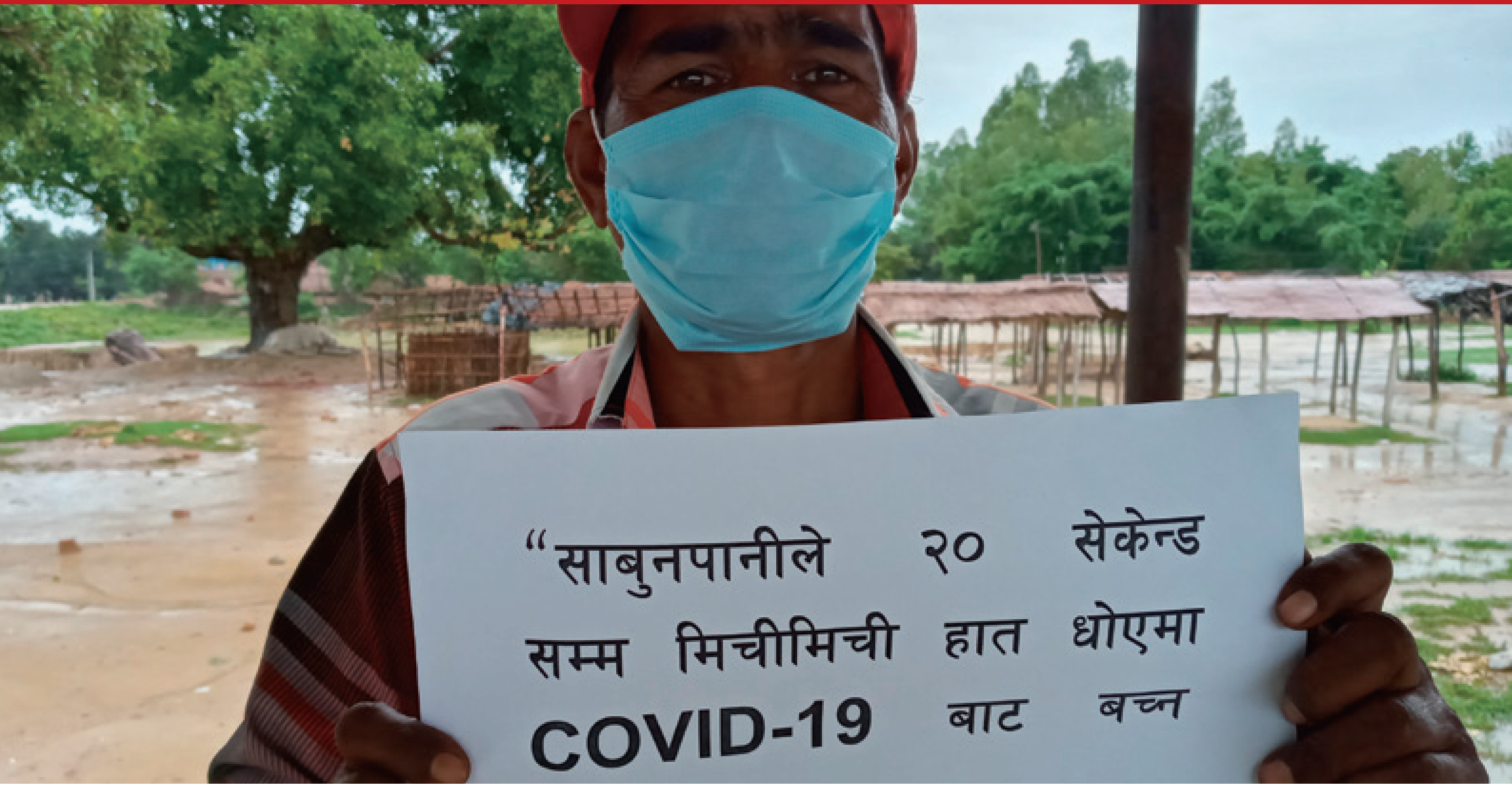
WHO GOODWILL AMBASSADOR'S NEWSLETTER

FOR THE Elimination OF Leprosy

Summer 2020 Edition

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



Kishori Nadav, facilitator of the Yagyabhumi Self-Help Group in Danusha district, Nepal, with advice to “protect yourself and others from COVID-19.”

