

LEPROSY BULLETIN

NO. 111 SEPTEMBER 2022



Innovations for addressing leprosy's remaining challenges

Message from the ambassador

Persons affected by leprosy, more than any doctors or researchers, have firsthand experience of leprosy's problems. Believing that the people with the most direct experience of the problem should have a central role in finding solutions, I have been encouraging the development of people's organizations of persons affected by leprosy around the world since the 1990s. The Ethiopian National Association of Persons Affected by Leprosy (ENAPAL) is an inspiring example of what these organizations can be.

On Sept. 2, I attended the opening ceremony for a six-story building that is entirely owned by ENAPAL. The building is the result of their efforts to secure land from the government and construction funding from the Sasakawa Health Foundation. With rental income from leasing the building, they have become a financially independent and sustainable organization. ENAPAL's managing director, Tesfaye Tadesse, summarized the significance of the building in his speech: "Today is a day to celebrate the realization of our dream. This building is not just an asset to generate income. It is a symbol of restoration of dignity for persons affected by leprosy in Ethiopia and around the world."

In the world we have now, deep-rooted stigma and lack of prompt diagnosis and treatment link leprosy to disability. ENAPAL is part of the Federation of Ethiopian Associations of Persons with Disabilities, and they are speaking up for persons affected by leprosy in national conversations about disability-inclusive development. ENAPAL is showing how a people's organization can lead the way in making a more inclusive society a reality, and I hope that they will continue to break new ground for other organizations to follow.

A handwritten signature in blue ink, consisting of stylized characters that appear to be 'Sasakawa Yohei'.

Yohei Sasakawa
WHO Goodwill Ambassador for Leprosy Elimination

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Stefanie Weiland
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Duane Hinders
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Kefyalew Bekele
Chairperson, ENAPAL
Ehite Yitayew
Board Member, ENAPAL

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

VIEWPOINT



Stefanie Weiland
Executive Vice President of Programs, American Leprosy Missions

Stefanie Weiland oversees all programs at American Leprosy Missions (ALM), the oldest and largest Christian organization in the United States dedicated to breaking barriers to health and restoring hope for people suffering from the pain and stigma of neglected tropical diseases like leprosy.

<https://leprosy.org>

LepVax: A new tool for prevention and treatment

For more than 100 years, doctors and scientists have labored to find ways to prevent and treat leprosy. From chaulmoogra oil in the early 1900s to sodium glucosulfone (promin) in the 1940s to the introduction of dapsone in the 1950s, there was limited success at treating this debilitating and isolating disease. Since 1981, the World Health Organization (WHO) has recommended implementation of multidrug therapy (MDT) with dapsone, rifampicin and clofazimine, which has cured more than 16 million people. Yet MDT cannot reverse neuropathy nor prevent leprosy transmission. WHO's Global Leprosy Strategy 2021–2030 recognizes that "Passive case detection and treatment with MDT alone have proven insufficient to interrupt transmission. . . . Trials of . . . new vaccines, including LepVax . . . , may result in an important new tool for leprosy prevention"¹

The quest begins

In 2002, ALM began the search for the world's first leprosy-specific vaccine. In early studies, armadillos were used to test the candidate vaccine, which was named LepVax. After nine months, only 12.5% of vaccinated armadillos



Sample label for a LepVax vaccine vial. Photograph provided by American Leprosy Missions. Used with permission.

had suffered nerve damage, compared with 87.5% in the unvaccinated group. Moreover, a good immune response and bacilli reduction were observed in vaccinated mice and armadillos. Results indicated that LepVax had the potential to prevent, and even treat, leprosy.

With these exciting results, the U.S. Food and Drug Administration approved LepVax for a first-in-human clinical trial in the U.S. By 2019, the Phase 1a clinical trial

with healthy adults had been successfully completed. The study showed that the vaccine was safe and elicited strong immune responses.

Next step: Testing in Brazil

The next step is to study LepVax in people living in a leprosy-endemic area. For the Phase 1b/2a clinical trial we selected as partners Brazil's Oswaldo Cruz Foundation (Fiocruz), the most prominent institution of science and technology in health in Latin America. The trial will evaluate LepVax safety and immunity, and it may address the vaccine's preliminary effectiveness as a therapeutic vaccine for treating leprosy. The trial will enroll healthy participants and patients with pauci-bacillary leprosy.

