significance (of this history) lies in the fact that people were not treated as human beings. We want to ensure that this does not happen to others." Now in his eighties, Nakao has spent 69 years in the sanatorium, where he was sent under Japan's Leprosy Prevention Law at the age of 13.

Like Nakao, Chor Seng Lee is another who saw his freedoms curtailed by government policy against the disease. He is the vice president of Sungai Buloh Settlement Council, an association of residents of the former Sungai Buloh leprosarium in Malaysia, where persons diagnosed with leprosy were sent to prevent the disease from spreading. "We suffered a lot in the past.... I hope people will remember our contribution to the country," he said.

Heritage expert Deirdre Prins-Solani of South Africa provided a further reason for preserving this painful heritage. "Those of us who are complicit have been



Chor Seng Lee (right) and Eannee Tan speak about Sungai Buloh. harmed, too. Cultural heritage can be a catalyst for healing and teach us how to be more humane," she said.

#### NO TIME TO WASTE

The words of Nakao and Lee, elderly gentlemen linked by a shared history of isolation and exclusion, underscored why a sense of urgency is required. The generation that can talk about these experiences is dying off. Getting down all the facets of their stories before it is too late is essential. "We need to do this while people are still here," said Anwei Law, international coordinator of IDEA. "We need to make their history part of the permanent history of the world."

The sense of urgency extends also to physical locations and how they are preserved, with criteria such as authenticity and integrity essential to a successful World Heritage application. The Sungai Buloh settlement lost 25% of its area in 2007 to redevelopment, and pressures to repurpose and redevelop locations associated with leprosy as resident populations decline are widespread.

From Brazil, Artur Custodio of MORHAN underlined the important role that civil society has to play in preserving leprosy history. Speaking of the fate of Brazil's 28 remaining hospital colonies from a heritage standpoint, he said, "The government takes the decisions, so civil society must shape those decisions through action."

The stance of the government is important, too, for possible World Heritage or Memory of the World listing, as it is the government that submits the application to UNESCO.

With the application process both lengthy and complex, participants debated whether hopes of getting registered are realistic for some leprosyrelated sites, and whether a transnational approach should be adopted.

At the same time, many could see how preparing the groundwork had merit in its own right as a tool of heritage preservation, whether or not an application was accepted or even submitted.

"It helps sites develop plans and push for legislative change to protect them," Prins-Solani said. "It's a useful process."

# 'Their Names Will Be Their Voices'

Non-profit works to ensure that residents of Kalaupapa will never be forgotten.

More than 20 years ago, Kalaupapa leader Bernard K. Punikai`a was worried about the future of the place he called home in Hawaii. Who will carry on the wishes of the people of Kalaupapa when they are no longer there?

Bernard was well aware that he and his neighbors were getting older and their numbers smaller. He wondered how their voices would continue to be heard so that the future of Kalaupapa would be guided as they imagined.

The result: Ka 'Ohana O Kalaupapa ("The Family of Kalaupapa"), a nonprofit organization of Kalaupapa residents, family members/descendants, friends, clergy, students and anyone interested in preserving this important history. The 'Ohana is committed to remembering the estimated 8,000 people sent to Kalaupapa by their names and as individuals who were accomplished, loving and strong.

"You have to hear the voices to feel the people. You have to know their names," said Punikai`a in an interview in 2007. "If you don't say the names, it's like something has been lost. We have to echo what was said. I feel lucky that my voice was part of it."

#### **LEFT OUT OF THEIR OWN HISTORY**

For much of the 150 years since Kalaupapa was selected as a place to isolate people thought to have had leprosy in Hawaii, the names of most of those taken from their families and sent there have been missing. The people of Kalaupapa had been mostly left out of their own history and their legacies were in danger of being forever lost.

With the vision of Punikai`a, Ka 'Ohana O Kalaupapa has made it a priority to remember the people of Kalaupapa by their names, to present the history of Kalaupapa in their own words and to recognize the importance of the families they were separated from because of government policies.

