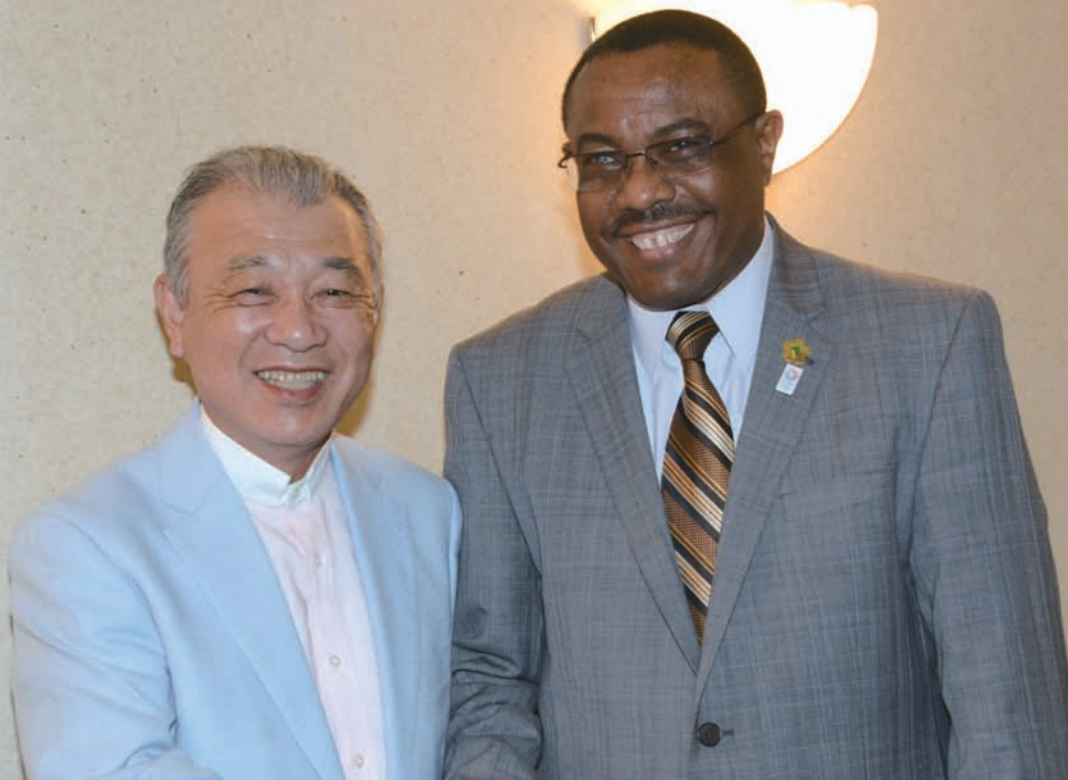


FOR THE Elimination OF Leprosy

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



The Goodwill Ambassador with Ethiopian Prime Minister Hailemariam Desalegn during the latter's visit to Japan in June.

MESSAGE

Leprosy Summit

In 1991, the World Health Assembly resolved to reduce the prevalence of leprosy below 1 case per 10,000 people, a decision that generated momentum and secured political commitment for eliminating leprosy as a public health problem. At the time, 88 countries had yet to pass that milestone; today only one country has still to do so.

But the current situation does not fill me with optimism. On the contrary, I feel a sense of alarm. As I travel the world, I get the clear impression that health ministries are losing interest in leprosy. Actually, you can see this in the figures. In recent years, annual new case numbers have stopped declining. In some countries, the numbers are even going up; many report pockets of high endemicity.

While the burden of leprosy in the world is much less than in the past, we must not grow complacent and allow our hard work to be undone. We need to generate fresh momentum and secure renewed political commitment. Health ministries face many pressing issues, but leprosy has caused untold damage to human beings and we are at a

critical juncture in our fight. With a shared sense of crisis we need to review our course of action. This is why I am organizing a Leprosy Summit in July in Bangkok, in conjunction with the WHO Southeast Asia Regional Office.

