WHO GOODWILL AMBASSADOR'S

LEPROSY BULLETIN

NO. 109 MAY 2022

Initiatives in Africa and South America

Message from the ambassador

Nine months have passed since the "Don't forget leprosy" campaign was launched in August 2021 to coincide with my 20th anniversary as WHO Goodwill Ambassador. Thanks to the efforts of many people, these nine months have included production of six webinars, five videos, and requests to the governments of 55 countries for their cooperation. Persons affected by leprosy, non-governmental organizations, and research institutions have carried out awareness activities around the world. I am grateful to everyone who has helped to spread the message of the campaign, and I am happy to announce that we will be extending it.

On May 22, the World Health Assembly opened an in-person session for the first time since 2019. Making my first visit to Geneva in four years, I resumed my pre-pandemic tradition of seeking meetings with health ministers to remind them about leprosy-related issues. Fortunately, I was able to meet with ministers from 12 countries. I know that they have all been extremely busy because of the pandemic, and so I appreciated that they listened earnestly when I pointed out that leprosy is humanity's oldest infectious disease and persons affected by leprosy and their families have always everywhere suffered from unjustified prejudice and discrimination. Health ministers from countries where the COVID-19 situation has calmed down encouraged me to visit in the near future.

As expected, I also received confirmation that case detection activities have been suspended in many countries because of the pandemic, and there are many people around the world who are not receiving treatment or disability care. I am determined to use my role as WHO Goodwill Ambassador and the momentum of the "Don't forget leprosy" campaign to help countries return to making progress in their leprosy elimination efforts.

Yohei Sasakawa
WHO Goodwill Ambassador for Leprosy Elimination

Contributing to this issue:

Alice Cruz
United Nations Special Rapporteur

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Acting Team Leader, Global Leprosy Programme

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Coordinator, Intergenerational Department, Morhan

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Legal Representative and President, Felehansen

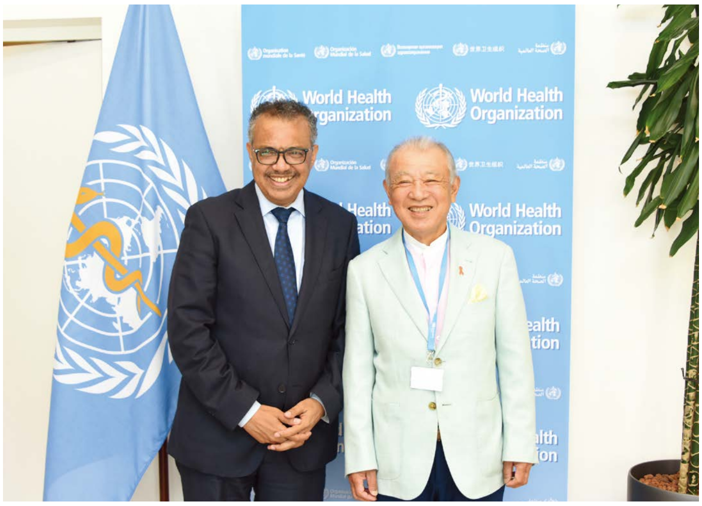
LEPROSY IS CURABLE. MEDICATION IS FREE. STOP DISCRIMINATION NOW.

AMBASSADOR'S JOURNAL

Toward post-pandemic revitalization of leprosy elimination efforts

WHO Goodwill Ambassador Yohei Sasakawa attended the 75th World Health Assembly[1] in Geneva, Switzerland, where he met with health ministers from around the world and urged them to work actively to combat leprosy. He also met with the director-general of WHO, Dr. Tedros Adhanom Ghebreyesus, and the directors of four WHO regional offices (AFRO, SEARO, WPRO, PAHO). They agreed to strengthen their cooperation in order to reach the goal of zero leprosy.

