

FOR THE Elimination OF Leprosy

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



National Forum India's G. Venugopal and V. Narsappa (center), flanked by Law Society President Lucy Scott-Moncrieff (left) and Baroness Helena Kennedy QC, attend the launch in London of Global Appeal 2013 to end stigma and discrimination against people affected by leprosy on January 24. (see pp 2-3)

MESSAGE

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Remembering Dr. Nakajima

I was in Vietnam when I learned of the passing of former WHO Director-General Dr. Hiroshi Nakajima, who died on January 26 in Poitiers, France.

Between 1978 and 1988, Dr. Nakajima served as Regional Director of the WHO's Western Pacific Region, where he took a keen interest in leprosy. Later, as Director-General, he would kick off the campaign to eliminate leprosy as a public health problem — something we must never forget.

One of Dr. Nakajima's successors as Director-General, Dr. J.W. Lee, was also committed to eliminating leprosy. As a promising young doctor, he had received a fellowship from Sasakawa Memorial Health Foundation to study in Hawaii. He later became acquainted with Dr. Nakajima on a plane, which led to him being recruited by the WHO.

During Dr. Nakajima's 10-year term from 1988, he was operated on for stomach cancer; however, that did not stop him from traveling the world. Throughout his tenure, he maintained a humanitarian perspective and took very seriously the concept of "health for all," which he strove hard to

achieve. He always attached importance to having a hands-on approach and going to see the situation for himself, as evidenced when he visited then-Zaire following the outbreak of the Ebola virus. In this respect, he had a big influence on the way I do things.

Dr. Nakajima presided over the 1991 World Health Assembly, which adopted a resolution to eliminate leprosy as a public health problem by the year 2000. Three years later, at a conference in Hanoi, I announced that The Nippon Foundation would pay for the free distribution of multidrug therapy (MDT) for five years from 1995. I did so convinced that the elimination of leprosy — defined as reducing the prevalence of the disease to below 1 case per 10,000 population — was possible under Dr. Nakajima's strong leadership.

Dr. Nakajima was a wine-lover and sommelier. I regret he will not be able to toast the day when Brazil becomes the final country to pass this public health milestone. May he rest in peace.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Laws in the Spotlight

The 8th Global Appeal takes aim at outdated legislation on leprosy.



Around 200 people gathered at the Law Society in London for the launch of Global Appeal 2013.

Although leprosy is now curable and there are no medical reasons for isolating those who suffer from the disease, there are still laws in existence that discriminate on the basis of leprosy.

Global Appeal 2013 shines a light on this issue. Launched at the Law Society in London on January 24, this is the eighth in a series of annual appeals initiated in 2006 by Goodwill Ambassador Yohei Sasakawa to end stigma and discrimination against people affected by leprosy. It is also the third appeal to have been launched in London, following those supported by human rights-oriented NGOs (2008) and by religious leaders (2009).

Laws that remain help to fan the flames of prejudice and discrimination.

Endorsed by the International Bar Association (IBA) and 46 member associations from 41 countries and regions, this year's appeal targets laws and regulations in different countries — such as India, where leprosy is considered grounds for divorce, or the United States, where “leprosy, infectious” remains on a list of diseases of public health significance and can be a reason for refusing a visa.*

“It may be that these laws are not deliberately kept up, but have remained on the statute book, largely forgotten,” Sasakawa said. “But while they remain, they help to fan the flames of prejudice and discrimination.”

Some 200 people attended the ceremony and heard from Baroness Helena Kennedy QC, the

co-chair of the IBA's Human Rights Institute, who gave the keynote address, as well as Akira Kawamura, the IBA's immediate past president.

Baroness Kennedy said national governments have a responsibility to educate citizens against outdated misconceptions relating to leprosy as an incurable and highly contagious disease. “Pivotal to this mission is the repeal of discriminatory legislation; governments have a duty to lead by example,” she said.

Kawamura commented: “All of us here must raise awareness about the harm caused by stigmatizing people simply because they are unwell, and we must lobby our lawmakers in all of our countries to overturn antiquated, biased legislation.”

