

FOR THE Elimination OF Leprosy

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



Abdul (left) visits a Salvation Army clinic in Dhaka, Bangladesh, accompanied by his mother and son.

MESSAGE

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Discriminatory Laws and Words

As I have mentioned before, in December 2010 the UN General Assembly unanimously adopted a resolution on elimination of discrimination against persons affected by leprosy and their family members. However, the resolution is not binding. We must use it as a tool to carry forward the fight.

To this end, I have planned a series of five regional symposia on Leprosy and Human Rights to familiarize governments, policy makers and related bodies with the Principles and Guidelines that accompany the resolution. The first symposium took place in Brazil in February, attended by representatives of governments, international organizations and NGOs from the Americas. Preparations are now going ahead for the second symposium. Focusing on Asia, it is scheduled for India in October.

The Principles and Guidelines include an important section calling for the abolition of discriminatory laws and regulations. In the Indian state of Orissa, legislation that prevented people affected by leprosy from contesting local elections is being amended. Only a few years

ago, India's Supreme Court allowed a ruling made under the law in question to stand. India still has laws that discriminate on the grounds of leprosy, and it would not surprise me if similar laws still exist in other countries too.

Earlier this year, activist Jose Ramirez, Jr. was quick to alert colleagues to a scene he found objectionable in a trailer for an animated movie about pirates. As a result of protests over the way the scene would affect perceptions of the disease, Aardman Animations and Sony Pictures agreed to make a change to the version that went on worldwide general release.

In films, plays and especially the news media, use of the discriminatory term "leper" is still all too frequent. Please let me know when you see an example of this and I will respond. As Goodwill Ambassador, I believe that one of my most important roles is to resolve problems one by one in hopes that these efforts will add up. With your help, I believe they will.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Let's Hear It for CLAP

A multi-sectoral national coalition on leprosy takes shape in the Philippines.



Participants in the 1st National Workshop of Organizations of People Affected by Leprosy, held in Manila in March.

Any attempt to control or eliminate leprosy has to go beyond killing the bacteria, since leprosy is far more than a medical condition or public health concern. The effects of stigma and discrimination associated with the disease are often worse than the disease itself, extending to other members of the family.

Since leprosy is made more complex by its social dimensions, it is important to take into consideration the perspectives of those affected by it. They must be an important part of all the processes that concern them, and their right to chart their own future must be respected. Proceeding on this basis will pave the way toward a more comprehensive, sustainable and holistic approach to improving the quality of life of people affected by leprosy.

EXISTING NETWORKS

In the Philippines there are many formal and informal groups and networks of people affected by leprosy, distributed throughout the country's eight leprosy sanitariums. Many have been around for years and have been increasingly recognized and supported by the government, NGOs and religious groups.

However, there has not been sufficient discussion among them about how they should work with the government's leprosy control program and other departments, whether they should have a shared vision, and how they might establish and strengthen partnerships with other groups, such as people with disabilities, to bring about positive change for people affected by leprosy at every level.

To help chart a course for the future, a three-day national coalition-building workshop was held from March 7 to 9 in Manila.* The meeting

brought together different stakeholders in leprosy in the Philippines, including government agencies and NGOs, as well as leaders of almost 20 people's organizations.

It resulted in the formation of the Coalition of Leprosy Associations in the Philippines, or CLAP, made up of organizations that believe in the same vision and share the same objective of improving the quality of life of people affected by leprosy and their families.

The coalition will provide different people's organizations with a platform for advocacy and lobbying on issues such as economic deprivation and social exclusion. It also provides a formal structure under which NGOs and government organizations can network on programs and activities that relate to people affected by leprosy. In addition, the coalition can become a potent and effective partner in the implementation of the WHO guidelines on strengthening the participation of people affected by leprosy in leprosy services.

This coming together as a national coalition would not have been possible without the recognition that this is a multi-sectoral and multi-disciplinary concern and that leprosy is everybody's business. It is an acknowledgment that people affected by leprosy are not only clients on the receiving end of policies but also partners with a role in addressing the social dimensions of the disease as well as in supporting leprosy control.

Now we have come together, the bigger challenge will be to stay together and work together to build a truly inclusive society. Going forward, the role of funding partners and other government agencies in nurturing this effort will be critical. ■

AUTHOR:

Arturo C. Cunanan, Jr.



Arturo C. Cunanan, Jr. MD, MPH, PhD is Chief of the Culion Sanitarium and General Hospital, Department of Health, Philippines.

FOOTNOTE

*Organized by the Culion Sanitarium and General Hospital (Culion Leprosy Control and Rehabilitation Program) in collaboration with the National Leprosy Control Program (DOH), Sasakawa Memorial Health Foundation and Culion Foundation, Inc.