MESSAGE

You Have My Support

In 2019, I made 27 trips abroad in various capacities. But this year, because of the COVID-19 pandemic, I have not had the opportunity to travel overseas as Goodwill Ambassador since my trip to India at the beginning of February to visit Delhi and Gujarat state. In the more than 40 years I have been fighting leprosy, this is the first time my activities have been brought to a standstill, and it is most regrettable. But I am optimistic that the day will soon come when I can fully resume my work to eliminate leprosy from the world. In the meantime, I know people at the frontlines are doing the best they can under the circumstances and I commend their efforts.

While many countries have had to suspend case-finding and other activities because of the measures they have taken against the novel coronavirus, that doesn't change the fact that many persons affected by leprosy and their family members remain socially vulnerable. Many belong to the poorest stratum of society and have been severely impacted by the pandemic, including loss of livelihoods. Governments have taken some steps to assist them, and I would ask that they consider doing more.

I think it is important too that persons affected by leprosy take the initiative to help themselves. I look back on the efforts of the Association of Persons Affected by Leprosy (APAL) in India, an organization formed from those living in the country's 750 self-settled colonies. In recent years, it has been successful in several states in obtaining special allowances for persons affected by leprosy following approaches to state premiers and health ministers. Based on my experience of contributing in a small way APAL's establishment and assisting in its advocacy for the special allowances, I support the growing efforts of people's organizations around the world to find solutions to their problems through their own actions, rather than just being recipients of assistance, and I am encouraged by the examples I see.

In the meantime, I stand ready to assist persons affected by leprosy to the extent that I can. Even from Japan, there are things I can do, so please don't forget to count on me.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Helping People to Help Themselves

COVID-19 response projects aim to assist and empower persons affected by leprosy.

The COVID-19 pandemic and measures to prevent the spread of the novel coronavirus are having a disproportionate impact on the most vulnerable members of society, among them persons affected by leprosy and their families.

Initiatives are taking place around the world to help communities of persons affected to stay safe, receive daily necessities and have access to needed healthcare.

Among these, Sasakawa Health Foundation (SHF) has been funding projects in Indonesia, Nepal and Bangladesh to provide comprehensive support through a three-pronged approach in which organizations of persons affected play a key role, supported by a trusted partner on the ground.

Before launching the projects, SHF liaised with key stakeholders including the Global Partnership for Zero Leprosy (GPZL), the International Federation of Anti-Leprosy Associations (ILEP), organizations of persons affected by leprosy, the UN Special Rapporteur on leprosy and regular recipients of SHF funding to assess the situation in each country.

> SHF concluded that “ownership” of projects by people’s organizations should be part of the equation.

What these preliminary investigations found was that communities of persons affected are facing many challenges, including loss of livelihoods, curtailed access to health services, and the risk of further stigmatization because of COVID-19.

In keeping with its commitment to the empowerment of people’s organizations, SHF concluded that support should go beyond the provision of supplies and that participation in and “ownership” of the projects by persons affected should be part of the equation.

This resulted in an approach consisting of: 1) responding to the direct needs of the community through providing food, medicine and other relief supplies, and offering guidance on COVID-19 as well as information on self-care for leprosy; 2) advocacy to ensure people have access to existing government schemes and to ask the authorities to consider additional measures; and 3) disseminating information to communicate details of activities and outcomes via SNS and use this information to help raise funds via crowdfunding.

Projects were chosen based on the prevalence of COVID-19 in the area, while the people’s organizations were selected according to the following criteria: active membership, young members included among their leaders, experience relevant to the project (e.g. of distributing supplies to designated beneficiaries in a fair manner), and the existence of external support to assist with activities that may be difficult for them to handle, such as grant management and communicating in English with SHF.