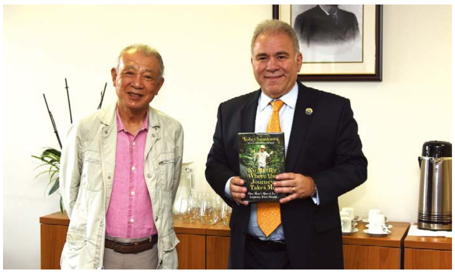
The World Health Assembly opened on May 22 with a high-level session that included speeches from the Assembly's president, heads of state, and special guests. After making his address, Dr. Tedros announced this year's recipients of the WHO Director-General's Global Health Leaders Award. For over 40 years of commitment to leprosy elimination, including the social as well as medical aspects of the disease, Yohei Sasakawa was selected as one of the six recipients. A prior engagement prevented him from accepting the award in person, but he was able to send a video message that called for cooperation with the "Don't forget leprosy" campaign as humanity tries to make it through the "last mile" of leprosy elimination.



Dr. Tedros, Director-General of the World Health Organization, standing with Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination, at the 75th World Health Assembly in Geneva, Switzerland (May 2022).

After arriving to Geneva on May 23, the goodwill ambassador exchanged views on leprosy issues with health ministers from 12 countries where leprosy is endemic: Brazil, Bangladesh, India, Indonesia, Nepal, Ethiopia, Micronesia, Cote d'Ivoire, Mozambique, Nigeria, South Sudan, and Kiribati.

Meetings with health ministers

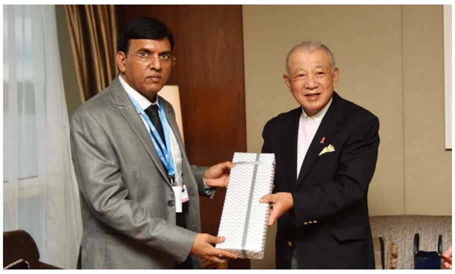


Dr. Marcelo Antônio Cartaxo Queiroga Lopes, Minister of Health, Brazil

In Brazil, many diseases have been overlooked because of the spread of COVID-19. In the case of Hansen's disease, strengthening early detection and ensuring prompt and correct treatment so that disabilities do not develop is most important. The minister confirmed that efforts to eliminate prejudice and discrimination against persons affected by leprosy are also necessary, and expressed his interest in continuing to work actively with the goodwill ambassador.

Dr. Lia Tadesse Gebremedhin, Minister of Health, Ethiopia

Ethiopia still has a large number of hotspots, and so the presence of health workers who engage in early detection and treatment of cases at the community level is essential. The minister mentioned a five-story building being constructed by the Ethiopian National Association of Persons Affected by Leprosy (ENAPAL). The income-generating model for this building has potential to become a good practice for organizations of persons affected by leprosy, and the government would like to support it.



Dr. Mansukh Mandaviya, Minister of Health, India

Mahatma Gandhi, known as "Father of the Nation," dreamed of eliminating leprosy. While the government has made significant efforts to control the disease, it also recognizes that 75% of the world's cases still originate in India. The current National Activity Plan aims for zero leprosy by 2030. The minister would like to create communities where people think positively and help one another. He feels that the goodwill ambassador's activities embody Gandhi's ideas and ideals, and he wants to work actively together.

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[1] The World Health Assembly is the main decision-making body of the World Health Organization (WHO).

Mr. Birodh Khatiwada, Minister of Health, Nepal

Nepal eliminated leprosy as a public health problem in 2010, but as actions being taken against the disease have decreased, the number of cases has increased. In response, the government is creating a new strategy. To promote early detection, leprosy is now searched for along with tuberculosis.