In 2021, ALM filed regulatory paperwork with the Brazilian National Health Surveillance Agency, ANVISA. We anticipate ANVISA approval by late 2022, with results from the two-and-a-half-year study expected in 2025.

Closer than ever to ending leprosy

With LepVax's promising results, we are closer than ever to ending leprosy burden and transmission. Recent epidemiological modeling indicates that if LepVax is rolled out between 2028 and 2040, 823,000 new cases of leprosy-related disability could be prevented and transmission intercepted.

When I recently spoke with Artur Custodio Moreira de Sousa, MORHAN National Coordinator and Member of the Health Surveillance Commission of the National Health Council – MOH, Brazil, he said, "We need innovation like this vaccine to end Hansen's disease."

The millions of people affected by leprosy are eagerly awaiting new tools like a leprosy vaccine to bring an end to this disease's debilitating effects. We believe LepVax will be an innovative new way to stop the transmission of leprosy and the only way to protect people long term. We are seizing this historic opportunity to help end leprosy and leave a lasting legacy.

¹ World Health Organization, Towards Zero Leprosy: Global Leprosy (Hansen's disease) Strategy 2021–2030 (2021): 16, <https://www.who.int/publications/i/item/9789290228509>.

VIEWPOINT



Duane Hinders
Programme Manager PEP++, NLR

Duane Hinders is a public health policy specialist who was the national director of NLR's field office in Brazil for over eight years before moving to his current position in Amsterdam. NLR, founded in 1967 as "Netherlands Leprosy Relief," today is an international nongovernmental organization (NGO) working for a world where "No Leprosy Remains."

<https://nlrinternational.org>

A beacon of hope: Enhanced preventive treatment for leprosy

For many years effective multidrug therapy (MDT) has been available to treat millions of people who are diagnosed with leprosy, resulting in a considerable decrease in new cases worldwide. However, the annual number of new cases has remained stable over the past 10 years at 200,000. This shows that treatment of new cases with MDT is not enough to stop transmission — prevention is the key.

Recent efforts focus more on active case finding, resulting in effective and feasible interventions, such as contact screening combined with the provision of a single dose of rifampicin as post-exposure prophylaxis (SDR-PEP). SDR-PEP reduces the risk of leprosy by 57% when administered to contacts of leprosy patients. The World Health Organization (WHO) has incorporated this preventive treatment in its guidelines.

NLR and Erasmus Medical Center Rotterdam have carried out modeling research to predict the population at risk of developing leprosy in order to achieve a significant reduction in the annual number of new cases of leprosy. The population at risk is defined as the number of contacts to be treated with SDR-PEP. The model predicts that to achieve a 50% reduction in new cases of leprosy within five years, 20.6 million people (cumulatively) need to be treated with PEP. A 90% reduction can be achieved in 22 years if 40.2 million people are treated preventively. The time to reach a 90% reduction could be shortened through effective innovations such as providing an enhanced PEP regimen.¹

NLR is undertaking a research project called "Stop the transmission of leprosy!" to reduce the number of new patients in five countries, two districts each, with a high leprosy burden: Bangladesh (in partnership with The Leprosy Mission International), Brazil, India, Indonesia, and Nepal.

The main element of the project is a block randomised controlled trial of an enhanced PEP regimen consisting of a combination of two existing antibiotics (rifampicin and clarithromycin) given three times at four-week intervals.

This new regimen, called PEP++, is expected to be 80-90% effective to prevent leprosy disease. Within the PEP++ intervention area, approximately 20 close contacts (household and family members as well as neighbours/social contacts with frequent interaction) of each leprosy patient receive the new regimen. In the control areas, those close contacts will receive SDR-PEP and the two arms will be compared for regimen effectiveness. For cluster areas (at least two cases within 500 meters of one another) within the intervention area, a blanket campaign is implemented and an additional 80 contacts receive SDR-PEP. Control areas also have blanket campaigns for cluster areas, with the difference that everyone, including close contacts, receive SDR-PEP. These active case-finding and PEP interventions, combined with epidemiological mapping and context-specific educational messaging countering stigma, are expected to help interrupt the transmission of leprosy in these areas.

Through this project, around 220,000 close contacts and as many as 550,000 other community contacts will be examined for signs of leprosy and receive preventive treatment. The number of annual new cases within project areas is expected to drop by 50% at the end of the project period. With a further continuation of the project, a 90% reduction in the number of annual new cases by 2030 is foreseen.