Last month, I met with health ministers and officials from some dozen countries at the World Health Assembly in Geneva, urging them to attend the summit. At the beginning of June, I spoke with six African leaders at a major international conference in Japan, where I asked them to redouble their efforts against leprosy and send representatives to Bangkok. They responded positively.

At this summit, I want political leaders who understand the critical situation in their countries to renew their commitment to leprosy control. I believe this will inject new life into our fight. We still have a long way to go. Every person suffering from leprosy and its consequences deserves our utmost efforts.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Meetings with Ministers

Health ministers and their representatives pledge ongoing commitment.

The Goodwill Ambassador met with health ministers and their representatives at the recent World Health Assembly in Geneva for an update on leprosy and leprosy control activities in their countries.

INDIA

Keshav Desiraju, Secretary, Ministry of Health and Family Welfare

While many states have shown good progress, we still have something like 125,000 new cases each year. In statistical terms, it is a small number, but in actual numbers it is very big. We are speaking to state governments about this. One problem is that people don't seem to find leprosy work interesting. In some states the post of leprosy officer is not filled. It may be that somebody who is trained to do that job is being used elsewhere because leprosy is not seen as a priority. We regard leprosy as a very important area of our work. It is a priority for us, even if it is not a priority for state governments.



each state. We want to use the data we gathered to secure a strong commitment from the states and municipalities most affected. This year we undertook a unique initiative, in conjunction with neglected tropical diseases, screening around 16 million children, focusing on the poorest municipalities. We plan to do this every year. We are also addressing the human rights issue. Brazil was one of the first countries to provide compensation for people confined in colonies and we are also looking for children who were separated from their parents.

MOZAMBIQUE

Juvenal Arcanjo Dengo, 1st Secretary, Permanent Mission to Geneva

The leprosy situation is stable but we think we can do more, particularly in the north and center of the country. Leprosy is being featured in schools, where children are being taught how to identify the disease. We believe this will contribute to early diagnosis. One area where we are weak is in social mobilization. We are determined to mobilize more information and to cover more districts and more people. By partnering with NTDs we hope to improve. We are interested in the experiences of other countries in integrating leprosy with NTDs.



INDONESIA

Dr. Nafsiah Mboi, Minister of Health

Although we have eliminated leprosy as a public health problem at the national level, we still have pockets of the disease in 14 out of 34 provinces, such as Aceh and Papua.

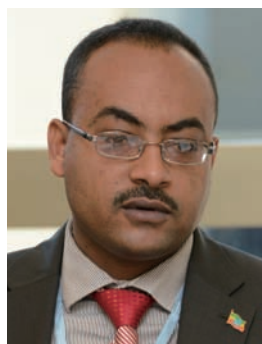
When we visited Papua last December, we found a community of 332 people with 108 cases of leprosy. Areas such as Papua are more challenging because of the geographical situation, but if we can get local leaders involved and secure their commitment, I believe we can do a lot.



ETHIOPIA

Dr. Kesetebirhan Admasu Birhane, Minister of Health

Leprosy has never been out of our top priorities. It is something that we monitor regularly. We have an extensive network of primary care facilities and community extension workers. Eight years ago, we only had 600 primary health centers; today we have 3,000. By the end of this year, this will rise to 3,500. At some of the new health facilities, new health workers do not have the necessarily skills to diagnose leprosy. During their training they are exposed to diseases such as HIV/AIDS, malaria and TB. But leprosy patients are less common and concentrated in a few areas, so the majority of health workers do not see what the early signs of leprosy look like. We need to continue to improve their skills.



BRAZIL

Dr. Jarbas Barbosa, Vice-Minister of Health Surveillance

Many states in Brazil now have a very low prevalence of leprosy, but in some states — the poorest ones — prevalence is still high. We have just completed a leprosy elimination monitoring process for



Poster for campaign to screen children for leprosy and intestinal parasites in Brazil

TANZANIA

Dr. Donan W. Mmbando, Acting Chief Medical Officer, Union Ministry of Health and Social Welfare

We would like to ask you for your continued cooperation because we still have some pockets of leprosy in the country. We are working hard not to be complacent. It is very important to us that we continue to tackle leprosy. We also thank you for your role in realizing the U.N. General Assembly resolution on eliminating discrimination against persons affected by leprosy. This is necessary because of the stigma attached to people with the disease.