CALL FOR ACTION

Representing people affected by leprosy were the vice chairman and chairman of the National Forum India (NFI), Guntreddy Venugopal and Vagavathali Narsappa, who spoke of their experiences of the disease and called for action against discriminatory laws.

“We are ambitious and determined to improve the quality of lives of leprosy-affected people in India and enable them to live dignified lives without stigma and discrimination,” said Venugopal. “Our ultimate aim...is a world with no leprosy and no discrimination against people affected by leprosy,” said Narsappa.

For the NFI chairman, addressing the ceremony was a personal landmark in the fight for dignity and recognition. He later said: “I do not have the words to express how privileged and proud I felt to represent my country at the Law Society as a grassroots activist and as a person affected by leprosy.” ■



A PDF of Global Appeal 2013 can be downloaded from The Nippon Foundation website.

FOOTNOTE

* Some countries are reviewing their policies. Last year, the UK Border Agency amended its policy advice to make it clear that having leprosy is not grounds alone for refusing entry into the United Kingdom.

‘No Longer Room for Excuses’

Speakers highlight the role the legal profession can play in effecting change.

Akira Kawamura, Immediate Past President, International Bar Association (IBA)



Like many people, I thought leprosy had been completely eliminated and was confined to history. Furthermore, I had not appreciated that leprosy was not just only a medical problem but also a human rights issue because of the stigma and the highly developed discrimination faced by the people who suffer from the disease.

As I began to learn more about leprosy, it struck me forcefully that the pernicious and outdated attitudes and laws around leprosy caused great suffering to many people. I must admit that I was absolutely naïve. But now there is no longer room for excuses. With members of the legal profession across the world, we have an opportunity to work together and correct the situation.

Baroness Helena Kennedy QC, Co-chair of the IBA's Human Rights Institute



As we know, lawyers are integral to the protection of human rights and to upholding the rule of law in their country of practice. Lawyers are also key players in initiating and promoting meaningful law reform. We have often been the voice of the voiceless.

So, today, with bar associations and members of the legal profession from across the globe coming together to endorse this Appeal, promoting an end to all stigma and discrimination against persons affected by leprosy, we have two further, specific goals: One, to spread awareness among the world's legal profession, across all jurisdictions, about the discrimination on grounds of leprosy that persists and of the discriminatory laws that reinforce such discrimination; and two, to bolster the international legal profession to work toward the repeal of such legislation in their respective countries.

Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination

In 2010, the UN General Assembly adopted principles and guidelines on eliminating leprosy-related discrimination. These clearly state that



all existing laws and regulations that discriminate must be abolished.

It gives me great confidence, therefore, that this year's Global Appeal has the support of the International Bar Association — the world's leading organization of international legal practitioners, bar associations and law societies. Today marks a giant step forward in the battle against discrimination. It holds great significance for people affected by leprosy and their families.

Guntreddy Venugopal, Vice-chairman, National Forum India (NFI)



The living standards of people affected by leprosy have improved drastically and stigma and discrimination are also in decline — but the challenge is a decades-old mindset that is slow to alter.

We now need to increase the pressure for change and work harder to confront human rights violations and challenge the existing 15 discriminatory laws in India that work against us.

Vagavathali Narsappa, Chairman, NFI



I should like to thank the International Bar Association for supporting this appeal against the discrimination that leprosy-affected people have to suffer on a daily basis. We need the full support of the legal profession in our campaign for justice and human rights.

Our ultimate aim for our country, India, and the wider community, is a world with no leprosy and no discrimination against people affected by leprosy. If the International Bar Association can help us change discriminatory laws, a huge step forward will have been taken. ■

Looking Forward to Brussels

The 18th International Leprosy Congress meets this September in 'the capital of Europe'.

Despite advances in medical science, it is a great disappointment to see that an age-old disease such as leprosy is still with us in the 21st century and still affects significant numbers of people around the world.