A number of setbacks — such as difficulties with getting ethical approval for the study, a change to the original regimen, and the COVID-19 pandemic — have caused a delay in the roll-out. However, much progress has been made in 2022. In Brazil, over 1,000 close contacts received PEP, and Nepal has also started the trial. Bangladesh, India, and Indonesia are soon ready to begin pre-testing. If PEP++ turns out to be effective as hoped, zero leprosy may truly be on the horizon!

The project is funded by the Dutch Postcode Lottery through its Dream Fund with additional support from The Leprosy Mission International for Bangladesh.

¹ Taal AT, Blok DJ, van Brakel WH, de Vlas SJ, Richardus JH (2021) Number of people requiring post-exposure prophylaxis to end leprosy: A modeling study. *PLoS Negl Trop Dis* 15(2): e0009146. <https://doi.org/10.1371/journal.pntd.0009146>

LETTER



Kefyalew Bekele
Chairperson, Ethiopian National Association of Persons Affected by Leprosy (ENAPAL)

ENAPAL is a community-based nonprofit organization committed to addressing leprosy-related issues in Ethiopia. Areas of focus include prevention of leprosy-related disabilities, rehabilitation, capacity building, education, and stigma reduction.

<https://www.enapal.org>

ENAPAL's new building is a symbol of dignity for persons affected by leprosy

Ethiopia reported over 2,500 new cases of leprosy in 2021, and the World Health Organization has designated it a priority country. Our organization, a community-based nonprofit called Ethiopian National Association of Persons Affected by Leprosy (ENAPAL), has been dedicated to securing full participation and equal opportunity for persons affected by leprosy in Ethiopia since 1996. Currently, we have over 20,000 members.

In 2011, ENAPAL approached the Ethiopian government about the possibility of receiving land for a new head office building. Six years later, in 2017, the government took the unprecedented step of transferring a 1,500-square-meter plot to our organization. Through Mr. Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination, we connected with the Sasakawa Health Foundation, and they agreed to finance the construction costs. Over 10 years after we started the process, our building finally reached completion in 2022. The opening ceremony ribbon was cut by Dr. Ergogie Tesfaye, Minister of Women and Social Affairs; Dr. Lia Tadesse, Minister of Health; and Mr. Sasakawa.



ENAPAL's new six-story building. The building is located in a newly developed area of Addis Ababa, Ethiopia's capital city.

For me and fellow members of ENAPAL, the opening ceremony marked an unforgettable day in the history of our organization. Getting to this point was not easy. During the COVID-19 pandemic, we had to cope not only with restrictive measures

related to stopping the spread of infection but also with electricity shortages and skyrocketing prices of construction materials. In some cases, we had to pay nearly 10 times more than we had expected at the beginning of the project. We had no choice but to discuss each case one by one, considering our options and then making the best choice possible.

Throughout, we reminded ourselves that ENAPAL is the first nongovernmental organization in Ethiopia to be granted land by the government. Persons affected by leprosy have suffered from stigma and discrimination for a very long time. This building is a symbol of our dignity, and we are feeling happy and proud of what we have accomplished together.

As an organization, one of our goals has been to establish financial independence and stability. Although eventually we hope to move ENAPAL's headquarters to the building, for now we are leasing the entire space in order to maximize the rental income.

Many challenges remain for persons affected by leprosy and their family members. ENAPAL will continue to work toward a society where every person affected by leprosy can live with hope and peace of mind. We would like to express our sincere gratitude to the WHO Goodwill Ambassador for Leprosy Elimination and the Sasakawa Health Foundation for working with us to make our dream a reality.



WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa surrounded by ENAPAL members at the opening ceremony for ENAPAL's new building (Sept. 2, 2022).

NEXT GENERATION



Ehite Yitayew
Board Member, Ethiopian National Association of Persons Affected by Leprosy (ENAPAL)

ENAPAL is a community-based nonprofit organization committed to addressing leprosy-related issues in Ethiopia. Areas of focus include prevention of leprosy-related disabilities, rehabilitation, capacity building, education, and stigma reduction.

<https://www.enapal.org>

ENAPAL's leadership includes many women and young people

I am a person affected by leprosy in Ethiopia, and I am a new member of ENAPAL's board of directors. Previously, I served as a secretary of a local chapter. I am happy to be joining the board, and at the same time, I feel the weight of responsibility. I have no visible disabilities because of early detection and treatment, but there are many people around me who were not as fortunate. I am looking forward to working together to achieve ENAPAL's objectives for the benefit of the entire ENAPAL community and all persons affected by leprosy throughout the country.