The projects are in operation between the middle of May and the end of August, depending on the country.

INDONESIA

Indonesia has reported cases of COVID-19 in all 34 provinces. South Sulawesi, a leprosy-endemic province in the middle of the country, has seen a high number of novel coronavirus infections.

The project targeted 1,500 persons affected by leprosy in five districts: North Toraja, Jeneponto, Bulkumba, Makassar and Gowa. It is being carried out by the South Sulawesi branch of PerMaTa, an organization of persons affected by leprosy, with support from Yayasan Dare This Indonesia (DTI).

PerMaTa members in the districts received training from PerMaTa/DTI at the provincial level, before carrying out door-to-door visits to deliver leaflets on COVID-19, soap and masks, and dispense advice. Among the target population, 600 persons identified by the teams as being in the most difficult economic circumstances are receiving food purchased and distributed once a month.

Regular visits have been made to provincial district and village offices to share information on the status of persons affected by leprosy. Information on those who have not received government assistance is reported so that, for example, ID cards can be issued and they can be added to the list of beneficiaries.

Tough going: a team from PerMaTa climbs a steep and muddy road to reach out to people in need.

Handing out masks in Nepal to help prevent infection from COVID-19

When a suspected case of COVID-19 is found during house visits, the authorities are notified and cases are followed up to make sure that appropriate treatment and support are being given.

Rain, muddy roads and steep inclines have made this project a challenge at times, and not everyone can be reached because they have moved, died, or their address is unclear. In one instance, the team had to climb a mountain to reach a man who was too ashamed to live in his village because he had leprosy.

Visits were in most cases warmly welcomed; nearly all recipients have been grateful—even inviting the team in for food and drink. A few were unhappy because they didn't want to be identified as having had leprosy. In some cases, it became apparent that health workers—fearful for their own safety—had previously concealed a diagnosis of leprosy from a patient.

In addition to passing on information about COVID-19 and food aid, the visits have also led to the discovery of individuals in need of treatment for leprosy and its consequences—and team members have been able, amongst others, to assist in the process of helping children return to school after they were treated for the disease, and in obtaining national health insurance and medical treatment for impairments.

"We have been doing home visits before, but we didn't realize there are so many people affected by leprosy that need support," PerMaTa reports. "Although this was a COVID-19 project, we found more people facing hardship due to leprosy."

House visits about the coronavirus have provided PerMaTa with a chance to find out how people are coping with leprosy and its consequences.

"Of course, we were afraid of catching COVID-19, visiting so many homes, but we tried to stick to the safety protocols by PerMaTa/DTI as best as possible and thus felt safe."

"We think our visits really were useful. Most people were very happy about the attention and, in some cases, we were successful in getting them the help they needed…Hopefully, we can continue this kind of work in the future because there are so many other areas and districts."

NEPAL

Nepal implemented a nationwide lockdown of cities from March to mid-June, disrupting the lives of citizens. The lockdown had a particularly severe impact on persons affected by leprosy, an economically vulnerable group who also face stigma and discrimination. With the measures introduced against the coronavirus, they struggled to eat as their jobs as day-laborers dried up.

The Nepal Leprosy Trust operates a major leprosy services center in the Terai region bordering India and runs programs to promote the social and economic empowerment of persons affected by leprosy. Lalgadh Leprosy Hospital and Services Center (LLHSC) in Danusha district supports 112 self-help groups (SHGs), which have been divided into four large groups that have been registered as NGOs. For this project, the beneficiaries are members of the SHGs, who have also been called on to play an active role in planning, mobilization and implementation of the project.

SHG members have been delivering food packages and sanitation kits consisting of rice, beans, cooking oil, soap and masks to beneficiaries. They have also been providing information on how to take precautions against COVID-19. A ward chairman in one of the areas where the project has been taking place was very appreciative of the local SHG's intervention and donated 5,000 Nepal rupees (about US$40) to their efforts.

