

LEPROSY BULLETIN

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Persons affected by leprosy as partners in change

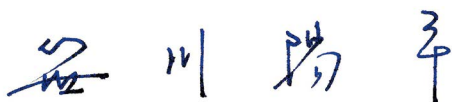
Message from the ambassador

Last month, Nov. 19–23, I visited India, where more new cases of leprosy are detected per year than anywhere else in the world. In the years that I have worked for the elimination of leprosy, I have visited India more than 60 times and traveled to nearly every state, urging approaches that address both the medical and social aspects of the disease.

During this visit, I stayed in New Delhi, where I met with the Minister of Health and Family Welfare as well as the WHO Regional Director for the South-East Asia Region. I also had the moving experience of participating in the 10th anniversary ceremony of the Dalai Lama–Sasakawa Education Scholarship. The scholarship began as a matching fund in 2014 when the 14th Dalai Lama and I visited one of India's approximately 750 leprosy colonies together. His Holiness thought of using his own book royalties to support young people living in the colonies to pursue higher education. The Nippon Foundation matched the contribution, and the Sasakawa-India Leprosy Foundation (S-ILF) joined as an administrative partner.

During the event, I heard from past scholarship recipients who found stable employment after graduating, and some of them told me that they have moved with their families out of the colonies into nearby towns.

Although I felt heartened by the success stories, I also thought about those who still lack opportunity. I want the scholarship program to continue so that more young people in the colonies can pursue higher education and the social integration that it facilitates. A schedule change prevented me from traveling to Dharamsala this time, but I hope to make the trip soon to talk with the Dalai Lama in person about the program's results so far and my ideas for its future.



Yohei Sasakawa

WHO Goodwill Ambassador for Leprosy Elimination

Contributing to this issue:

José Ramirez, Jr.
Chair of Board of Directors, IDEA

Luzia Alves
Facilitator, MORHAN Piauí

Ashwini Nannaware
Member Leader, SKSS

LEPROSY IS CURABLE. MEDICATION IS FREE. STOP DISCRIMINATION NOW.

50th Anniversary of WHO–TNF/SHF Partnership



José Ramirez, Jr.
Chair of Board of Directors
International Association for Integration, Dignity and Economic Advancement (IDEA)

José Ramirez, Jr., advocates internationally for persons affected by Hansen's disease and works as a clinical social worker in Houston, Texas, USA. He joined IDEA in 1995, and he has been the chair of the board of directors since 2017.

<https://www.ideaadvocates.org/>

With support, I embarked on a journey to reverse stigma and became an advocate

My introduction to Hansen's disease happened when I was diagnosed with the illness in Laredo, Texas, in 1968 after many years of unexplained pain, blisters, and fevers. My diagnosis resulted in three traumatic events for me. The first was with my parents sobbing and asking me for forgiveness as they believed that God was punishing them for their sins via my stigmatizing illness. I was unable to console them on their pain as leprosy creates horrific negative images and is oftentimes linked to sins referenced in the Bible. The second was seeing my 19-year-old girlfriend forced to face the dilemma of whether to stay with me or abandon our relationship. The third was the immediate separation from all I knew. I was sent 750 miles (1,207 kilometers) away from my parents and 12 siblings to a national leprosy hospital in Carville, Louisiana, where I ended up staying for seven years. These events allowed me to realize that it is not only those of us affected by Hansen's disease who experience unfathomable pain and sorrow, but also those around us.

My lengthy stay at the hospital in Carville pushed me into a world of stigma. Although Carville is thought of as a "national" leprosy hospital, the 400+ patients came from 25 different countries. We all had stories of being separated in some way: from a relationship, from a spouse, from children, from extended family, from jobs, from dreams, from a future. My peers at the hospital, who shared my experience of institutionalization, urged me to not allow painful experiences to fester in my mind and spoil my goals for eventual cure and discharge. They inspired me to not lose faith in speaking my mind on things that were wrong. The hospital social worker also inspired me to seek comfort in my fate as an advocate, opening doors for me to continue my college education, obtain a Master's degree, and eventually become a licensed clinical social worker in Houston, Texas.