Leprosy is an intriguing disease with many obscure pathophysiological mechanisms that remain to be elucidated. After a boom in interest in leprosy at the turn of the 20th century, driven by public health concerns, and marked improvements in treatment with the adoption of multidrug therapy (MDT) in the 1980s, leprosy has gradually become a less important subject in medical schools and a low priority on the agenda of health authorities.

Although widespread use of MDT and improvements in patient care during the WHO campaign to eliminate leprosy as a public health problem have led to a reduction in case numbers worldwide, as well as to changes in the epidemiologic features of the disease, it is clear that leprosy continues to be a major problem for a number of countries. This is due not only to the continued transmission of the disease but also because of the potential risk of developing disabilities and deformities, with devastating social and economic consequences.

The Congress is a chance to find out whether scientists have found some answers.

We are once again at a critical point in the history of leprosy. Clinical expertise is progressively being lost and will probably disappear as the number of new cases of leprosy decreases.

HIDDEN CHALLENGES

There are a considerable number of scientific aspects of leprosy that remain unclear and even unknown to scientists and researchers. They represent hidden challenges that need to be addressed. We desperately need to shed light on them if we intend to resolve the burden of leprosy in the world.

To give a couple of examples:

1) Research in infectious diseases is mostly based on the availability of the causative organism. *M. leprae* has not been successfully and reproducibly cultured in artificial media (*in vitro*) and its reproduction *in vivo* is very limited. This is still a challenge for scientists, since the

provision of live, viable *M. leprae* would enhance studies on various biologic mechanisms of this mycobacterium.

2) Leprosy is a multifactorial and multigenic disease. So far, there are no efficient genetic markers (either for the host or the pathogen) that are unequivocally linked to the risk of developing the disease. Advances in this area would do wonders for protective public health measures.

PLATFORM FOR DISCUSSION

Molecular immunology and genetics are emerging as key areas of research to address these hidden challenges. This September, there will be an opportunity to ask the international scientific community whether they have found some answers when the 18th International Leprosy Congress (ILC) convenes in Brussels.

And if and when they do find answers, there needs to be a way to turn the sophisticated results of basic science into practical applications the field. Here, too, the Congress has a role to play, providing a platform for scientists and health personnel to sit together, exchange ideas and find solutions to their concerns.

Under the capable direction of Professor Cairns Smith, the Scientific Program will reflect the multidisciplinary character of leprosy and bring us up to date on the latest research in different fields. Symposia planned for the 18th ILC include those on chemoprophylaxis, chemotherapy, detection and treatment of reactions, epidemiology, genomics, neglected tropical diseases and leprosy, relapse and drug resistance, and vaccines.

But the Congress will also be a place to consider the history of leprosy, human rights and discrimination, community-based rehabilitation and the role of people affected by leprosy in leprosy services.

Meanwhile, the Brussels-based Damien Foundation, the host institution for the Congress, is doing a wonderful job to prepare for the event and ensure that this important gathering runs smoothly and takes place in an agreeable atmosphere.

The 18th Leprosy Congress will be a major opportunity for all concerned with alleviating the burden of leprosy in the 21st century to share their experiences. On behalf of the International Leprosy Association, I look forward to seeing you there. ■

AUTHOR:
Marcos Virmond



Dr. Marcos Virmond is president of the International Leprosy Association.

Mobility Man

How the Pacific Leprosy Foundation helped give Issac freedom of movement.

The Pacific Leprosy Foundation is a not-for-profit foundation that has been working in the Pacific with people affected by leprosy for over 80 years. It is based in Christchurch, New Zealand, and has programs in Kiribati, Samoa, the Solomon Islands, Fiji, Vanuatu and Tonga.

The foundation works in two main ways — first, alongside each country's health ministry, providing assistance in monetary and technical terms for the provision of a sustainable leprosy program; and second, in providing assistance to people disabled by leprosy, who tend to be a low priority for governments with limited resources.