Nepal is currently in the midst of the rainy season and the Terai region where the pilot project is taking

Lepra Bangladesh and federations of persons affected by leprosy have been distributing food and relief supplies during the coronavirus pandemic: in July, 1,100 people benefited from food and cash assistance.

place has seen flooding. This has made deliveries difficult, but activities have not been interrupted and SHG members have continued to receive support.

As part of advocacy activities, rallies have been held and petitions have been handed to the authorities appealing for the provision of emergency relief supplies to persons affected by leprosy and also asking for free health insurance. One such petition was organized by Sita, the facilitator of the Bengadawor SHG in Danusha district. Impressed at her initiative, the local ward chairperson requested her to arrange relief support for 20 vulnerable families, "making her feel more valuable."

To spread awareness about COVID-19 prevention, radio jingles are streamed 32 times a day in the Nepali and Maithili languages.

Because of the terms of the project, relief packages could only be distributed to self-help members. This led to feelings of guilt on the part of some members, who felt there were others in the community who were more in need than they were. One of the lessons learned, therefore, was that future projects should build in additional support for others, as the situation is critical for everyone, not just members of SHGs.

BANGLADESH

Coronavirus infections have been escalating in Bangladesh, with many areas affected. For the emergency assistance project, four districts of Rajshahi division, a leprosy-endemic area in the west-central part of the country, were selected.

The beneficiaries were some 5,000 persons affected living in Bogura, Sirajgonj, Natore and Pabna districts. The project has been implemented by four community-based federations of self-help groups, once in each district, together with Lepra.

The project has utilized "Community Champions"—people who have been trained by Lepra to recognize signs of leprosy. Along with federation members, they have received orientation on COVID-19. In addition, groups of "Corona Fighters" have been formed.

Information leaflets on COVID-19 prepared by the government have been delivered to between 1,000 and 1,400 people per district, along with masks and disinfectant. These door-to-door visits also serve the purpose of data collection, enabling databases to be updated and beneficiaries of relief supplies to be confirmed.

> "We think we have an umbrella over our heads," said one grateful beneficiary.

Meetings have been held between district officials and representatives of people's organizations and these have created an opportunity to discuss community problems and needs. Officials from the Social Welfare Department have also been present and showed an interest in including more persons affected by leprosy with disabilities in the government's social safety net program. But they also requested that support be provided to more people and for a longer duration due to the impact of COVID-19 and flooding.

Further, while the project has been welcomed for the assistance provided to a vulnerable population, there has on occasion been political pressure to support others in the community, not just persons affected by leprosy.

Beneficiaries have been grateful. "We think we have an umbrella over our heads," one man said. Another recipient, as she contemplated the approach of the important Muslim celebration marking the end of the holy month of Ramadan, expressed her thanks thus: "The Eid festival will be much more special."

By enabling the federations of persons affected by leprosy to identify those in the community who are most in need and distribute relief supplies to them, the project motivated them to work hard and get the job done. "We have learned how to implement a project within a short period," one said. "We feel peace in our hearts." ■

Going Forward Together

Sasakawa-India Leprosy Foundation's new CEO is a strong believer in partnerships.

PROFILE
Dr. Vivek Lal is CEO of Sasakawa-India Leprosy Foundation (S-ILF). Prior to joining S-ILF in June 2020, he served as director of health for the German Leprosy & TB Relief Association in Kolkata.

You have joined amid a pandemic. How is S-ILF responding to COVID-19?
S-ILF has been able to promptly respond to the initial phases of the pandemic through ensuring basic supplies of food and hygiene products to leprosy colonies. Through our strong relations with the Association of People Affected by Leprosy (APAL), committed staff and generous donors, we have been able to reach more than 6,000 households. These are unprecedented times. We are wary that they threaten to further neglect colony residents and we plan to undertake a rapid survey with APAL to understand how COVID-19 has impacted their livelihood, health and the education of their children. This knowledge will enable us to respond better through reprogramming of our support and advocacy.