Becoming an advocate did not occur overnight as I struggled with the centuries-old stigma associated with Hansen's disease, also known as leprosy. I had seen how laws and practices isolated persons with the disease, resulting in bitterness, lost opportunities, divorce, substance abuse, lost jobs, physical disabilities, mental anguish, and stress in

one's life. I searched for answers and finally chose to embark on a journey to reverse stigma, which I define as "an act of labeling, rejection, or unexplained fear of a person."

In 1995, I became the editor of *The Star*, a magazine started by Carville resident Stanley Stein for "radiating the light of truth on Hansen's disease." That same year, I joined the International Association for Integration, Dignity and Economic Advancement (IDEA), the first international association of persons affected by Hansen's disease. My activities earned me an invitation to attend a symposium in Japan. With this invitation to travel outside the United States, I took my first step into the world of advocacy. I received the invitation from Yohei Sasakawa, who I knew as an international advocate for persons who have experienced Hansen's disease, and The Nippon Foundation, the organization of which he was president at the time. Also invited were Dr. Gopal, a brother from India who, like me, had experienced the disease and also had training in social work, and a physician from Vietnam who had treated many persons with the disease.

We were invited for two reasons. First, the organizers wanted to introduce us to the changes occurring in Japan after the repeal of the Leprosy Prevention Law. The law had mandated segregation for life in one of 13 sanitariums for persons diagnosed with the disease. The second reason was to introduce those institutionalized in Japan to advocacy as it was being carried out by others around the world with similar experiences of physical, emotional, and spiritual pain simply due to being carriers of Hansen's bacilli.

I met Mr. Sasakawa again the following year. The Nippon Foundation was instrumental in helping IDEA develop and implement an exhibit titled "Quest for Dignity." The exhibit was held in October 1997 at United Nations Headquarters in New York City, with Secretary General Kofi Annan formally opening the event. A dinner was held in the evening and Mr. Sasakawa asked me to serve as Master of Ceremonies. Persons affected by Hansen's disease from 25 countries were awarded "Fighting Spirit" medals, which were inspired by a

top prize in sumo given to wrestlers who have demonstrated courage and persistence. Portions of the exhibit were later shown in seven different countries.

Significant events strengthening advocacy and expanding education about the pain caused via stigma have been the brainchild of IDEA, but these could not have occurred without the unconditional support of Mr. Sasakawa. With the backing of The Nippon Foundation and the Sasakawa Health Foundation, he has given life to numerous projects never seen prior to the birth of IDEA. These projects include

- presentations by IDEA members to the United Nations Human Rights Commission;
- participation and presentations at multiple International Leprosy Congresses;
- creation of IDEA chapters in 20 different countries;
- empowerment workshops for women who have experienced the disease;
- oral history projects for gathering first-person testimonies;
- identifying Hansen’s-disease-related contributions from poets, artists, and other people who have engaged in self-expression;
- meetings to formally address the roles and responsibilities of persons experiencing Hansen’s disease to build capacity and foster empowerment and advocacy;
- a two-day workshop on “Holistic Care” at Vatican City and a summary of presentations shared with Pope Francis; and
- global, monthly peer-to-peer knowledge learning series via Zoom called “The Gathering.”

Hansen’s disease has scarred my soul with memories linked to stigma. However, my many blessings have been illuminated by support from my family, wife, children, brothers and sisters with the disease, the hospital social worker, and Mr. Sasakawa.



José Ramirez, Jr., and his wife, Magdalena, attend a leprosy heritage meeting in 2012 along with fellow persons affected by Hansen’s disease and their family members from Japan, Brazil, Colombia, and Taiwan.



Yohei Sasakawa, Chairman of The Nippon Foundation and the WHO Goodwill Ambassador for Leprosy Elimination, stands with José Ramirez, Jr., and his family members during a visit in May 2018.



José Ramirez, Jr. (seated fifth from left) attends a WHO meeting on “Developing Guidelines for Strengthening Participation of Persons Affected by Leprosy in Leprosy Services” in Manila, Philippines, in 2010.



Along with human rights advocate and former Kalaupapa resident Bernard K. Punikai’a, José Ramirez, Jr., participates in a workshop on “The Last Leprosy Hospitals and the People Who Call Them Home” in Fontilles, Spain, in 1997.