Dr. Osagie E. Ehanire, Minister of Health, Nigeria

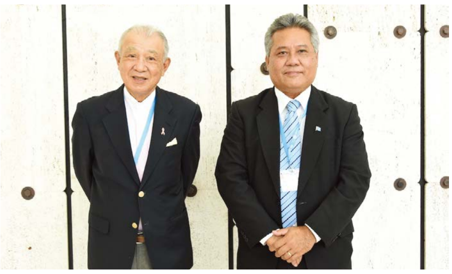
Because Goodwill Ambassador Sasakawa has been steadfast in his efforts, many people think of leprosy elimination when they see him. This kind of recognition is extremely effective in the fight against leprosy. The minister would like to continue to work with the goodwill ambassador.

Mr. Pierre N'gou Dimba, Minister of Health, Côte d'Ivoire

Cote d'Ivoire has just finished creating a roadmap and action plan for achieving zero leprosy by 2030. The minister asked the goodwill ambassador for advice related to achieving this goal.

Mr. Zahid Malek, Minister of Health, Bangladesh

Prime Minister Sheikh Hasina's support at Bangladesh's National Leprosy Conference in 2019 catalyzed a national movement to reach zero leprosy by 2030. The government would like to resume activities that were postponed because of the COVID-19 pandemic.



Mr. Marcus Samo, Secretary of Health, Micronesia

Before COVID-19, the goodwill ambassador had been planning to visit Micronesia, but he had to cancel because of the pandemic. Now that the situation is improving, the minister hopes that the goodwill ambassador will visit soon.

Dr. Armindo Daniel Tiago, Minister of Health, Mozambique

Collaboration with WHO and the goodwill ambassador is essential for eliminating leprosy from Mozambique. The minister wished Goodwill Ambassador Sasakawa 100 years of life, and asked him to continue his work until leprosy is completely eliminated.

Dr. Tinte Itinteang, Minister of Health, Kiribati

Kiribati would like to strengthen its leprosy program so that it can move more independently to achieve elimination of leprosy as a public health problem. The government would also like to be proactive in administering prophylaxis with single-dose rifampicin, as recommended by WHO.

Ms. Yolanda Awel Deng Juach, Minister of Health, South Sudan

Leprosy is not a highly contagious disease, but when one person is affected, the impact on the community is significant. Intervention is needed as well as capacity building.

Dr. Maxi Rein Rondonuwu, Director-General of Prevention and Disease Control, Indonesia

Indonesia's leprosy control program aims to achieve elimination as a public health problem at the provincial level by 2024, and its activities include awareness-raising in communities, new case detection, and prophylaxis with single-dose rifampicin.

INTERVIEW

Alice Cruz
United Nations (UN) Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members

Twitter: @srleprosy

Alice Cruz has held the mandate for UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members since it was first established by the Human Rights Council in 2017. Her first official visit to Angola took place April 28-May 10, 2022.

UN Special Rapporteur Alice Cruz resumes country visits, starting with Angola

LB (*Leprosy Bulletin*)**:** This was your first official country visit as Special Rapporteur since you visited Japan in February 2020, after which the coronavirus pandemic made such visits difficult. What were your objectives and expectations going into this visit?

AC (Alice Cruz)**: My objectives are always the same for any country visit: to assess the human rights situation of persons affected by Hansen's disease and their family members, as well as to provide constructive recommendations to improve that same situation to the respective government. This mission was of particular importance given the fact that Angola is one of the 23 WHO priority countries, and also that this was my first mission to an African country. I was also interested in the fact that Angola has been taking a leadership role in the African Union and that it is now chairing the Community of Portuguese Language Countries. I am always interested in promoting synergies and catalyzing joint efforts between regional partners and other forms of partnership between countries, since I am convinced that in order to fight discrimination on the basis of Hansen's disease, international cooperation is of the essence.**

LB: In this issue of the *Leprosy Bulletin*, we are focusing on Africa and South America. How do you compare the situation in Angola to that in Brazil, the first country you visited as Special Rapporteur? What do the two countries share in common in terms of attitudes toward leprosy, and how do they differ? Is it possible to draw broader conclusions about similarities and differences between Africa and South America as a whole?