Until recently, the history of Kalaupapa had been written almost exclusively from English sources, ignoring all that had been written in Hawaiian by the people of Kalaupapa and others in Hawaii concerned about their plight.

To tell the early history of Kalaupapa from the perspective of the people—90 percent of them Native Hawaiian—historian Anwei Law has had hundreds of early letters and other documents translated from their native language, enabling us to see this history in a much more inclusive and accurate way. Interviews with more recent residents ensure that they will tell their own history into perpetuity.

#### **HELPING FAMILIES RECONNECT**

To keep the legacies of the people of Kalaupapa alive, the 'Ohana has been helping descendants learn about the lives of their ancestors who were sent there through our "Restoration of Family Ties" program.



Forming a "Circle of Remembrance" on Kalaupapa (All photos by Valerie Monson)

The 'Ohana has developed a digital library that contains information on more than 7,000 of those who were taken from their families and relocated there. The library includes data from admissions registers, marriage records, birth records, death records, Census records, petitions and letters, church minutes and nearly 1,000 photographs.

# These are almost always life-changing events for the family members.

Traveling exhibits and schools outreach across Hawaii help the 'Ohana connect to more family members while educating teachers, students and the public about a more accurate history of Kalaupapa.

The 'Ohana also arranges overnight visits for descendants so they can walk in the footsteps of their ancestors, learning what life might have been like for them, visiting their graves and learning the history of Kalaupapa from a knowledgeable 'Ohana leader. These are almost always life-changing events for the family members as they feel the spirits of their ancestors.\*

#### A LASTING MEMORIAL

All of these programs are leading up to The Kalaupapa Memorial, which will list the names of those sent to Kalaupapa. Because fewer than 1,000 people have identifiable gravestones, the memorial will bring the names back to the landscape of the history they helped to create.

The 'Ohana needed the approval of the United States Congress to establish the memorial. Congress gave the memorial its full support. The legislation was signed by former President Barack Obama.

The memorial design incorporates two interlocking circles. The larger, upper circle represents

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#### **FOOTNOTES**

- \* In the past seven years, the 'Ohana has helped nearly 700 families reconnect to their ancestors or loved ones at Kalaupapa.
- \*\* The memorial is now in Phase II of the design phase



A man contemplates the grave of an ancestor he did not know about.

the people who were sent to Kalaupapa and will feature a curved wall engraved with their names. The lower circle represents the families who were left behind and their descendants. The place where the circles overlap is what Ka 'Ohana O Kalaupapa has always envisioned: reuniting the people of Kalaupapa with their families and descendants.\*\*

Bernard Punikai`a died in 2009. Before that, he made the first donation to The Kalaupapa Memorial. Last year, Mr. and Mrs. Miyoji Moriomoto made the first donation from Japan.

"I hope the names live on," said Bernard when talking about The Kalaupapa Memorial. "The names will be their voices. I want to hear their voices. The voices are so beautiful, so sweet. The voices say 'This is our song to you.' The monument of our voices is so beautiful."

The Kalaupapa Memorial will be a living memorial. Future generations will visit the memorial, find the name of their ancestors and become part of this important history. The descendants will make certain that Kalaupapa will have a living history where their ancestors will always be remembered and the history will be told in the words of the people for generations to come.

Just as Bernard envisioned.

#### 'I FINALLY FOUND MY MOM'



Ed holds the photo of his mother on the day he received it.

"Before I leave this Earth, I want to see a picture of my mother."

That was the emotional wish Edward Weight expressed to his wife, Naomi, many times over. Ed was born in Kalaupapa in 1930.

Because of government policies he was immediately taken from his parents and placed in a nursery at Kalaupapa, then later sent to an orphanage on Oahu. From there, he lived in a series of foster homes.

Ed never knew his parents, Harold Weight and Marcia Ka-ne, who were both sent to Kalaupapa because they were diagnosed with leprosy. He eventually found a photograph of his father, but could not find one of his mother despite years of searching.