NEXT GENERATION



Luzia Alves
Facilitator, MORHAN Piauí

MORHAN Piauí launched a project in 2024 for documenting institutional discrimination experienced by persons affected by Hansen's disease in Teresina, the capital city of Piauí, Brazil. Luzia Alves joined the project as a facilitator for conversation circles.

<https://www.instagram.com/morhanpiaui>

An opportunity to strengthen myself as a person affected by Hansen's disease and as a woman

My name is Luzia Alves. I am 35 years old, married, and a mother. I live in Teresina, the capital of the state of Piauí, Brazil. I am also a woman who has been cured of Hansen's disease. This is my story.

At the end of 2018, I began to feel changes in my body. My skin itched endlessly, especially at night. Soaps and moisturizers aggravated the condition. What worried me most was the change in the color of my skin. I went to see a general practitioner, and he gave me some tests, but he was not able to make a diagnosis. He referred me to a dermatologist.

The dermatologist looked at all my tests, and asked to see my body. There were no spots, and my skin was clean. I told her about the unbearable itchiness and the irritation from soaps and moisturizers. I also explained that I would end up scratching, and then I would get little bumps. She confirmed Hansen's disease based on a skin biopsy. When I heard the diagnosis, I temporarily left this world. What do you mean? How did I catch it? All I could think about was my son, my family, and whether I had passed it on to them.

The very polite, very helpful doctor talked to me, calmed me down, and went on to explain the treatment to me. I was told to go on living my life as normal because there was treatment and I would be cured. I was also told that I shouldn't sunbathe or drink alcohol during the treatment. I was not told anything about possible reactions.

My treatment took one year, starting from January 2019. I tried to live my life as normal, as the doctor said, but it wasn't easy. I felt fine until the third dosage of medication, when my strength decreased to the point that Brazil's social security agency, the INSS, authorized three months' leave from my job in the beauty sector. I dealt with the reactions and carried on. After that, I just had a small color change in my skin because of the medications. I completed my treatment in January 2020, and I was told that I was cured. Thank God!

But later that year my skin blistered all over with swollen lesions that looked like they were going to catch on fire, and I couldn't walk. I asked for help at the hospital, but at

the time I was also suffering from COVID-19 and the doctor who saw me said she couldn't do anything for me because she did not understand what was happening. I went back to the dermatologist, and she explained that I was having Hansen's disease reactions. She referred me to Centro Maria Imaculada (CMI), a public medical center for the disease in the city of Teresina.

At CMI, I was immediately welcomed, touched, and examined. I started taking medication for the reactions and I felt God's hands touch me and calm me down. While doing physiotherapy, I found out about the Movement for the Reintegration of Persons Affected by Hansen's Disease (MORHAN).

Connecting with MORHAN changed my life. Listening to members' stories helped me to feel newly grateful for my family. They have been by my side since the beginning of my treatment, giving me support and never showing prejudice, only caring. I've also been able to start changing how I feel about myself. Until I started sharing my own story through MORHAN, only God and I had known how ashamed I was to talk about having had this health problem and my skin having become blemished.

About a year ago, I met Dr. Alice Cruz, who advises the Sasakawa Health Foundation on human rights issues, and Faustino Pinto, MORHAN's national coordinator. They were organizing a project for documenting instances of institutional and intersectional discrimination, and Alice emphasized the importance of a young woman taking part. I was invited to join the project team as a facilitator for the rounds of conversations with persons affected by Hansen's disease.

From the conversations, I have learned that some people have stories like mine, and others have suffered more. I try to help others by talking about my experiences, even when strong feelings come up because all of this is recent for me, too. This project has given me the opportunity to strengthen myself as a person affected by Hansen's disease and as a woman. It is a learning experience that I wish I'd had from the start.

NEXT GENERATION



Ashwini Nannaware
Member Leader
Saksham Kushthanteya Swabhimani Sanstha (SKSS)

In Marathi – the official language of the state of Maharashtra, India – “Saksham Kushthanteya Swabhimani Sanstha” means “Pride Organization of Empowered Persons Affected by Leprosy.” Ashwini Nannaware is one of four members of SKSS who lead small teams of field investigators as part of a research and advocacy project.