AC: Allow me to start with your second question. I am always very cautious in speaking about any continent as a whole. I think it would be a mistake to analyze South America as a whole, as I think it would be a mistake to analyze Africa as a whole. What I do believe is that more missions, from me or from other key stakeholders, to African countries are urgent. I am also worried about countries that aren't English or French-speaking ones being left outside international cooperation. There was not even one international organization working in Angola in the field of Hansen's disease, which is surely contributing to the dehumanization of persons who experience the disease, due to the decrease of domestic resources and expertise for addressing Hansen's disease's related problems. I certainly wish that Brazil and Angola, which are both Portuguese-speaking countries, could strengthen ties and develop South-South cooperation in the field of Hansen's disease. With regard to your first question, let me say that I have always believed that stigmatization on the basis of Hansen's disease must be contextualized, and the comparison between Brazil and Angola proves just that. Stigmatization in both countries has quite different root causes and that is why we will never eliminate it unless we involve communities and persons who experience Hansen's disease in such a fight. The latter are of the essence as experts who know the social, cultural and political factors behind stigmatization and the former are key to change those same factors. There is no universal answer to the issue of stigmatization, as there is no magic bullet to solve it. Interestingly, the similarities I found between both countries are connected to failures and gaps within national healthcare systems and the consequences such failures and gaps have on people's lives. But I must say that the failures and gaps within the Angolan healthcare system are far more worrying than those in the Brazilian healthcare system, which is also related to the distinct historical developments of each country.

At Funda Health Center (near Luanda, Angola's capital city) on May 2, 2022.

For the complete interview, visit
https://bit.ly/LB109_Interview_AliceCruz

VIEWPOINT

Dr. Venkata Ranganadha Rao Pemmaraju

Acting Team Leader, Global Leprosy Programme
World Health Organization (WHO)

Dr. Pemmaraju has decades of experience in all aspects of leprosy control. His technical and administrative knowledge is balanced by time spent with persons affected by the disease. As the acting team leader for WHO's Global Leprosy Programme, he works to ensure that the disease burden continues to decline in all countries.

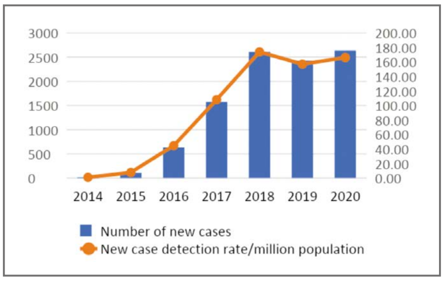
Somalia is accelerating efforts to eliminate leprosy

Somalia, located in the horn of Africa and in antiquity an important commercial center, has an estimated population of 16.5 million people (2021). Agropastoralism remains the most common lifestyle, along with some nomadic livestock herding. "Elders" influence decisions and actions at home and in the community. Prolonged war and civil conflict compounded by famine for over three decades caused population movement. Life expectancy is low; the Human Development Index is low (0.285 out of 1 in 2021); and the Gender Inequality Index is very high. Communicable diseases, including leprosy and other neglected tropical diseases (NTDs), are clustered in central and southwest regions of the country as endemic pockets. In recent years, however, a number of new leprosy patients were reported from northern regions as well, which can be attributed to the displacement of people. Reproductive health problems, malnutrition, non-communicable diseases, and mental health issues have also been reported.

Casho, a person affected by leprosy in Somalia, holding a leprosy medication blister pack. Casho's diagnosis came too late to prevent disabilities. Photo courtesy of NLP Somalia.

Casho, a mother of two children living in an internally displaced persons camp near Mogadishu, noticed a patch on her right hand when she was a child. The disease progressed and deformities were developed. She did not venture to move out for treatment as she could not afford treatment outside the camp. Prevailing stigma about the disease was also a barrier. She had to wait for over 6 years until staff from the federal government's Ministry of Health and Human Services (FMOH) visited the camp. She received a leprosy diagnosis and was treated, but because there was a delay, disabilities could not be prevented. Casho's story reflects the situation of leprosy services.