In the summer of 2011, Naomi Weight saw a notice about the work of Ka 'Ohana O Kalaupapa in helping families find their ancestors at Kalaupapa. She called the phone number listed and, within days,

the 'Ohana had located a photograph of Ed's mother. The 'Ohana also located another photo of his father and of his grandmother, Stella Waiamau, who he never knew was at Kalaupapa.

When Ed held the picture of his mother in his hands for the first time, he felt a piece of him missing for so long had been restored.

"She was a dream," he said during an interview with this writer a few months later. "I stared at her photo for the longest time. I talked to her for a while. I couldn't believe it, that I finally found my Mom."

Ed said he talked to his mother "about everything and anything. To say something to my Mom that I never did. I love her, love her."

A month later, Ka 'Ohana O Kalaupapa invited Ed to join them for their annual gathering at Kalaupapa where he met other descendants who told their stories of reconnecting to their Kalaupapa ancestors.

"It was like having a big family gathering together, sharing each other's stories and sorrows," he remembered. "I hope (the 'Ohana) continues. I think it's great for all of us to get together like we did, that was the greatest."

Ed and Naomi named their eldest daughter for Ed's mother and called her Marci for short. Marci Weight Lyons has now become a leader of Ka 'Ohana O Kalaupapa.



The family of Ed Weight gathers on the porch of the Kalaupapa home where his parents lived.

"Even when I had not seen a picture of my grandmother, I was honored to have her name because we knew so little of my father's history," said Marci. "Now that I see her, I am still getting used to having a face for her. I'm glad my Dad has her for his identity. I'm glad I have her name. I connect with her eyes, I wish I knew her. I'd like to think we're kind of alike.

Ed died December 7, 2014, barely three years after he had seen a photo of his mother for the first time. His family received permission to have his ashes buried at the graves of the parents he never knew at Kalaupapa. It was another of Ed's last wishes.

"He was separated from his parents in life so he wanted to be with them for eternity," said Naomi Weight.

## Visits to India and Switzerland

The Goodwill Ambassador travels to the state of Odisha for meetings with top officials, and to Geneva for a summit on Neglected Tropical Diseases.

#### INDIA (March 17-22)

At the request of India's Association of People Affected by Leprosy (APAL), I visited the state of Odisha in March. During my stay I met with the governor, chief minister, health minister and other senior officials to discuss the situation of people affected by leprosy in the state.

Over 10,000 new cases of leprosy were discovered in Odisha last year, or some 8% of the national total. The prevalence rate of the disease was 1.35 cases per 10,000 population, well above the national rate of 0.65. Like its neighbor Chhattisgarh, which I visited the previous month, Odisha one of the few states in India yet to reach the elimination milestone of less than 1 case per 10,000 people.\*



Chief Minister Naveen Patnaik Commission for a

On arrival in the state capital Bhubaneswar, I was met by APAL state leader for Odisha Umesh Nayak and his colleagues. From the airport we headed directly to the office of the Human Rights Commission for a meeting with the acting

chairperson Justice B.K. Misra. APAL presented him with a list of 23 cases where improvements in living conditions are needed. It was clear that the Justice Misra took a real interest in the subject: he had even invited 15 students from the National Law University Odisha to sit in on our meeting and learn about the problems people affected by leprosy face.

At Odisha's Department of Health & Family Welfare, I was told that a leprosy case detection

campaign (LCDC) carried out in the state between September and October last year uncovered 4,498 new cases. Accredited Social Health Activists (ASHA) and other volunteers went from house to house looking for persons with symptoms of leprosy, and clearly they had some success. Health Secretary Dr. Pramod Kumar Meherda told me that Odisha is not only looking for new cases but also putting efforts into reconstructive surgery and rehabilitation in order to promote social reintegration.

Dhenkanal district is a three-hour journey by car from the state capital. At



APAL's Umesh Nayak presents Health Minister Dr. Pradip Kumar Amat with a petition.