BANGLADESH

Prof. A.F. Ruhul Haque, Minister of Health and Family Welfare

Case numbers have come down, but we have pockets. As you well know, the last mile is always the most difficult. I am an orthopedic surgeon and used to see a lot more leprosy cases earlier in my career. Patients would come with foot drop, but such cases are much rarer these days. Our prime minister attaches special importance to addressing the needs of the poor and instructs us to make them a priority through various programs. I am also pleased to report that Bangladesh abolished a discriminatory leprosy act that dated back to the 19th century.



MYANMAR

Dr. Pe Thet Khin, Minister of Health

Since eliminating leprosy as a public health problem, we have become a little complacent. I think we need to apply ourselves harder. Because the number of patients in Myanmar is now quite small, young doctors are not so interested in the disease. I would like to do something to stimulate their interest. For example, one way would be to include leprosy as part of the medical school curriculum.



SRI LANKA

Dr. Maithripala Sirisena, Minister of Health

Sri Lanka had 30 very difficult years due to terrorist activities. Democracy and human rights were violated by terrorist groups. People's lives, the economy and social development were all impacted. Today, following the war, democracy has been established in the country to the fullest extent. A lot of development is taking place in the north and east, especially in the health and education sectors. The government is concerned to see development occur in an equitable manner.



CHINA

Dr. Li Mingzhu, Deputy Director-General, Dept. of International Cooperation, National Health and Family Planning Commission

Since the 1950s, the incidence of leprosy has been coming down very quickly, particularly in the first 40 years. Since the 1990s, numbers have remained flat. Most of the problems we face relate to the difficulty of detection. Perhaps people and organizations have become complacent. The government is training doctors and nurses and making efforts to educate the public about leprosy to reduce stigma, but we still face challenges.



PHILIPPINES

Dr. Enrique T. Ona, Secretary of Health

Although we have eliminated leprosy as a public health problem, there are still a number of pockets in the country where cases are present, but not in the context of the very serious deformities we have seen in the past. I would like to utilize dermatologists to help general practitioners identify early cases of leprosy. I would also like to do something for people still living in leprosaria. We have to be more active in helping them to re-assimilate into the community. As long as people continue to live in leprosaria, the stigma will always be there. ■



Begging for Education

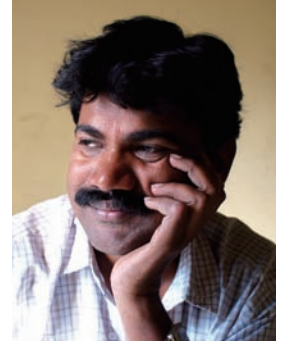
A story of discrimination in India—and the determined efforts to overcome it.



The colony's children with their tutor, Sanju Devi (Photo credit: Ram Barai Sah)

AUTHOR:

Ram Barai Sah



Ram Barai Sah is a trustee of National Forum India. He lives in Little Flower, a colony for people affected by leprosy in Bihar state near the border with Nepal.

Last November, a delegation from National Forum India (NFI), an organization of people affected by leprosy founded in 2006, visited a colony in Areraj, a small town between Patna and Raxaul in Bihar state. The colony's population includes 29 children. When we arrived one morning, we were surprised to find them playing outside.

"Why aren't the children at school?" we asked the colony leader. "None of the schools will accept them," he replied. "I've tried sending them, but the teachers send them back."

I was ashamed that I had not been aware of this problem and decided to take up the children's cause. There are four government-run primary schools in Areraj. I visited all four schools, accompanied by the 29 children. When we met the school principals, each gave the same reply: "Your colony is not in our area. Please go to another school."

"Your colony is not in our area," each of the principals told us. "Please go to another school."

As none of the schools were prepared to take the children, I approached the head of the local panchayat (village council). He accompanied me when I called at the residence of one of the school principals and again requested that she admit the children to her school.