As the new CEO, what do you see as S-ILF's priorities?
Medical and social responses in leprosy are intertwined—one without the other would render our efforts futile. This is brought out through the analogy of the two wheels of a motorcycle as described by Mr. Sasakawa. Enabling resilience through sustainable livelihood approaches, building capacities through skilling and continued educational opportunities will be our priorities. People affected by leprosy and their families deserve equal opportunities in an inclusive world.

What lessons or experiences from your career to date will you be drawing on in your role?
The success of public health programs is determined through the active participation and ownership of the beneficiaries. It is vital, therefore, to remain connected to the beneficiaries and build in flexibility in our approaches. I am a strong believer in partnerships and that public health goals cannot be achieved in isolation. S-ILF can help play a complementary role to the efforts of government and other organizations working in the field of leprosy, and as CEO I have a sense of urgency to seek these relationships.

From your perspective, what are the main challenges India faces regarding leprosy?
India holds the key to globally alter the face of leprosy, and thus our greater responsibility. At a community level, myths and stigma regarding leprosy are still rife. Much of the success in the leprosy program is born out of timely detection of cases; demystifying the disease for the general community is therefore of paramount importance. Keeping expertise in leprosy alive through the involvement of the next generation is vital and programming in leprosy must be holistic, addressing both medical and social aspects of concern to the affected person. The latter could be achieved through continued active engagements with persons affected by leprosy. At the advocacy level, we need to underscore that the disease still occurs—that elimination as a public health problem must not be misconstrued as eradication of the disease.

COVID-19 relief supplies organized by S-ILF being distributed at Santigram Leprosy Colony, Bolangir, Odisha.

S-ILF works closely with APAL. How important is that relationship?
APAL is the representation of the needs and aspirations of persons affected by leprosy. S-ILF's work is a response, ultimately aimed at restoring dignity in their lives. To me, this relationship is as intricate and integral as one of a sense organ and the brain—one beautifully complementing the other!

If somebody asks why leprosy matters, how do you respond?
It matters because even 150 years after its discovery as an infectious disease, leprosy remains elusive; there are still more than 200,000 new cases detected worldwide every year. It is one of those very rare diseases wherein for the optimal 'treatment,' the community's response and a medical cure are equally important—a community without stigma and discrimination must go hand in hand with multidrug therapy. Until we find solutions to the problems that persons affected by leprosy face, including the stigma and discrimination that have no place in an advanced, humane society, our pursuit of universal health coverage and the goal of 'no one left behind' will go unfulfilled.

Are you an optimist, a pessimist or a realist?
Definitely not a pessimist. Whilst being a realist allows me to look for solutions to deal with existing problems and challenges, it is the optimist in me that drives my work. In this pandemic, our efforts will need to be magnified several-fold. Only through great passion fueled by a strong sense of optimism can we realize our goals. ■

Lessons from Brazil

Thoughts on “elimination” in leprosy and some of its ironic consequences.

For much of the past decade, I have been researching the scientific, political and social aspects of Hansen’s disease in Brazil, culminating in a Ph.D. in social anthropology for which I focused on the historical and present-day entanglements between the treatment of Hansen’s disease and global efforts to eliminate the disease as a public health problem.

Drawing on literature from science and technology studies and based on multi-sited ethnographic fieldwork in Brazil, I investigated the historical roots and long-term impact of both multidrug therapy (MDT) and elimination campaigns—what I describe as a ‘bacillus-centered approach’ to Hansen’s disease.

In my dissertation, published in 2019, I examined the infrastructure and services of some ex-colonies transformed into hospitals specialized in Hansen’s disease in Brazil; traced the recent history of the recognition of Hansen’s disease as a human rights issue and the central role of Brazilian activists in shaping political agendas; and analyzed still ongoing ‘old’ scientific debates regarding different aspects of Hansen’s disease and its pathological agent and how through time these debates shaped governmental interventions.

> My ultimate aim was to explore the impact of the bacillus-driven approach against Hansen’s disease.