Taking on the responsibility of being a leader has changed me

I am Ashwini Pundalik Nannaware from Mohali Naleshwar village, Sindewahi block, Chandrapur district, Maharashtra state, India. I studied up to pre-degree (12 years of school) in arts, and I have a family of four: my husband, a son, a daughter, and myself.

I was diagnosed with leprosy in 2019 at the Leprosy Referral Centre (LRC) in Sindewahi. I had a numb patch on my hand. At that time, I was working as a community counselor for the Leprosy Elimination Action Program–Human Rights Based Approach (LEAP-HRBA) project organized by the Association for Leprosy Education Rehabilitation and Treatment–India (ALERT-India). My mother had leprosy and a disability due to delay in diagnosis, but it never crossed my mind that I might contract leprosy from contact with her or with those I met through the project. I was fully aware of the cause of leprosy and how it occurs.

In 2019, the year that I was diagnosed, SKSS was in the process of being set up. The concept of having an organization for Kushthanteya¹ living outside of leprosy colonies had emerged during a LEAP-HRBA project implemented by ALERT-India and the Association of Women Awareness and Rural Development (AWARD) in 2016-17. Two years later, on May 24, 2019, Kushthanteya from Gadchiroli and Chandrapur districts co-founded SKSS, and the organization received its official registration on Dec. 5, 2019. I joined immediately as a lifetime member. I had been helping Kushthanteya as a community counselor. From this point forward, I would work alongside them as a peer.

In 2022, SKSS carried out a project with financial support from the Sasakawa Health Foundation (SHF) and technical support from ALERT-India to collect data on the impact of leprosy and COVID-19 on the lives of persons living in tribal/rural communities in Chandrapur and Gadchiroli districts. While collecting the data through interviews, we discovered that Kushthanteya are afraid to talk about their marital and family issues. This discovery led to the development of an additional project for learning about how discrimination affects their experiences of marriage and family relations.

The project launched this year, in 2024, again with the support of SHF and ALERT-India. This time, I was one of a few SKSS members selected to be a “leader.”

As a leader, I was involved in the 2024 project from the beginning. I participated in many stages of the process, including project planning, questionnaire preparation, workshops on tool development, trainer and field investigator training, and road map preparation. I felt a positive change in myself from each activity. Although I had participated in such types of activities before, this time I was able to learn more. My growth benefited SKSS, and I noticed that I was benefitting personally as well. I became totally free from fear psychosis.

I was given the responsibility to go to remote tribal parts in districts like Nandurbar and Gadchiroli and train field investigators. I faced many difficulties in following through on this responsibility. For example, in Nandurbar, the Kushthanteya that I needed to train speak 12 dialects and all of them were participating in this type of project for the first time.

I had a little less difficulty in Gadchiroli because I know the dialect and I am familiar with the living conditions of that area. But even with that knowledge, I still had to learn how to create environments that put others at ease. I discovered that I tend to laugh in places where I was not supposed to and that my laughing was sending the wrong message to others. Through this project, I corrected this habit.

Within Gadchiroli, I also had the opportunity to visit Desaiganj (Wadsa) for the first time. Even though it is in the same district as my home village, it is far away, and there were many difficulties in mobility. But I accepted the challenge, and in the end I successfully overcame the difficulties.

The research and advocacy project confirmed that Kushthanteya have many problems. But until one understands and becomes aware of one’s own problems, one cannot plan solutions for them. Kushthanteya need to embrace things like participating in various processes and using new technologies. Once we understand the problems, we must raise our own voices and advocate through organizations.

¹ “Kushthanteya” is the Marathi term for “persons affected by leprosy.” It has been used throughout this article at the author’s request.

VIEWPOINT



Dr. Venkata Ranganadha Rao Pemmaraju
Program Advisor for Medical Issues
Sasakawa Health Foundation

As an epidemiologist and Acting Team Leader of WHO's Global Leprosy Programme, Dr. Pemmaraju contributed to the development of effective global strategies for elimination of leprosy. He joined the Sasakawa Health Foundation as a program advisor for medical issues in July 2023.