This time she promised she would, but on one condition: the children must bring their own lunch plates with them and keep them separate from those belonging to the other children.

Next day, I took the 29 children to the school. After watching them enter, I went to the market to buy them lunch plates and stationery. I donated Rs. 300 from my own pocket and the panchayat head contributed another Rs. 300. But as I was making my purchases, I saw the children. "Our teacher has sent us home," they told me.

PETITION

Apparently, the principal, who was absent that day, had told her teachers I was from the education department, to convince them to take the children. But when one of the teachers learned from the children that I also came from a leprosy colony, she decided it would be OK to send them away.

The next day, I wrote a petition to the District Educational Officer (DEO), seeking to have the children admitted to school. I also alerted a journalist from the local newspaper. I submitted my petition to the DEO the following day.

In front of me, he picked up the phone and called Areraj's Block Educational Officer (BEO), demanding that he suspend the teacher who had told the children to go home. The DEO told me, "If the BEO does not deal with the situation within three days, come to me again and I will suspend the BEO as well."

The next day, the BEO called me and instructed me to take the children to one of the other schools, which said it would accept them. When we arrived, I asked the pupils there to play with the colony children. "They are just like you," I said. My message to the teachers was: "These children are also your children. You see people coming door-to-door at the market, begging for food. We are not begging for food or money; we are begging for education."

MORE HURDLES

This was not the end of the story. Three days later, I heard that the children had been sent home again. As I was traveling to Chennai for an NFI board meeting, I asked Mr. Kamlesh, NFI's state leader for Bihar, to go to Areraj and follow up.

Within days, the BEO invited all teachers of the block to a meeting. He scolded them for rejecting the colony children. "Look at him," the BEO said, pointing to Kamlesh. "He's working very closely with leprosy-affected people, but he is not infected. Why should you be afraid?" He said this, not knowing that Kamlesh was also a person affected by the disease.

As a result of this meeting, the children were allowed to go back to school. They received stationery and uniforms, thanks to a donation from a German voluntary organization. These were presented to them by the BEO at a function I organized. I also invited members of Sam Uttan, a committee of people affected by leprosy in Bihar, which is affiliated with NFI. In addition, through my son, who is studying in Delhi, I invited the leader of the Bihar Students' Union, who happens to be from Areraj.

"I am also affected by leprosy," I told the gathering. "If this disease is infectious, my son should also be affected by it. But he is not; he is healthy. My son studies at university in Delhi. Why

can't these children study at primary school?"

The head of the panchayat was surprised to learn I was a person affected by leprosy. "But you have taken tea at my house many times," he said. He remains very supportive, but since then he offers me tea in a plastic cup.

SEARCH FOR A TUTOR

With the children's school admission finally settled, I went in search of a tutor to help them with their studies. I visited more than 10 prospects, always to be told, "Rent a room outside the colony and bring the children there. I will not go to the colony."

Once more, I consulted the panchayat head. He introduced me to Ms. Sanju Devi. She was the first and only teacher who agreed to tutor the children where they live. To my surprise, I found out that she is related to the teacher who sent the children home. She comes to the colony six days a week.

The colony's 29 children now attend school regularly. But they are made to sit outside the classroom and must bring their own plates.

When I raised this with the BEO, he told me, "Just as you have fought to have these children admitted to school, the villagers are fighting to have them sent away."

We have achieved much in Areraj, but discrimination continues — and so do our efforts to have the children fully accepted. ■

MUSEUM PIECE

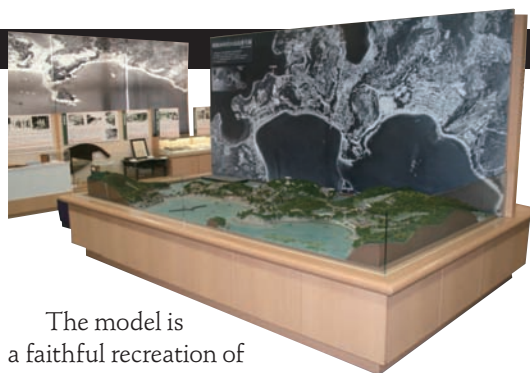
PANORAMIC MODEL

This panoramic model of Nagashima Aiseien, a leprosy sanatorium on an island in Japan's Inland Sea, was built by Heihachiro Takano, a patient, between 1951 and 1955.