I also reflected on some people’s lack of confidence in well-publicized campaigns about the disease’s curability, given that many return to hospital due to ‘leprosy reactions’ even years after finishing MDT.

Lastly, I tracked how the advent of MDT, together with efforts for elimination, directed the focus toward infection control, diminishing the attention given to ensuring the long-term care of patients facing reactions and permanent disability after finishing treatment.

ONGOING CARE

By exploring these specific topics, my study’s ultimate aim was to look at the impact of the deep-rooted bacillus-driven approach against Hansen’s disease.

Although MDT is highly effective in controlling the mycobacterial infection, it does not necessarily terminate the disease (as many patients might need specialized and urgent care for a longer period). However, the concept of elimination (based on prevalence rates) is closely associated with the patients’ completion of MDT. In short, the so-called “Hansen’s disease-free world” is populated by thousands of subjects fighting this disease daily.

During my fieldwork and interviews with patients, ex-patients, family members, activists, health professionals, hospital directors, scientists and policymakers, it became clear that, due to the link with how elimination has been measured, the focus on MDT treatment has created an ironic situation.

Although the elimination campaigns of past decades have mobilized people and resources, they may also have contributed to glossing over ongoing scientific uncertainties regarding the disease as well as the need of numerous patients for continuing care after the completion of treatment.

How do we get the government to invest in fresh research projects, campaigns of active surveillance, new public policies, and relevant infrastructures if it is taken for granted that Hansen’s disease is about to be eliminated? How does the announcement of the disease’s global elimination impact the lives of those patients suffering from leprosy reactions and related disabilities?

“LUCKY”?

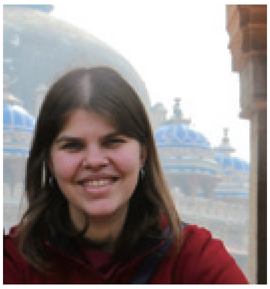
Although mine is not the first academic study to address the political effects of the elimination campaigns, it does offer an original glimpse into their impact on local infrastructures and services.

As one Brazilian activist suggested during our interview, the local community leaders and health professionals in Brazil are somehow “lucky” to work in a country that has not reached the elimination target, since the situation allows them to affirm out loud that Hansen’s disease is still a public health problem. Nonetheless, when all is said and done, convincing local policymakers and health planners that dealing with the problem requires much more than just the efficient distribution of MDT is not an easy task.

My research suggests that it might be time to change the global approach and announce that Hansen’s disease is not only a public health problem in Brazil, but it is still a current global issue that requires considerable public attention, new research funds, political commitments on all levels, and the continuous encouragement of organizations made up of those most affected—the patients and their families.

We may conclude that it is necessary to join forces to eliminate the general perception that Hansen’s disease no longer exists or is about to disappear. ■

Health poster: “Hansen’s disease: The sooner you find out, the sooner you will be cured.”



AUTHOR:
Glaucia Maricato
Glaucia Maricato holds a PhD in Social Anthropology from the Federal University of Rio Grande do Sul (UFRGS/Brazil) and is currently a Postdoctoral Fellow at the Institute of Social and Cultural Anthropology at Free University Berlin (FUB/Germany).

A Story Both Tragic and Uplifting

A family secret inspires a book on leprosy, stigma and the fight for justice.

AUTHOR:
Pam Fessler
National Public Radio correspondent Pam Fessler is the author of *Carville's Cure: Leprosy, Stigma, and the Fight for Justice.*

Photo: Allison Shelley/NPR

My father-in-law called my husband and I one night and said he had something to tell us, a secret he had kept for 63 years. When he came home from school one day in 1935 in New York City, his father was gone. He never saw or spoke to his father again and was not even sure—these many years later—where he had gone. He believed health officials had taken him to a "military hospital" somewhere in the southern U.S.

He did know one thing for sure—his father had leprosy. But his mother had told him never to tell anyone else because, if word got out, it would destroy the family. My father-in-law spent the rest of his life burdened by both the sorrow of losing his father and a nagging sense of shame.