FMOH created a department for NTDs in 2015, and leprosy case detection campaigns were started in camps for internally displaced persons along with mobile skin clinics for the general population. The case detection was strongly backed by intense information, education, and communication campaigns. New cases increased from 14 (2014) to 2638 (2020). Case detection trends demonstrate the commitment of FMOH to improve leprosy services and to reduce the leprosy burden. The statistics reflect the commitment of the staff and the political commitment and improved coverage of the program and quality of services. The increase in the number of new cases prompted WHO to include Somalia in the list of Global Priority Countries for leprosy and to advocate for more support from partners to the country. Sasakawa Health Foundation supported the initiative of FMOH of Somalia to improve the coverage of leprosy services.



Data for number of new cases and new case detection rates is from WHO's Global Leprosy Update, which is published annually in the *Weekly Epidemiological Record.*

Early case detection to detect all new cases before deformities are developed and improved quality of medical treatment still need to be expanded to cover all regions of the country. Stigma against the disease is high in communities. The influential role of Elders in the community should be leveraged to enhance preparedness in the community and self-reporting of patients to seek treatment. Such community response complements efforts of FMOH to eliminate leprosy.

WHO's technical assistance and supply of multi-drug therapy was instrumental in implementing leprosy services. Funds from Sasakawa Health Foundation improved coverage of leprosy services. ILEP supported the leprosy program in training the health staff of Somalia's national leprosy program. This is the time to organize persons affected by leprosy into a network to partner with FMOH for getting the voices of persons affected heard and combatting stigma against leprosy. FMOH commits to accelerating efforts to eliminate leprosy from the country. It is time that partners, including the persons affected and the community, join hands to strengthen efforts of FMOH to eliminate leprosy. There are great lessons from Somalia to learn in addressing the problem of leprosy in a very challenging situation.

REPORT

Dr. Gerson Fernando Mendes Pereira

Director, Department of Diseases of Chronic Condition and Sexually Transmitted Infections, Ministry of Health (Brazil)

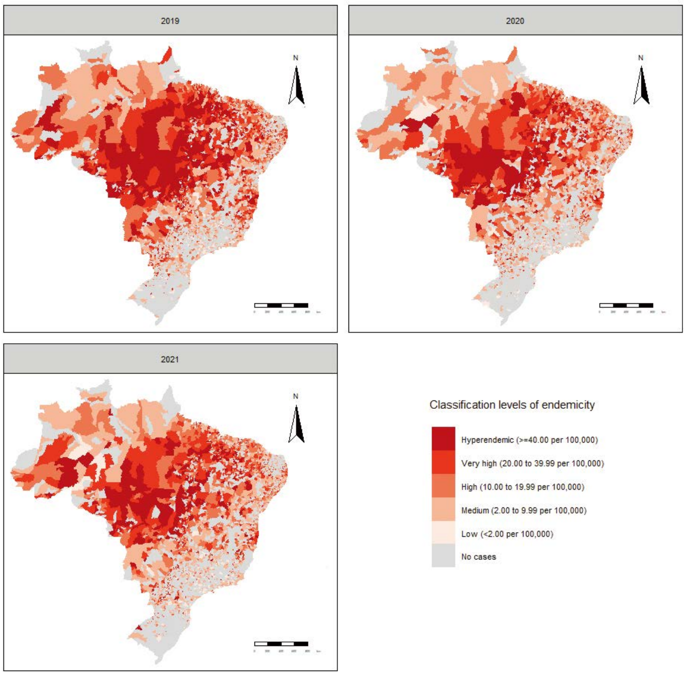
Deputy Secretary, Secretariat of Health Surveillance, Ministry of Health (Brazil)

This report was written by Dr. Mendes Pereira in collaboration with Ministry of Health colleagues: Carmelita Ribeiro Filha, Gustavo Laine Araújo de Oliveira, and Rodrigo Ramos de Sena.