Beltikiri community health center, I met with some of the state's ASHA health volunteers who do such important work. I also met a number of patients who had been diagnosed with leprosy thanks to their efforts. Among them was an 11-year-old boy who will not develop disability because of his early diagnosis and timely treatment.

On the outskirts of the state capital is Rama Krishna Pally leprosy colony. Of the 300 or so residents, 90 carry disability cards. The occupation of most of the card holders was listed as "beggar." The residents of the colony have no land rights and expect to be forced out at any time. Furthermore, what assistance they receive from the government is currently not enough to support a family's basic needs.

In my meetings with Governor Dr. S. C. Jamir, Chief Minister Naveen Patnaik and other top officials I said that people in the colonies were making efforts to stand up for themselves, but that severely disabled and elderly residents who had no way to make a living other than by begging required more assistance.

APAL's leaders presented their requests in detail. These covered areas such as enhancement of maintenance allowance, land allocation rights, provision of medical services, and welfare and



Addressing residents of Rama Krishna Pally leprosy colony

Kofi Nyarko thanks Dr. Chan (right); the Goodwill Ambassador with Dr. Chan upon receiving the "Health for All" Gold Medal (far right)



rehabilitation schemes. Umesh Nayak, who said he had been up all night preparing the materials, breathed a sigh of relief when the meetings were over. "I feel like I have just finished an exam," he told me.

I returned to Japan via New Delhi, where I had meetings at the WHO country office and with senior health ministry officials. The central government has increased the budget for leprosy eradication, which will enable more LCDCs to take place over the next three years. It is a clear sign of India's determination to reach as many new cases as possible. I applaud its efforts and will continue to offer my support in whatever ways I can.

#### SWITZERLAND (April 18-22)

At the Global Partners Meeting on NTDs on April 19, I was honored to receive the WHO's "Health for All" Gold Medal from outgoing WHO Director-General Dr. Margaret Chan for my services to leprosy elimination activities as Goodwill Ambassador. Needless to say, a great many people and organizations are involved in this work, and I accepted the award on behalf of them all.

What gave me greater pleasure still was the warm gesture of appreciation offered to Dr. Chan by one of the conference organizers, Uniting to

Combat NTDs, who had asked Kofi Nyarko of Ghana to convey the thanks of all those affected by NTDs to the director-general.

Kofi, who is the president of IDEA Ghana, is a person affected by leprosy whom I have known for many years. He told the summit how he had been diagnosed with leprosy at the age of 7 but had gone on to become a school teacher, start a family and is now helping people affected by the disease to return to their homes and families.

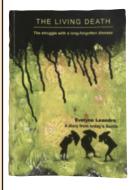
He thanked Dr. Chan for advancing the fight against NTDs and for shining a light on the people they affect. He then presented her with a beautiful silk scarf patterned on all the vectors and pathogens responsible for causing these diseases.

It is very important for us to look beyond the disease to see the person; that day, Kofi stood for every person affected by NTDs.

As I have said to people affected by leprosy over the years, "You are the experts," "You are the main actors." Therefore, together with people affected by leprosy, I intend to keep playing my own supporting role in working for a world without leprosy and its associated stigma and discrimination. It is the very least I can do, in consideration of the honor bestowed upon me.

#### **BOOK REVIEW**

#### THE LIVING DEATH



Evelyne Leandro, a Brazilian woman living in Germany, had the urge to write a book. After seeing a nicelooking diary in stationery shop window in Berlin, she hit upon the

form it would take: the diary of woman who has to spend a few days in hospital, told from the perspective of the patient. Little did she realize that she would soon be writing about herself.

The Living Death: The struggle with a longforgotten disease is an intensely personal account of the physical, mental and emotional challenges of being diagnosed and treated for leprosy. Adding a layer of complexity to Leandro's story is the fact she is in a foreign country, where leprosy is rare, and has to deal with medical staff in a foreign language. "I had to eliminate the prejudice that a foreign woman without perfect German could not be intelligent," she writes.