Takano entered the sanatorium in 1946 at the age of 26. He began work on the model to commemorate the awarding of the prestigious Order of Culture to Dr. Kensuke Mitsuda, the sanatorium's director, in 1951. Dr. Mitsuda, who was the country's most influential leprologist, served as director between 1931 and 1957.

Everything was made by hand. The hills were fashioned from paper clay made by boiling newspapers and adding starch. The buildings were carved from wood.

Takano had been a sign maker before entering Nagashima Aiseien and later worked as a carpenter. He also became a star of Kabuki plays performed at the sanatorium. He lived there twice: from 1946 to 1962 and again from 1996 until his death in 2001 aged 81.



The model is a faithful recreation of Nagashima Aiseien as it looked in the mid-1950s. Patients and staff lived in separate areas, demarcated by a red line on the model. Other features shown include a punishment cell for those who violated the sanatorium's rules, as stipulated under the Leprosy Prevention Law.

In 2003, with the opening of the sanatorium museum, the panoramic model was repaired by an expert and repainted. Today it forms one of the central exhibits, serving as an important aid for explaining life at Nagashima Aiseien in times gone by and as testament to Takano's skilled craftsmanship.

— Tomohisa Tamura

Science's Helping Hand

DNA testing in Brazil is reuniting people separated by a diagnosis of leprosy.

DNA testing involves analyzing the sequence of a person's genetic material. It can be used to test if people are related because DNA is inherited from one's parents and shared among members of the same family.

During the period of compulsory internment of people diagnosed with leprosy in Brazil, many families were split up. Sometimes parents were interned and their children were given up for informal adoption. In other instances, babies born inside hospital colonies were handed over just after birth to be raised by other family members — or given to complete strangers. As a result, there are many people today who don't know their parents or siblings, or have no formal proof of their relationship.

MORHAN, the Movement for the Reintegration of People Affected by Hansen's Disease, had the idea of searching for people who had been separated from their kin. In Argentina, DNA testing was being used to identify children taken from their mothers during that country's so-called "dirty war." But the idea of doing the same for people affected by leprosy in Brazil was not immediately practicable.

GOVERNMENT GRANT

In 2011, my institute was given a research grant for medical population genetics by the Brazilian National Research Council. We decided to use it to conduct DNA testing of people affected by leprosy as a way to demonstrate genetics to the public. We called the project "Reencontro," which means reunion.

The test subject gives a saliva sample, which is sealed in a container. We are present when the sample is given to verify its authenticity, and return at a later date to give the results in person. In some cases, the people we test don't know who their parents or siblings are; in others, they already know, but they have a false identity because they were registered under a different name to shield them from discrimination.



MORHAN meeting on the separation issue in 2011

The testing is important for two reasons: first, because people have a right to their own identity; and second, because MORHAN is trying to get compensation for these individuals. Since our laboratory is recognized by the Brazilian government, we are able to issue an official document to all those we test.

Each test costs around US\$300. This does not include the salary of those involved, as we are doing this work on a voluntary basis, or the travel costs, which we share with MORHAN. If you went to a private lab for a paternity test in Brazil, it would cost more than US\$1,000.

To date, we have conducted tests in around 12 states and had 200 positive matches. We have funds to test up to 1,000 people. MORHAN estimates that more than 10,000 people were separated from their family members, although it is unclear how many of them would need a DNA test to prove their identity.

Local media have been actively covering the tests, which have been well received. Many people did not know about this issue. Even though I had been aware of compulsory isolation, I had not known about children being taken from their mothers' arms.

"As I was giving the son the results — a positive match — he began to cry."