Immune-mediated leprosy reactions before, during, and after multidrug therapy (MDT)

Leprosy, also known as Hansen disease, is a chronic infectious disease caused by *Mycobacterium leprae* (*M. leprae*) or, less commonly, *Mycobacterium lepromatosis*. Multidrug therapy (MDT) is the recommended treatment for the disease. At any time following infection – before, during, or after MDT treatment – an immune response can cause acute inflammation that affects the skin, nerves, and other organs of the body. When left untreated or improperly managed, these immune responses, known medically as “immune-mediated leprosy reactions,” can result in disabilities, serious complications, or even death.

There are two main types of immune-mediated leprosy reactions: Type 1 (reversal reaction) and Type 2 (*erythema nodosum leprosum*, ENL).

Type 1 (reversal reaction)

A Type 1 reaction is caused by hypersensitive reaction to the *M. leprae* antigen, and it is characterized by acute inflammation of skin lesions. Enlargement of cutaneous and peripheral nerves causes pain and tenderness as well as loss of function. When treatment is not provided promptly, the nerve impairment results in sensory loss and muscle weakness in the eyes, hands, and feet, and further disabilities may develop as well.

Type 2 (*erythema nodosum leprosum*, ENL)

A Type 2 reaction involves the deposition of immune complexes in tissues by *M. leprae* antigens and the patient's antibodies. The complexes appear mainly under the skin, often as painful nodules. In some patients, this reaction becomes chronic and recurrent. Nerves and eyes can be involved, and without prompt and effective management, a Type 2 reaction can lead to disabilities.

Neuritis

While Type 1 and Type 2 reactions produce obvious symptoms, inflammation of the peripheral nerve system

called “neuritis” can sometimes be “silent.” The absence of warning signs such as pain or tenderness reduces the probability of prompt diagnosis and therefore increases likelihood of progression to disabilities.

Treatment and support

Treatment regimens for reactions and neuritis consist mainly of prednisolone, a steroid for lowering the body's inflammatory response. For chronic and recurrent Type 2 reactions, other anti-inflammatory drugs like clofazimine and thalidomide are recommended.¹ In addition to medicines, WHO recommends periodical nerve function assessment as well as physiotherapy and psychological aid.

Adverse reactions to the drugs used in treatment of immune-mediated leprosy reactions continue to be a challenge. Many studies have reported serious adverse drug reactions to prolonged use of steroids, and data from different countries indicates that a proportion of patients have developed steroid dependency. There have been reports of comorbidities, such as diabetes, as well as a very small number of deaths.

From the perspective of persons affected by leprosy, these reactions, especially when they recur, can cause a feeling of hopelessness. Family members and other primary care givers may feel anxious and overwhelmed, especially if they have not been told about reactions and how to respond. Obscure referral and follow-up processes can delay access to services.

Management of reactions, neuritis, and disabilities are a key part of WHO's Global Leprosy Strategy.² National health programs should (re)commit to recognizing immune-mediated reactions in leprosy promptly and to managing them holistically with medicines, physiotherapy, and psychological support. Persons affected by leprosy, who have experienced the disease and understand the challenges of navigating the local medical system, should be considered for roles in referral, follow-up, and counseling. Patients and their family members should be advised about the possibility of reactions and the need for prompt treatment.

¹ World Health Organization, “Leprosy/Hansen Disease: Management of reactions and prevention of disabilities” (2020), <https://www.who.int/publications/i/item/9789290227595>.

² World Health Organization, “Global Leprosy (Hansen's disease) Strategy 2021–2030” (2021), <https://www.who.int/publications/i/item/9789290228509>.

Goodwill Ambassador confirms value of supporting higher education for young adults from leprosy colonies during 4-day trip to India

In November, WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa visited India's capital city, New Delhi, for the first time in two years. During meetings with India's Minister of Health and Family Welfare, Mr. J.P. Nadda, and WHO Regional Director for the South-East Asia Region, Ms. Saima Wazed, he requested their cooperation and participation in the 20th Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy, which is scheduled to be held in Delhi in January 2025. Both leaders responded favorably.