The author is a go-getter, so to have her life and job disrupted by her disease hits her hard. The frustration and despair she conveys at not being able to live on her own terms is a gauge of how much she wants to achieve in life. Yet over the trials and tribulations that the diary format captures so unflinchingly, she copes with the pain and setbacks that accompany her treatment and seeks to find meaning in her illness.

In this, the author has the support of

her German husband and step children, and wonderful friends and family who offer love and advice in emails she includes in this account. "It's a small disease for a great woman!!" one writes.

Articulate, analytical and passionate, Leandro is particularly insightful about the toll that the disease and the different medications take on her. "The thalidomide deadens me and the other drugs corrode my stomach and gullet. My body hurts from straining. My knee and the inflamed nerves are swollen though the cortisone. I am ill either through leprosy or the drugs against it."

It is a grueling journey, but after 495 days she is able to write: "The disease is no longer the center of my life. I've taken up command again. I'm back in my life."

# **A Fuller Picture**

Artworks and film add a new dimension to the ILA—History of Leprosy website.

Art and Documentary categories have been added to the *International Leprosy Association – History of Leprosy* website. The new categories depicting works by people affected by leprosy and those close to them were unveiled at a symposium on leprosy heritage in April.

Paintings and photographs comprise the bulk of the over 300 items in the Art database, which also includes entries for ceramics, calligraphy and music among a total of 11 sub-categories. Most of the items are from Japan, with the remainder from China, Korea, Colombia and Russia.

They offer a window on the spirit of creativity that existed behind sanatorium walls, capture scenes from daily life as well as some of the brutal realities.

Among the photographs are those taken by Kunje Cho, whose images of Japanese sanatoria in the 1960s include a wife carefully pouring tea into her bedridden husband's mouth, and a young woman having her hair done at a beauty parlor. Paintings by Chang-won Cho show a burial ceremony for an infected toe at Sorokdo Hospital in Korea and the burning alive of the head of the hospital's patients' committee following an uprising there.

The Documentary section consists of six films – four shorts from China and two longer features from Malaysia. Among the former are the story of Ms. Jiao, who has lived on a boat for the past four decades looking after a man who like her is affected by leprosy, and of Mr. He, a blind basket maker who lost his sight to the disease. The Malaysian films



Painting, ceramics and more: new online offerings help to give the perspective of people affected by leprosy.

leprosyhistory.org

look at what happened to families broken up by leprosy and the fate of children born in the Sungai Buloh leprosy settlement, including two who go in search of their roots.

The *History of Leprosy* website has its roots in the ILA's Global Project on the History of Leprosy, which set out to create a database of leprosy archives to encourage further research into the disease. It was relaunched in a more user-friendly format in 2016.

For further information, and to offer artifacts for inclusion on the site, contact smhf@tnfb.jp

# FOR THE ELIMINATION OF LEPROSY

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#### FROM THE EDITORS

#### HAND IN HAND

As a conference in Geneva on eliminating, controlling and eradicating neglected tropical diseases (NTDs) was coming to an end, a symposium in the Japanese city of Setouchi on preserving the history of leprosy was beginning. While the impetus to eliminate and the impetus to preserve seem diametrically opposed, there is common ground.

NTDs are called that for a reason. They have been overlooked on the health agenda because they affected the world's poorest populations. Now these diseases are being addressed, the poor and marginalized are being acknowledged, along with their right to health and an improved standard of living.

The impetus behind preserving the history of leprosy is to ensure that those who were isolated and excluded by past policies and social prejudice are similarly acknowledged, and given a place in the collective memory.

In taking aim at NTDs, we should not forget who neglected them and why, and who suffered as a result, so that this may serve as a future reference. This is also what propels the current movement to preserve the history of leprosy—to make society aware of past injustices, and learn from them so that this history is not repeated. Instead of pulling in opposite directions, the instinct to eliminate and to preserve go hand in hand in this instance.

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