Breaking Down Barriers

Leprosy and Human Dignity project looks to bring about positive change.

Leprosy and Human Dignity-Southeast Asia (LHD-SA) is an initiative that aims to create a society in which people affected by leprosy are able to lead a dignified life in an equitable and inclusive environment.

Supported by The Nippon Foundation, its main activity is to invite and fund proposals from NGOs that help to achieve this objective. In particular, it is interested in projects that sensitize society, promote networks of people affected by leprosy and help build partnerships with different sectors.

With a Regional Coordination Office in Jakarta, LHD-SA covers Indonesia, Thailand, Vietnam, Cambodia and the Philippines. Program director Adi Yosep has personally experienced leprosy.

In 2011, the first three projects were approved: one in Cambodia and two in Indonesia. The project in Cambodia was implemented by Support Children Young (SCY), a Phnom Penh-based NGO that gives Cambodian young people the opportunity to participate in media advocacy. With its grant, SCY created radio and TV spots to disseminate information about leprosy. The head of the country's leprosy elimination program, Dr. Lai Ky, featured in these broadcasts.

The two projects in Indonesia also focused on awareness building. One was run by the School for Broadcast Media, and the other was a collaboration between PerMaTa (an organization of people

affected by leprosy) and the country's National Human Rights Commission.

GETTING THE WORD OUT



Lak Kiri (pictured with her son) was a speaker at the Phnom Penh workshop.

Prior to applications for 2012 grants being accepted, two workshops were held in Phnom Penh (February 28) and Hanoi (March 1) to publicize the initiative and answer questions. Around 150 people attended the two workshops, including NGO representatives, government officials and journalists. Also invited were people affected by leprosy, who spoke about their experiences with the disease and the

challenges they faced. This gave participants the opportunity to hear real-life stories at first hand and discuss what could be done to reduce stigma and discrimination. Many of them were encouraged to submit proposals.

At the Cambodia workshop, a representative of one of last year's grant recipients talked about the project his organization had run. SCY's executive director, Sophal Kann, said the broadcasts on leprosy had generated a considerable response from the public, who were interested in such questions as whether the disease is hereditary and how infection occurs. Noting that some radio listeners expressed the view they would not want to live next door to a person with leprosy, Sophal Kann said the experience had made him aware of the need for the public to be better educated about leprosy. He said he hoped to have further opportunities to continue this effort.

NON-LEPROSY NGOS

LHD-SA welcomes applications not only from NGOs that already work in leprosy but also from those with experience of working in other fields such as the rights of women, children and persons with disabilities.

For those NGOs without direct experience of leprosy, LHD-SA's program director Adi Yosep recommended that they approach the health ministry or an organization of people affected by leprosy to discuss their ideas and for help in formulating a proposal.

Further information about the Leprosy and Human Dignity Project can be obtained by contacting the LHD-SA Regional Office.* ■



Scene from the opening ceremony of the Cambodia workshop (top); in the offices of Support Children Young (SCY) in Phnom Penh (above)

FOOTNOTE

*Taman Semanan Indah, Blok E1 No. 75, Cengkareng, West Jakarta, Indonesia.
Tel / Fax: (+62) 21 54374207
www.return2humandignity.org/

One Message, Multiple Tongues

Global Appeal 2012 is translated into over a dozen languages.



Very appealing: From Amharic to Swahili, different versions of Global Appeal 2012 (see below for details)

Global Appeal 2012 is truly going global, linguistically speaking. Created in English and translated into Portuguese for launch in Brazil in January, the annual appeal to end stigma and discrimination against people affected by leprosy has since been rendered into over a dozen languages.

With the appeal endorsed this year by the medical profession, there has been particular interest in seeing its message reach as many people as possible.

In some instances, the job of translating, designing and printing the local-language versions has been undertaken by organizations of people affected by leprosy in their respective countries.* In one country (Indonesia), the local-language version has been endorsed by national health organizations.

In addition to English and Portuguese, Global Appeal 2012 has to date been translated into Chinese, Bahasa Indonesia, Amharic, Nepali, Spanish, Swahili, French, German, Russian, Japanese, Bengali and several more Indian languages.