The assistance to people disabled by leprosy is tailored to meet the needs of each individual and family and may include a living allowance, income-producing initiatives, housing, and education for their children. The foundation assists hundreds of families throughout the Pacific in this way and relies entirely on public donations to carry out this work.

ISAAC'S STORY

Isaac lives on Vanuatu. He has suffered from both leprosy and polio. He is unable to walk and could only get around by shuffling on his bottom until a hand-pedalled wheel chair was invented for him.

The foundation assisted his three children through school and they have all established successful careers; two work in the travel industry and one is now training to be a physiotherapist. Isaac makes beautiful carved jewellery, which he sells in the market.

His wife, Verongi, had to go everywhere with



A smiling Issac sits atop his mobility scooter in Vanuatu.

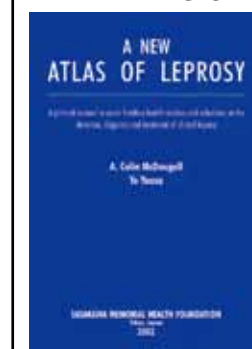
Isaac to help him up the many hills and over the rough ground he encountered on his way to and from the market. We wanted to find a way to make Isaac more mobile.

With limited equipment available locally, it was decided to ship a sturdy mobility scooter from New Zealand to his home in Santo, Vanuatu. Many people helped along the way, providing the scooter at a discount and offering reduced rates for shipping and insurance.

I was visiting Vanuatu soon after the scooter was delivered and met with Isaac, his family and friends to celebrate its arrival. What struck me forcibly was that for the first time in his life Isaac had freedom. He could come and go as he pleased and not be reliant on anyone else to assist him. The look on his face as he explained this was one of pure joy. He asked me to pass on his sincere thanks to all the people in New Zealand who donate to the Foundation for the freedom this had given him. ■

BOOK

A NEW ATLAS OF LEPROSY



While *A New Atlas of Leprosy* is not new — it was first published in 2000 and the original *Atlas* in 1981 — it remains a very useful tool in the fight against leprosy. Compiled by the late Dr. A. Colin McDougall and Dr. Yo Yuasa, it is a pictorial

manual to assist frontline health workers and volunteers in the detection, diagnosis and treatment of clinical leprosy.

The *New Atlas*, which features photographs of leprosy in different clinical settings, can now be downloaded in both high- and low-resolution formats from the Sasakawa Memorial Health Foundation website. It is available in seven languages: English, Bahasa Indonesia, Spanish, French, Hindi, Nepali and Portuguese.

<http://www.smhf.or.jp/e/publication.html>

The IBA Is 'On the Case'

Yohei Sasakawa wears two hats on a visit to Myanmar last December. Then, in January, he travels to the U.K. for the launch of the annual Global Appeal to end stigma and discrimination against people affected by leprosy.

MYANMAR (DECEMBER 21)

Myanmar eliminated leprosy as a public health problem in 2003, but continues to detect a steady number of new cases — 3,092 in 2011, according to the WHO. At the time of diagnosis, just over 15% were suffering from visible disability.

Visiting the country at the end of last year in my capacity as the Japanese government's Goodwill Ambassador for the Welfare of the National Races in Myanmar, I took time out from my schedule to visit a leprosy hospital in southern Mon State. I was accompanied by Mr. Tin Aung Swe, the vice president of the Myanmar Christian Leprosy Mission and president of the national council of the YMCA in Myanmar.

Mawlamyine Christian Leprosy Hospital is located in the Mon state capital, approximately 300 kilometers southeast of Yangon. It was founded in 1908 and at one time was run by the American Baptist Mission.

Today the hospital provides a range of in- and out-patient services for leprosy. These include ulcer care, plastic and reconstructive

surgery, physiotherapy, eye care, and prevention of disability education. There is also a workshop for making mobility aids and footwear for leprosy. In addition, the hospital offers livelihood training for people affected by the disease and their families.

I toured the hospital with its 35-year-old director, Dr. Chan Lwin, and spoke with a number of patients, young and old, who are receiving treatment. I also met with some people affected by leprosy living in the hospital precincts. Apparently there are around 50 such families living at Mawlamyine, in some cases, I am sure, because discrimination prevents them living elsewhere.