> They lost not only their freedom, but their civil rights and identities.

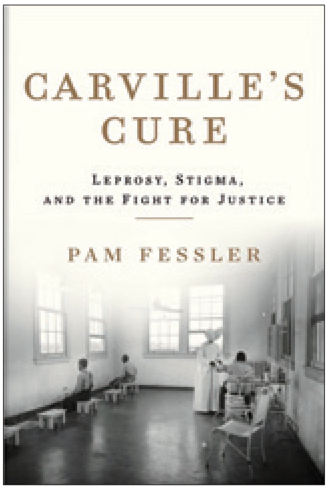
This was my introduction to a tragic slice of American history, and an experience repeated over the centuries and around the world. For almost 80 years, the U.S. government ran a leprosy hospital in the remote community of Carville, Louisiana. Thousands of Americans—including my father-in-law's father—were sent there to be treated, but also to be isolated from family and friends for the rest of their lives. They lost not only their freedom, but their civil rights and identities. Almost all the patients took aliases to protect their families from the stigma.

A PRISON AND A HAVEN

For some, Carville was a prison. But it was also a haven from a world that treated those with leprosy as the ultimate pariahs. Confined to the 350-acre site, many patients carved out meaningful lives. They formed deep friendships, fell in love, held Mardi Gras parades and published a crusading newspaper that become a leading advocate for people with Hansen's disease. Driven in part by the patients' determination, doctors at Carville discovered the medical treatment that would ultimately become the cure for millions.

The story of Carville is both tragic and uplifting—a tale of human resilience in the face of ignorance, cruelty and misguided government bureaucracy. I have wanted to tell that story ever since we brought my father-in-law to Louisiana to see where his father had died.

Even then, in 1998, Carville was home to those who had been cured of leprosy but had nowhere else to go. The National Hansen's Disease Program has since moved its operations to out-patient facilities across the country, so those who now contract the disease can be started on treatment and sent home.



A tale of human resilience

Still, the stigma lives on. Victims of leprosy are scorned and discriminated against in many parts of the world today. Anti-immigrant advocates in the U.S. have spread unfounded fears that those crossing the border will spread the disease. The pejorative "leper" is still used to mean someone who is to be avoided and despised.

WHAT CARVILLE TEACHES

There are many lessons to learn from Carville, including how people can respond to ignorance and fear in irrational ways. The leprosy hospital was started by those who believed that isolating patients was the best way to contain the disease. But it ended up doing more harm than good, discouraging people from seeking medical care and destroying countless lives in the process.

As the world deals with the current coronavirus pandemic—albeit a much more contagious and dangerous disease—it's sobering to see how little some things have changed. The demonization of Chinese Americans today is not much different than in the late 1800s, when "almond-eyed lepers" were blamed for spreading leprosy. Questions about the efficacy of quarantines and isolation persist. Despite sweeping scientific advances, we realize there's a lot we don't know. And these gaps in knowledge can lead to widespread and dangerous misinformation.

But amid the current crisis, as in past struggles with disease, there are bursts of kindness and humanity—doctors and nurses who devote countless hours to others, scientists who persist in their search for a cure, and those who turn tragedy into a chance to help fellow humans in a time of need. ■

Carville's Cure: Leprosy, Stigma, and the Fight for Justice was released July 14, 2020 by Liveright Publishing. For more information: https://wwnorton.com/books/9781631495038

Special Rapporteur's Term Extended

Persons affected by leprosy will continue to have a voice at Human Rights Council.

The UN Human Rights Council (HRC) has extended the mandate of the Special Rapporteur on leprosy for a further three years.

Alice Cruz is in the final year of her initial three-year term, and the decision by the HRC at its 44th session in July will see her continue as Special Rapporteur through 2023.