Pictured above are some of the versions that have been produced, with the name of the partner organization in parentheses. From top row, left to right are versions in: Bengali (The Leprosy Mission International – Bangladesh), Swahili (German Leprosy and TB Relief Association – Tanzania), Amharic (Ethiopian National Association of Persons Affected by Leprosy – Ethiopia), Chinese (HANDA Rehabilitation and Welfare Association – China), Spanish (Corsohansen – Colombia), Nepali (Nepal Leprosy Trust – Nepal) and Bahasa Indonesia (Ministry of Health, Indonesia). ■

FOOTNOTE

*In Ethiopia, for example, ENAPAL printed 3,500 copies, of which 2,200 have been distributed to government offices. Global Appeal was also introduced at ENAPAL's general assembly on March 24, in the presence of many government officials, NGO partners and journalists.

Meeting Dr. Romana Drabik

A German doctor of tremendous resolve has made leprosy the focus of her life.

AUTHOR:
Kay Yamaguchi



Kay Yamaguchi is Trustee of the Sasakawa Memorial Health Foundation.

I had long wanted to sit down and have a conversation with Dr. Romana Drabik, ever since I became aware of her more than 30-year involvement with leprosy and her knowledge of the disease in the post-Soviet states. Learning that she was to be in India last November, when I would also be there, we arranged to meet.

It was 10.30 on a Sunday morning, and the lobby of the hotel in Mumbai was crowded. But it wasn't difficult to pick out Dr. Drabik, a petite figure dressed all in white. For the next five hours, we talked about her three decades of leprosy work.

I say "work," but Dr. Drabik had until recently a full-time job running a doctor's surgery in her home town of Dinslaken, Germany. Her engagement with leprosy is more by way of a personal mission, conducted with professional dedication, unwavering resolve and exemplary humanity.

FIRST ENCOUNTER

It was the sight of people affected by leprosy begging on a street in Nairobi, Kenya in 1976 — her first encounter with the disease — that decided Dr. Drabik on how she would henceforth lead her life, both as a doctor and as a human being. A conscientious physician filled with a sense of justice and tremendous "get-up-and-go," the experience left her shocked and determined to act.

She and her husband returned to Africa several more times on holiday, always seeking out people with leprosy and looking to learn more about the disease. Back home, she also made contact with leprosy organizations. As she became more deeply committed, she told her husband, "I'm going to deal with leprosy." Discovering that India had the most cases of the disease, she made it her next destination, participating in a number of projects there during the 1980s.

A chance meeting on a beach in Tamil Nadu with visiting physicians from Latvia, then part of the Soviet Union, would lead Dr. Drabik in a new direction come the dissolution of the USSR. There was little information available about leprosy in



A fund-raising march in Dinslaken, Germany.



Dr. Drabik during a visit to Tajikistan's Hanaka Leprosarium in 2006

the 15 former Soviet republics and she made it her business to find out — establishing personal contacts with doctors and patients, researching the situation on the ground, arranging for needed supplies and promoting scientific exchanges.

NEW HORIZONS

Starting in the 1990s, she made the first of numerous journeys across the former USSR, accompanied as ever by her husband (a chemist) and sometimes by her teenage son, who is now a doctor. Traveling at her own expense, but taking drugs, medical equipment and other supplies paid for by fund-raising back home, she covered vast distances to visit out-of-the-way leprosaria in more than a dozen countries.

It wasn't easy going. She battled customs officials in Ukraine, who held up the medical supplies she brought with her. She braved dangerous roads in Armenia and a tense political situation in Tajikistan. In Turkmenistan she was shocked at the level of stigma, where even a doctor's colleagues shunned him because he worked with leprosy patients. But in the different countries she visited, she also encountered affection from patients and doctors — who were touched and astonished in equal measure that she had come to see them.

Now 75, she tells me during our conversation that the leprosy doctors she has befriended in Russia and elsewhere "are like family to me." She has invited many of them to her home in Dinslaken. Her approach is both professional and personal, which is reflected in her attitude to sanitarium residents as well. In the photos she shows me, Dr. Drabik is always right in among people affected by leprosy.

There is no doubt that her inner warmth communicates itself to everyone she meets. In recounting her experiences she says people often tell her, "Romana, you must come back!" After spending five hours in her company, I can see why. ■

Dateline Dhaka

The Goodwill Ambassador travels to Bangladesh, a country with a five-year national plan to further reduce the burden of leprosy.

BANGLADESH (APRIL 11-16)

In April I visited Bangladesh, a country that reported about 4,000 new cases of leprosy in 2011. It achieved the WHO's goal of eliminating leprosy as a public health problem in 1998 and has a five-year national plan to reduce the disease burden further.