Building back better: Brazilian pandemic-era innovations for increasing early diagnosis

The pandemic years 2020 and 2021 brought additional challenges for Brazil’s national Hansen's disease program. The restrictions imposed in response to COVID-19 during this period had a considerable impact on active search for cases and their family contacts by health care services. Detection of new cases, access to early diagnosis, and the timely provision of drug treatment all dropped in comparison to pre-pandemic 2019 data.

Specifically, there was a 35% reduction in the notification of new cases from approximately 28,000 in 2019 to about 18,000 in 2020. There was an even higher reduction of 43% in the number of new Hansen's disease cases in children under 15 years of age. Preliminary data for 2021 showed an increase of 1.2% in the detection of new cases when compared to the data for 2020. This finding may reflect a resumption of case detection activities by health care services.

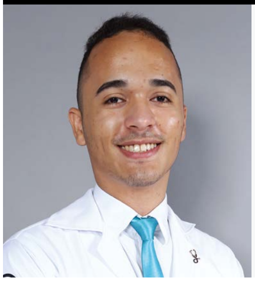


Spatial distribution of new Hansen’s disease case detection rate per 100,000 inhabitants. Brazil, 2019-2021.

As Hansen's disease is a silent condition and its diagnosis is essentially clinical, active search actions are urgent matters, especially for household contacts. With this urgency in mind, in 2022, the Ministry of Health of Brazil (MoH) encouraged states and municipalities to resume case identification actions, especially those related to case active search in communities. The MoH looked at Brazil’s 5,570 municipalities and identified the locations that had the highest proportional reduction in case detection for the last two years. These locations will be visited by specialists, who will train local health teams to assess the contacts of persons affected by Hansen's disease.

A remarkable fact about the active search actions in the Brazilian communities is that they will rely on new technological innovations developed in Brazil by public institutions to support the increase in Hansen’s disease diagnosis. One of them is a rapid test for serological detection of anti-*Mycobacterium leprae*, which uses a blood sample collected by finger prick. Another relevant innovation is a kit for detecting the genetic material of *Mycobacterium leprae* in the skin or a nerve biopsy. This kit, which uses real-time Polymerase Chain Reaction (qPCR), is appropriate for patients who need a more in-depth investigation. The Brazilian government funded and technically evaluated the development of both tests based on our strategy for Research, Development, and Innovation (RD&I). As Hansen’s disease is a neglected disease, the government sector is essential in Brazil for new technologies to be made available to the population.

Brazil reiterates its commitment to the rights of persons affected by Hansen’s disease, continues to support universal health access, and acknowledges the need to build comprehensive care response, based on human rights, dialogue with civil society, investments in research, and the timely coverage of new health technologies. Thus, Brazil will keep on strengthening the active search for cases and their family contacts, promoting early diagnosis and treatment, preventing physical disabilities, interrupting the transmission chain, and progressing towards eliminating Hansen’s disease in our country.



Marcos Vinicius Costa Santos
Coordinator, Intergenerational Department
National Morhan

Morhan is a non-profit organization and social movement in Brazil that raises awareness of Hansen's disease as a curable disease and advocates for public policies that uphold human rights and support effective treatment.

http://www.morhan.org.br

Morhan's Intergenerational Department encourages youth to represent themselves

The participation of young people in society is of paramount importance. Their participation is a tool for collective and democratic transformation, and they are the ones who must represent themselves when policies are being made. In Morhan's Intergenerational Department (DI-Morhan), we work with the purpose of encouraging young people to participate in representative entities that guarantee social participation. We empower them by providing them with knowledge and encouraging them to seek out their rights and duties.