A resolution submitted by Japan on behalf of a core group of countries consisting also of Brazil, Ecuador, Ethiopia, Fiji, India, Morocco and Portugal, and supported by 45 co-sponsors, was adopted by consensus on the final day.

During the session, Cruz presented three reports—two on country visits to Brazil and Japan that took place earlier this year, and a thematic report outlining a rights-based plan for fully implementing the Principles and Guidelines accompanying the UN 2010 General Assembly resolution on elimination of discrimination against persons affected by leprosy and their family members.

During testimony she delivered online from her home in Ecuador because of the coronavirus pandemic, Cruz expressed her "great regret" at the difficulties she had in gaining cooperation from states for country visits. "Nine out of 10 countries to which I requested a country visit did not invite me; two states which are top-priority countries for leprosy accepted the request but did not confirm dates despite several reminders."

On the plus side, she noted that her mandate had succeeded in mainstreaming the elimination of leprosy-related discrimination into the work of United Nations Human Rights mechanisms including the Treaty Bodies, universal periodic review and other special procedures, and that she had witnessed how the mandate had had an empowering effect on many persons affected by leprosy and their families.

Commenting on the HRC's decision to extend her term, she told the *Goodwill Ambassador's Newsletter* that it was "a result of the participation of persons affected by Hansen's disease in the work of my mandate during the first two and a half years. It is also a result of the cooperation between the main stakeholders in the field. Our joint work has sensitized the UN Member States to the vital importance of addressing Hansen's disease issues from a human rights perspective."

Cruz, who serves in an honorary capacity and is not paid for her work, said: "I feel encouraged, but I also feel the added weight of responsibility. Our expectations can now be more substantial and so my own work needs to live up to such expectations. I expect a lot of hard work in the next three years, which I will undertake with a great sense of personal honor for serving our community and for which I hope to continue to receive the key support from the Hansen's disease community."

She said her main priority will be to engage with relevant UN member states in supporting them to develop and implement a human rights approach to Hansen's disease in their respective countries with the meaningful participation of the national organizations of persons affected by Hansen's disease.

"I also aim at consolidating the mainstreaming of Hansen's disease within the overall human rights system and I am targeting the inclusion of Hansen's disease in one general recommendation of a relevant Treaty Body, in order to ensure that legally binding jurisprudence is elaborated and put in place."

Cruz: "I feel encouraged, but I also feel the added weight of responsibility."

INFO HANSEN DEBUTS

Launched this month, Informa Hanseniase (Info Hansen) is a new initiative out of Brazil to spread knowledge about Hansen's disease targeting academics, researchers, healthcare professionals, persons affected by the disease, as well as the general public.

Featuring a website, blog and YouTube channel, Info Hansen will feature scientific articles, opinion pieces, interviews, photo essays, virtual exhibitions and news of upcoming events.

Coordinating the project is Patricia Deps, a professor in the department of social medicine at the Federal University of Espirito Santo Vitoria in Brazil. "This is an educational project," she says, but also "a space for sharing new ideas."

Deps and a team consisting of academics from Brazil and overseas, as well as medical students from her university in southeastern Brazil, are producing, editing and translating content, which will be available wherever possible in Portuguese, Spanish, English and French.

They aim to show what is being done in Brazil and elsewhere to promote a better quality of life for persons affected by Hansen's disease and to achieve a future without the disease.

The first edition of Info Hansen appeared on August 10 on the theme of combatting stigma. ■

www.infohansen.org

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Publisher
Yohei Sasakawa
Executive Editor
Takahiro Nanri
Editor
Jonathan Lloyd-Owen
Layout
Ryo Mogi
Photographer
Natsuko Tominaga
Editorial Office
5th Floor, Nippon Foundation Building,
1-2-2 Akasaka, Minato-ku,
Tokyo 107-8404
Tel: +81-3-6229-5377
Fax: +81-3-6229-5388
shf_hd_pr@shf.or.jp
With support from:
Sasakawa Health Foundation,
The Nippon Foundation
www.nippon-foundation.or.jp/en/
www.shf.or.jp/e/