On the day following my arrival in the capital, Dhaka, I called on Minister of Health and Family Welfare Prof. A.F. Ruhul Haque. He recalled the days when Bangladesh had a very high number of cases of leprosy, but said the situation today was much different thanks to the measures that had been taken. He told me his ministry is working closely with the WHO and partners to ensure that leprosy control is sustained. He also pointed to the repeal of the archaic "Lepers Act," which formalized discrimination against people affected by the disease and allowed for anyone with leprosy to be forcibly incarcerated.

In the afternoon I attended a partners meeting at the offices of the National Leprosy Elimination Program (NLEP). Taking part were The Leprosy Mission International - Bangladesh (TLMI-B), Damien Foundation, LEPROA Bangladesh, Rangpur Dinajpur Rural Service (RDRS), Health, Education and Economic Development (HEED) Bangladesh, Dhanjuri Leprosy Center, PIME Sisters, the Salvation Army and the International Centre for Diarrhoeal Disease Research, Bangladesh (icddr, b). Together with the government and the WHO, the partners have formed the Leprosy and TB Coordinating Committee (LTCC), which meets to coordinate leprosy and TB policy in Bangladesh.

After opening remarks from Dr. A.K.M Ali Ashraf, Assistant Director (Leprosy), NLEP, there was a presentation about the current situation in Bangladesh from Dr. Safir Uddin Ahmed, Deputy Program Manager (Leprosy). This was followed by a presentation of the five-year national strategy for 2011-2015. This strategy has been developed in consultation with partners, NGOs and the WHO, to enhance efforts to achieve and sustain the goal of a leprosy-free Bangladesh.

Based on the principles and guidelines laid down in the WHO's global strategy, it proposes introducing a national target of reducing the rate of new cases with grade-2 disability per 100,000 population by at least 35% by the end of 2015, compared to the baseline at the end of 2010. In addition, it promotes the greater involvement of



Partners examine the five-year plan.

persons affected by leprosy in leprosy control services.

At the meeting, NGOs gave a brief overview of their activities. TLMI-B, for example, is carrying out rural health and community-based rehabilitation in 15 districts and runs the Coordination for Advocacy and Networking (CAN) project to promote and protect the human rights of people affected by leprosy. It is also involved in some very significant research into leprosy, including new diagnostic tools for early detection of leprosy in the field.

I told the meeting that Bangladesh's achievement of the WHO's elimination target at a relatively early stage was a credit to the government, the WHO but above all to the NGOs who work so tirelessly to control the disease. I welcomed the national five-year plan and hoped it would be successful in tackling the challenges Bangladesh still faces. I also noted my appreciation of the efforts that resulted in the repeal of the 1898 Lepers Act last year.

The five-year strategy aims to enhance efforts to achieve a leprosy-free Bangladesh.

On April 13, I visited a leprosy clinic run by the Salvation Army in Mirpur, a subdistrict of Dhaka. This well-run clinic provides multidrug therapy and offers a wide range of services, including ulcer treatment, counseling and footwear; runs skin camps; and refers cases for reconstructive surgery. That day, those calling at the clinic included Abdul (picture on the cover), who is receiving treatment for leprosy reaction.

From the clinic I moved on to a saree factory in the handloom weaving area known as Mirpur



Patients and a member of staff (standing) at the Salvation Army clinic.

Banarasi Palli. The factory is run by a person affected by leprosy. It was started with a loan he received from his self-help group — a group supported by TLMI-B. The factory now employs 40 people, including non-leprosy affected. The factory shop sells around 1,000 sarees a month.

Next I called at the home of a person affected by leprosy in the Bashbari area of Mohammadpur. A self-help group mentored by TLMI-B meets here. Through buying and selling fish and vegetables, members make a monthly contribution to a bank account the group has opened. This sum is used for loans to members.

On April 14, the day that marked the Bengali New Year, I travelled six hours by road to Srimangal, a tea-growing region in Sylhet Division



At work in the saree factory

in the northeast of the country. The next morning I was briefed by HEED Bangladesh about its activities in the area.

HEED was established in 1974 to promote national development through improving the socio-economic position of the disadvantaged and underprivileged. In 1976 it discovered and began treating cases of leprosy in the tea plantations. Over the years it has provided inpatient and outpatient services, including ulcer care, reconstructive surgery and physiotherapy, as well as supplying footwear and offering skills training. It has also sought to educate the public about leprosy through such means as puppet plays and folk songs.

In recent years, however, because of funding difficulties, its work has largely been confined to dispensing drugs. HEED Bangladesh's president is Pastor Anwar Hossain. "Pray for Bangladesh and people affected by leprosy," he said. "And let us join forces to work on their behalf."