Being able to give people a document showing they have a parent or a child, or a sibling, has been very rewarding. For me, the most emotional time was when we traveled to Acre state to give the result of tests done on a possible father and son. As I was giving the son the results — a positive match — he began crying. It turned out his father had since died; but he was relieved that he would be able to pay his respects at his father's grave. It was all I could do not to start crying myself.

Lay people tend to have a rather negative view of genetics, based on what they have seen in science-fiction films. But with this project we are able to show that science also does good things, especially when you consider that the people we are testing are those who were separated from their families on the basis of scientific assumptions at the time. We can't repair all the damage that was done, but at least we are giving something back — and as a scientist that gives me real satisfaction. ■

AUTHOR:

Lavinia Schuler-Faccini



Dr. Lavinia Schuler-Faccini is a geneticist with Brazil's National Institute of Population Medical Genetics (INAGEMP) and president of the Brazilian Medical Genetics Society.

Geneva at the Double

The Goodwill Ambassador visits Geneva twice in May, laying the groundwork for Global Appeal 2014 and attending the 66th World Health Assembly.

SWITZERLAND (MAY 5-7, 21-23)



Addressing ICC delegates in Geneva on May 7

For the next Global Appeal to Eliminate Stigma and Discrimination against Persons Affected by Leprosy, to be launched in January 2014, I am seeking the endorsement of national human rights bodies. The 26th annual meeting of the International Coordinating Committee (ICC) for National Human Rights Institutions, held from May 6 to 8 at the Palais des Nations, Geneva, was the perfect opportunity to make my case.

On May 7, the ICC and The Nippon Foundation organized a lunchtime event to introduce the Global Appeal concept to delegates and to highlight leprosy-related discrimination. The session was chaired by Dr. Mousa Burayzat, the outgoing ICC chairperson. Representing people affected by leprosy were Jose Ramirez, Jr., managing editor of *The Star* newspaper in the United States, and Vagavathali Narsappa and Guntreddy Venugopal, chairman and vice chairman, respectively, of National Forum India.

In my remarks, I said: "If all of you who represent the various national human rights institutions around the globe could declare that you stand by the people affected by leprosy in your region, it would not only be of great encouragement to them but also be a tremendous step toward safeguarding their human rights and helping them to regain their dignity."

Two attendees — Ms. Bernadetha Gambishi from Tanzania and Ms. Ann Munyiva Kyalo Ngugi from Kenya — tabled an emergency motion that allowed me to address the main ICC session for five minutes later in the afternoon. I appreciated the opportunity and the warm reception given to my Global Appeal proposal.

A fortnight later I was back in Geneva for the 66th World Health Assembly. Each year I speak at the award ceremony for the Sasakawa Health Prize, but I also take the chance to talk with

visiting health ministers about leprosy issues.

This year I had a full schedule of meetings with delegations from a dozen countries: India, Brazil, the Philippines, Sri Lanka, Indonesia, Myanmar, Mozambique, Madagascar, Ethiopia, Bangladesh, China, and Tanzania. These are some of the 18 countries that have been invited to Bangkok in July to attend a Leprosy Summit that I am organizing with the WHO's Southeast Asia Regional Office. With leprosy seemingly slipping down the list of health priorities in some countries, there is a need to refocus our efforts for leprosy control and so I urged them to participate.

During my stay, I also called on U.N. High Commissioner for Human Rights Navanethem Pillay. Her office helped to lay the groundwork for the Human Rights Council resolution on elimination of discrimination against people affected by leprosy, later adopted by the U.N. General Assembly. Referring to the Principles and Guidelines approved by the resolution, she said, "You have a document that member states have adopted. You have achieved what many people on the outside, knocking on doors, are still trying to do. Now you have to ensure it is implemented."



With UNHCHR Dr. Navanethem Pillay

JAPAN (JUNE 1-2)

At the start of June I gave a speech at the Tokyo International Conference on African Development (TICAD). On the sidelines, I arranged meetings with the presidents of Benin, Ghana, Mozambique and Uganda; the vice president of Nigeria; and the prime minister of Ethiopia.