While in New Delhi, the Goodwill Ambassador also attended a board meeting for the Sasakawa-India Leprosy Foundation (S-ILF) and an event celebrating 18 years since the organization's founding in 2006. He was especially happy to see the board's chairman, Mr. Tarun Das, who he had not met with in person since before the COVID-19 pandemic. In addition, he had opportunities to talk with persons affected by leprosy from a nearby leprosy colony as well as members of the Association of People Affected by Leprosy (APAL).

The Goodwill Ambassador also enjoyed interacting with graduates of the Dalai Lama–Sasakawa Scholarship program. He asked them about the kind of work they are doing now and was told that some are traveling the world as cabin attendants, others are working as journalists, and still others are working in hospitals. They spoke of how their jobs, made possible by the education they received while in the program, have allowed them to move with their families out of the colonies and into nearby towns.

In addition to continuing support for access to higher education, the Goodwill Ambassador wants to facilitate improved communication between the colonies and local governments so that the governments can base their plans for assistance on accurate information. He hopes that systems will be put in place for promoting integration between colony residents and people in neighboring areas, and believes that the eventual disappearance of the colonies as integration proceeds will be a sign of progress toward the elimination of leprosy-related stigma and discrimination.



The Goodwill Ambassador enjoyed talking with Mr. Tarun Das, Chairman of Sasakawa-India Leprosy Foundation (S-ILF) (Nov. 21, 2024).



The Goodwill Ambassador listened to persons affected by leprosy from a nearby colony (Nov. 21, 2024).



Recipients of the Dalai Lama–Sasakawa Scholarship told the Goodwill Ambassador about how their lives changed after receiving support for higher education (Nov. 20, 2024).



The Goodwill Ambassador met with representatives of the Association of People Affected by Leprosy (APAL) (Nov. 21, 2024).

Empowering persons affected by leprosy to know their rights and how to claim them

Contributed by Dr. Alice Cruz

While we still lack systematic evidence that would enable us to identify good practices for eliminating discrimination on the grounds of leprosy in an accurate manner, tangible outcomes have surely resulted from access to justice and strategic litigation in at least three countries: Japan, India, and Brazil. However, in the majority of countries, oversight institutions fail to monitor discrimination on the grounds of leprosy. Access to fundamental rights by persons affected by leprosy continues to be hindered by multiple barriers, and justice, remedies, and reparation are seldom provided. Can a right without a remedy be considered a right at all? Hardly. One of the main barriers for persons affected by leprosy to accede rights and remedies is the systemic denial of their right to access to information, as a result of limited access to education. That is why empowering persons affected by leprosy to know their rights and how to claim them is of the essence for fighting systemic and structural discrimination against them.

With this need to empower in mind, the Sasakawa Health Foundation (SHF) decided to promote partnerships between bar associations and organizations of persons affected by leprosy. The goal is to strengthen the legal literacy of persons affected by leprosy and their representative organizations. Bar associations can provide training on entitlements provided by domestic law; domestic mechanisms for filing complaints and acceding remedies and reparations; free legal aid services; social protection and disability benefits (among other relevant programs, such as those for reducing poverty or promoting gender equality); and administrative procedures.

Recognizing that Nepal has yet to abolish discriminatory norms against persons affected by leprosy under its Civil Code, and that there are also positive normative opportunities within the country's legal framework, SHF decided to launch a project with the Nepal Law Society

(NLS). Such a project was thoroughly discussed with the representatives of the organizations of persons affected by leprosy in Nepal. Some of these representatives will be hired as experts. The project will start with legal research on national legal frames that can protect persons affected by leprosy and promote their rights. Then it will identify gaps in the current normative framework, as well as barriers to its implementation. Based on the legal research, it will provide training to the leaders of the organizations of persons affected by leprosy from the seven provinces of Nepal. Next, the leaders of the organizations will train persons affected by leprosy at the grassroots on their rights and how to accede entitlements and benefits. NLS will also work further on legal and policy change, always in partnership with the organizations of persons affected by leprosy and their partners. The project aims for positive cascade effects and long-term, sustainable impact.



Dr. Alice Cruz, Program Advisor for Human Rights Issues, Sasakawa Health Foundation, met with members of the Nepal Law Society and representatives of people with lived experience of Hansen's disease, on Dec. 1, 2024, in Kathmandu.