I am from a region where reliable information and quality care were scarce. I developed a moderate discomfort and a feeling of dissatisfaction, and with that I had the thought of looking for improvements in the health system offered to people who were undergoing treatment for Hansen's disease in the municipality. I started to take several courses and improve my knowledge about the disease, how to treat it, and how to identify it. However, I was only looking for knowledge in my area of specialization (health sciences).

Over time, I saw that the problem went beyond just treating the individual and that we should encourage health promotion and education activities. At that point, I encountered Morhan, an organization that is an invaluable resource in terms of quality information on Hansen's disease. I had my first contact with the national coordinator of Morhan, Artur Custódio, in a congress that I joined in Foz do Iguaçu, a city in the state of Paraná, and from there we started the discussion for the implementation of a Morhan nucleus in the city where I currently live. After months of structuring, we did it.

Two Morhan representatives met with Vice President Councilman Zé Gota of the Barra do Garças City Council to discuss effective public policies for tackling Hansen's disease (August 2021).

After that, we founded another nucleus in Barra do Garças, a city in the state of Mato Grosso. This is where I currently coordinate. We developed several activities for education, promotion, and prevention in health for the community, and we have taken countless actions and obtained many fruits with the community.

DI-Morhan was created at the time of the restructuring of Morhan National's statute. As I was one of the youngest coordinators of a nucleus, I was selected together with Tatielle Naiara, my vice coordinator, to represent youth and take on responsibility for the department. It's now in full swing: producing information, promoting exchange of knowledge, and formulating proposals to better serve young people affected by Hansen's disease. As John F. Kennedy said, "Let us not seek to fix the blame for the past. Let us accept our own responsibility for the future."

Twitter post showing coordinators of Morhan's Intergenerational Department, Marcos Vinicius Costa Santos and Tatielle Naiara, involved in an event live-streamed on Morhan's YouTube channel (April 19, 2022).

We are many. We have desires. We have voices, rights, and we must fight so that our right to voice and social participation is not impeded, but prevails!

WISH LIST

Lucrecia Vásquez Acevedo
Legal Representative and President, Felehansen
https://felehansen.org

Lucrecia Vásquez Acevedo, her son, and her infant granddaughter all experienced leprosy (Hansen's disease). As a leader of Felehansen, a national people's organization with over 700 volunteers, she works to ensure the social inclusion and rehabilitation of persons affected by leprosy in Colombia.

For each issue, the *Leprosy Bulletin* asks a person affected by leprosy or an individual involved in leprosy-related work for a "wish list" of things that they wish could happen. We ask contributors to be bold in order to stimulate thinking and inspire new approaches.

1. A vaccine for preventative control.
2. Inclusion of persons affected by leprosy at tables where decisions are being made so that rules and laws are informed by our experiences.
3. A requirement that future healthcare professionals learn about leprosy (Hansen's disease) as part of their training so that they can make accurate and timely diagnoses that minimize disabilities.
4. Agreement that mental health care for persons affected by leprosy is an urgent matter and that services should be provided as part of global health programs.

LETTER

Empowering ourselves through Felehansen

In 2014, a group of persons affected by leprosy (Hansen's disease) in Colombia created what is now called Federación de Asociaciones de Personas Afectadas por Lepra – Hansen (Felehansen). Our group brings together hundreds of people from around the country. Each one of us has a living story with varying levels of sadness and difficulty. Together we strengthen ourselves and endeavor to be managers of our own development.

With unity as our base and empowerment as our principle, we made progress even during the pandemic. Now we are resuming the activities that were postponed and taking on the new challenge to engage in political advocacy. Making our voices heard and being included in spaces where regulations and laws are being made requires that we stay courageous and firm. We will persevere and share the message throughout Colombia and the world that leprosy must not be forgotten.

Felehansen members at the First Latin American and Caribbean Meeting of Organisations of People Affected by Hansen's Disease (Rio de Janeiro, Brazil, 2019).

SASAKAWA
LEPROSY
HANSEN'S DISEASE
INITIATIVE

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