Reflecting on this visit, I hope that Myanmar remains vigilant against leprosy and works hard to reduce the percentage of new cases with disability. No one with leprosy should have to suffer disability because they were not diagnosed soon enough, and no one should have to endure being stigmatized by the disease and its consequences.

UNITED KINGDOM (JANUARY 23-26)

In January I flew to London to participate in the 8th annual Global Appeal to end stigma and discrimination against people affected by leprosy. This year's appeal was endorsed by the International Bar Association (IBA) and launched in the splendid setting of the Law Society building, which dates back to 1832.

If last year's appeal was of great significance, because the medical profession spoke out to dispel myths and misconceptions about the disease, then I believe this year's appeal is equally important, as it has trained the sights of the legal profession on discriminatory legislation. All laws that discriminate on the grounds of leprosy need to be abolished without delay. Therefore, to know that the IBA is "on the case" is a very encouraging development indeed.

I understand that the IBA plans to engage in a dialogue with its member associations about the role that bar associations can play in lobbying for any discriminatory legislation to be repealed in their respective countries. Needless to say, I will do everything in my power to follow up these efforts. Abolishing discriminatory laws is an essential step for restoring the human rights of people affected by leprosy and there is still much to do.

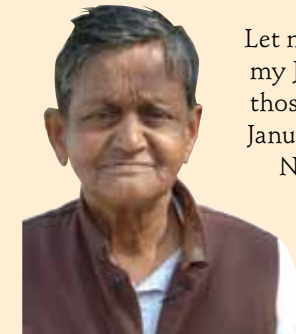


With a resident of Mawlamyine Christian Leprosy Hospital (top); hospital exterior (above)



Splendid setting: the Law Society

I would like to thank Lucy Scott-Moncrieff, the president of the Law Society of England and Wales, which hosted the event, and her colleagues. I extend my gratitude to Baroness Kennedy and Akira Kawamura, who spoke eloquently and passionately at the launch ceremony. In particular, I thank Chairman Narsappa and Vice-chairman Venugopal of the National Forum India. When addressing the ceremony they gave a real insight into what it means to be affected by leprosy and demonstrated what I have often said, that the voices of people affected by the disease carry more weight than anything I might say on their behalf.



Let me close this entry of my Journal by remembering those we have lost in January. In addition to Dr. Nakajima, who I have written about in my Message, and my friend Dr. Gokhale, who is recalled below, I would also like mention Mr. S.K. Dutta.

An activist who lived in a leprosy colony in Delhi, Mr. Dutta selflessly devoted his life to fighting for the underprivileged, making them aware of their rights and teaching them how to use those rights. He was a man of action, passion and persistence, who endeared himself to one and all, whether they were of high social status or grass-roots workers. As I write these words I can see his charming smile. I will miss him. ■

TRIBUTE

DR. S.D. GOKHALE: GIVING LEPROSY A HUMAN FACE



As the founder of the International Leprosy Union (ILU), Dr. S.D. Gokhale, who died in January aged 87, brought empathy, erudition and eloquence to the anti-leprosy movement.

Although he was not medically qualified, he was an internationally renowned social scientist who looked at leprosy in all its aspects. This was reflected in the goals of the ILU, which he established in Pune, India, in 1986: "While the goal is to eliminate and if possible eradicate leprosy, the focus will be on the individual affected by leprosy, to help them regain their lost dignity, recognize their human rights and bring

them back into the mainstream of society."

The media-savvy Dr. Gokhale, who edited a newspaper and authored many books, also recognized the important role that news organizations have to play in demystifying the disease. The second goal of the ILU, therefore, was to use advocacy and develop media involvement "to help demolish stigma and (the) stigmatizing environment," while educating people affected by leprosy, their families and the communities around them.

The ILU was also ahead of its time in its determination to put people with leprosy in charge of their own destiny, with its third and final goal being "to work towards the empowerment of people affected by leprosy so that they can participate in decisions affecting their lives."