Since Ethiopia is the venue of the next regional symposium on leprosy and human rights I am organizing, I was encouraged to hear Prime Minister Hailemariam Desalegn say he would be attending, and that he would be sending his health minister to Bangkok. "We are strongly committed to leprosy control," he told me. "People affected by leprosy need public attention." ■

VOICE

"There are many differences in language, culture, geography, politics and religious belief throughout the world. However, one common thread to all who are labeled by the "L" word is the injustice and discrimination that accompanies this tiny bacillus." — Jose Ramirez, Jr.

Kalaupapa — A Collective Memory

Extensively researched story of Kalaupapa wins Hawaii Book of the Year Award.

On January 6, 1866, the first 12 people were sent to the remote Kalaupapa peninsula on the island of Molokai in Hawaii because they were thought to have leprosy. By 1949, nearly 8,000 people had been isolated there, over 90 percent of them native Hawaiians.

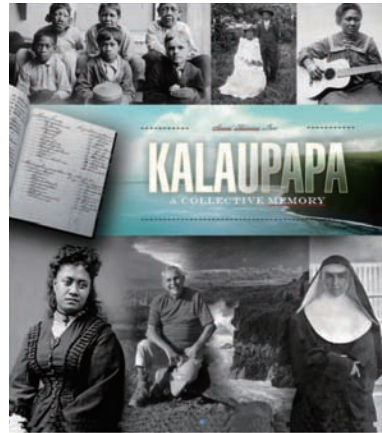
Kalaupapa — A Collective Memory tells the story of these people in their own words. For its “very important contribution to Hawaiian history,” the book recently received the Samuel M. Kamakau Award for Hawai‘i Book of the Year for 2013 from the Hawaii Book Publishers Association.

Author Anwei Skinsnes Law, who first visited Kalaupapa in 1968 as a teenager, based her book on extensive research of letters and petitions — more than 300 written by the early residents and translated from Hawaiian — and over 200 hours of oral history interviews. The work also includes 295 photos.

It has long been assumed that those sent to Kalaupapa were unconcerned with the world they were forced to leave behind, but this book shows that residents remained actively

interested and involved in life beyond the confines of the peninsula that had become their home.

“The people of Kalaupapa have been speaking to us clearly and definitively for more than 145 years,” Law writes in the Preface. “The objective of this *Collective Memory* is to bring those voices back into the history of Kalaupapa, the history of Hawaii, and the history of the world.” ■



Kalaupapa — A Collective Memory was published by the University of Hawaii Press in 2012. The author is international coordinator of IDEA.

FROM THE EDITORS

PAPAL REMARK

Leprosy is one of the oldest diseases known to humanity. Down the centuries it has caused untold suffering — physical, emotional and psychological. Despite the fact the disease is now completely curable, it continues to stigmatize those it affects because of the myths and misconceptions that surround it. In some countries, leprosy is now called Hansen’s disease to separate it from the negative connotations the word has acquired through the ages.

How disappointing, then, to see Pope Francis quoted recently by the Catholic News Service as saying, “Careerism is a leprosy, a leprosy!” He was addressing students of the Pontifical Ecclesiastical Academy, which trains priests to serve as Vatican diplomats, and urging them not to put personal ambition ahead of service to the Church.

The Pope had a point to make, but we are sorry he had to undermine efforts to reduce the stigma attached to the disease in the process.

May we not expect greater sensitivity from the head of the world’s largest Christian church?

His comment was all the more regrettable as the Catholic Church annually publishes a supportive message on World Leprosy Day and has made saints of two people who lived and worked with people affected by leprosy on Molokai in Hawaii.

In 2009, 17 faith leaders — among them the president of the Vatican’s Pontifical Council for Health Pastoral Care — signed Global Appeal 2009 to end stigma and discrimination against people affected by leprosy. These representatives of the world’s leading religions noted the persistence of mistaken beliefs about leprosy, which perpetuate social and economic discrimination. “All of us must be part of the social healing process,” they stated. We are sure it was never Pope Francis’s intention to cause anguish to people affected by leprosy with his recent comment and believe he would endorse the sentiments expressed in the Global Appeal.

FOR THE ELIMINATION OF LEPROSY

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