After the meeting, I visited a HEED clinic, a hospital run by a tea estate and a government hospital for TB and leprosy. At the Chatlapur Tea Estate Hospital about 20 people affected by leprosy had gathered. Among the people I met were a basket maker; a woman who works as a seamstress after receiving HEED skills training; a tea estate worker; and a young girl being treated for the disease.

I came away from this visit to Bangladesh with a renewed awareness of the important role that NGOs play at the grassroots level, and of how essential to a nation's leprosy strategy for there to be a solid partnership between the government, the WHO and NGOs. It is also important that people affected by leprosy become more involved in leprosy control activities and make their voices heard. I hope to see this happening more in Bangladesh and I shall be following its progress closely. ■

Presenting a United Front on NTDs

Partners pledge action on neglected tropical diseases at London conference.

A major conference held in London this January saw drug companies, governments, the Bill & Melinda Gates Foundation, the World Bank and other global health organizations unveil a new coordinated push to eliminate or control 10 neglected tropical diseases (NTDs) by the end of the decade.

NTDs, which include leprosy, are believed to affect to 1.4 billion people worldwide, many of them among the world's poorest.

Partners put their names to The London Declaration on Neglected Tropical Diseases, which pledges new levels of collaborative effort and tracking of progress.

To guide this effort, the World Health Organization (WHO) has unveiled a new strategy, *Accelerating work to overcome the global*

impact of neglected tropical diseases—A roadmap for implementation, that sets targets for what can be achieved by the end of the decade.

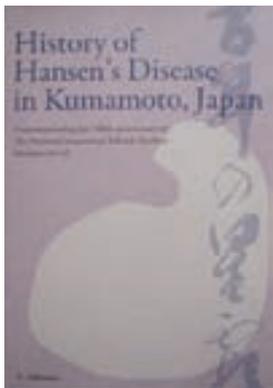
"These ancient diseases are now being brought to their knees with stunning speed," said Dr. Margaret Chan, Director-General of the WHO.

Concerning leprosy, Novartis will extend its commitment to provide the drugs used in multi-drug therapy (rifampicin, clofazimine and dapsone) to leprosy patients worldwide in "a final push" against the disease.

Among those giving their backing to the initiative is American Leprosy Missions. President and CEO Bill Simmons said in April, "American Leprosy Missions recognizes that only through true collaboration will we be able to conquer leprosy and related diseases."

NEWS EXTRA

The Pacific Leprosy Foundation is to receive the Dr. LEE Jong-wook Memorial Prize for Public Health at the World Health Assembly in May.



LEPROSY IN KUMAMOTO, JAPAN

A book that Japan's National Sanatorium Kikuchi Keifuen published to mark its 100th anniversary in April 2009 was recently released in abridged form in English. Kikuchi Keifuen is located in Kumamoto, where leprosy, or Hansen's disease, has a long history. The book chronicles treatment and care at the sanatorium, the lifestyle of patients and moves to "return Keifuen to society" following the abolition of the Leprosy Prevention Law. It provides fascinating insights into the disease experience in Japan.

NEWSLETTER PDF

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Publisher

Yohei Sasakawa

Executive Editor

Tatsuya Tanami

Editor

Jonathan Lloyd-Owen

Associate Editor

James Huffman

Layout

Eiko Nishida

Photographer

Natsuko Tominaga

Editorial Office

5th Floor, Nippon Foundation Building,
1-2-2 Akasaka, Minato-ku,
Tokyo 107-8404
Tel: +81-3-6229-5601
Fax: +81-3-6229-5388
smhf@tnfb.jp

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FROM THE EDITORS

DEATH BY STIGMA

In her inspiring memoir, *To Light a Candle — Reminiscences and Reflections*, published in translation in 1987, German-born physician Dr. Ruth Pfau recounts life in Pakistan, where she helped to establish the national leprosy program, train field workers in leprosy and run the highly-regarded Marie Adelaide Leprosy Center in Karachi. The book is full of wisdom and insight.

There is a story she includes about a young man called Aminuddin. The recollection of his case causes her much anguish. Born into a well-to-do family, he developed leprosy and was kept out of sight by his brothers, who feared for the family's reputation if word got out. Only when his condition became severe was he

driven to the leprosy center, but by then it was too late to save him.

Dr. Pfau writes: "Aminuddin died as a result of stigma. Nothing should have prevented him from being cured, getting married and taking his rightful place in society.

"Who denied him his share of life and happiness? Where did *we* fail — all of us who make up public opinion and social beliefs?"

Her question still resonates today. Despite the decrease in the number cases in the world, fear of leprosy remains deeply ingrained, and is expressed in words and deeds that stigmatize those with the disease. The work of changing public opinion and social beliefs has a long way to go, and we all have a role to play. ■