Recalls Dr. Yo Yuasa: "I had the privilege of knowing Dr. Gokhale since

the late 1970s and he always treated me as a close coworker in leprosy. Our greeting was not a handshake but a hug.

"His great contribution was to see leprosy as a general medical and social issue, and not as a unique problem all of its own, as had been the case in the past. In order to solve current and future leprosy challenges, we are going to need more people like Dr. Gokhale."

In a distinguished career, Dr. Gokhale also founded the International Longevity Center-India and the Community Aid and Sponsorship Program. He served as a consultant to the United Nations, UNDP, UNICEF, the WHO and the Government of India

Dr. Gokhale was the recipient of many awards, including, for his outstanding contribution to leprosy work, the International Gandhi Award (1998) and the Sasakawa Health Prize (2006). We mourn his passing.

Recognizing Enterprise

SILF presents Rising to Dignity Awards on Anti-Leprosy Day.



Every year, January 30 — the martyrdom day of Mahatma Gandhi — is observed as Anti-Leprosy Day in India. It is also the day when the Sasakawa-India Leprosy Foundation (SILF) presents its Rising to Dignity Awards. The awards recognize outstanding examples of successful micro-enterprises that have received grants from SILF under the livelihood funding initiative it started in 2008.

The winning projects are all based in self-settled colonies of persons affected by leprosy. They were selected on the basis of the hard work and commitment demonstrated by those running them.

Honored this year were a tile-fitting unit from Maharashtra, a goat-rearing enterprise from Odisha and a hawkker-vendor enterprise from Uttar Pradesh.

Handing out the prizes at a ceremony in New Delhi were former railway minister Dinesh Trivedi and Madhu Goud Yaskhi, MP. They are the convenors of an informal cross-party parliamentarians' group that was set up to generate awareness of leprosy and end the stigma it attracts.

ILEP CONDEMNS DISCRIMINATION



In his annual Message on the occasion of World Leprosy Day, the president of the International Federation of Anti-Leprosy Associations (ILEP) addressed the issue of discriminatory laws. ILEP President René Stäheli stated: "A disease is no reason to discriminate against anyone — ever. The role of the law in influencing behavior cannot be underestimated. Unfortunately centuries of fear and misunderstanding of leprosy have perpetuated the existence of legislation that allows discriminatory behavior on grounds of leprosy, even though laws should protect people. The continued existence of such laws should not be taken as evidence of their need and justification."

RAPID DIAGNOSTIC TEST

A rapid diagnostic test for leprosy was registered in Brazil in January. The test has been developed by the Infectious Disease Research Institute (IDRI) of the United States with the support of American Leprosy Missions.

The blood test, said to be similar to a pregnancy test, is intended to diagnose cases of leprosy early, before nerve damage sets in. IDRI is also working to develop a leprosy vaccine. ■

FROM THE EDITORS

#60

This is the 60th issue of this newsletter. Its publication coincides with the 60th World Leprosy Day, the day launched in 1954 by French humanitarian Raoul Follereau and celebrated on the last Sunday in January.

Folleureau inaugurated World Leprosy Day as a "universal mobilization of hearts and minds" to draw attention to leprosy and the issues facing those afflicted by the disease. This newsletter was started in the belief that making more people aware of leprosy would assist the campaign to eliminate it as a public health problem.

In the ten years since our first issue in April 2003, much has happened.

We are now looking beyond the leprosy elimination campaign to ways of further reducing the burden of leprosy in the world. Addressing the human rights aspect of the disease has assumed increasing importance. A UN resolution adopted in 2010 was a historic development in this regard, but there is still much work to do.

The late Raoul Follereau would doubtless have found it bittersweet that the day he initiated is still being marked. But while there is still leprosy in the world, the day he created has become an important way of remembering that the job is not done. We salute Follereau's humanitarian legacy and pledge to complete what he started.

FOR THE ELIMINATION OF LEPROSY

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