I especially want to work on issues affecting women and children. In the Amhara region where I am from, I make myself available to women affected by leprosy and their family members so that they have someone to talk to about their problems. I hear about how their biggest problem is lack of income, and because of it, often their children have to drop out of school. There is a domino effect where one problem causes another.

In my community, we have implemented a project to build stoves for cooking. Traditionally, we collect wood and cook over an open fire, but the problem is that this method doesn't deliver heat efficiently. The wood burns up quickly and meanwhile we don't get a lot of heat for our cooking. If we use mud and stones to build stoves that deliver the heat more efficiently, we can get the heat that we need and use less wood.

To gather wood for fuel, women have to walk for hours. Naturally, this means that there is no time for other work. In the case of persons affected by leprosy, often their limbs are injured and walking long distances worsens their disabilities. Also, many persons affected by leprosy lack feeling in their hands or feet, and so they are more likely to suffer from burns.

After we formed a women's group, received training, and then built the cooking stoves together, the amount of time spent gathering wood dropped and the number of cases of worsened disabilities and burns decreased as well. More women had time to do other work, and the experience of interacting in the group seemed to energize them. I was so happy to see their expressions change and their spirits improve.

Women are strong. I want them to have opportunities to flourish, and I believe that supporting women results in better outcomes for children as well.



Woman cooking injera in her house (Gheralta, Tigray, Ethiopia). Credit: CharlieFleurene, CC BY 4.0 (<https://creativecommons.org/licenses/by/4.0>), via Wikimedia Commons.

I think ENAPAL is a progressive organization. It has many women and young people holding positions on the board and in local chapters. I want to work together with men, women, and young people to do our best.



Ehite Yitayew (left) with two other female board members elected at a board meeting held at the end of June 2022.

In Ethiopia, celebrating ENAPAL's new building

WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa visited Ethiopia to spread his "Don't Forget Leprosy" message and celebrate with the Ethiopian National Association of Persons Affected by Leprosy (ENAPAL) as they opened their new six-story building in Addis Ababa, the country's capital city.

The new building represents over 10 years of effort and collaboration. ENAPAL first approached the Ethiopian government around 2011 about the possibility of receiving land for a new headquarters. Six years later, the government transferred a 1,500-square-meter plot to the organization, the first case of its kind in Ethiopia involving a local non-governmental organization (NGO). After securing the land, ENAPAL approached Goodwill Ambassador Sasakawa during his visit to Ethiopia in July 2018 for support. Sasakawa Health Foundation (SHF) reviewed the plans, and a year later agreed to underwrite most of the construction costs. ENAPAL's



New six-story building in Addis Ababa, Ethiopia, owned by the Ethiopian National Association of Persons Affected by Leprosy (ENAPAL).

members also contributed from their limited incomes. After more than three years of construction, including many unexpected challenges because of the COVID-19 pandemic, the building was completed.

For now, ENAPAL will lease the building. The rental income will give ENAPAL financial independence from international NGOs for the first time since the organization was founded in 1996. In the context of centuries of stigma and discrimination against persons affected by leprosy, the building stands as a symbol of dignity and hope.

Sept. 1: Don't Forget Leprosy stakeholders' symposium

Participants: Approximately 100 representatives from Ethiopia's Ministry of Health, Ministry of Women and Social Affairs, ALERT, Armauer Hansen Research Institute, Mehal Meda Hospital, German Leprosy and TB Relief Association (GLRA), The Leprosy Mission International Ethiopia (TLMIE), South Wello Health Bureau, ENAPAL, and Sasakawa Health Foundation (SHF)

Together they called for eliminating leprosy through a combination of activities, including awareness-raising, training for healthcare workers, and support for rehabilitation.

Goodwill Ambassador Sasakawa unexpectedly returned early enough from community visits to surprise participants with words of encouragement regarding the anticipated opening of ENAPAL's building the following day.

Sept 2: Opening ceremony for ENAPAL's building

Honored guests: Dr. Ergogie Tesfaye (Minister of Women and Social Affairs); Dr. Lia Tadesse (Minister of Health); Dr. Boureima Hama Sambo (WHO Country Representative for Ethiopia); Takako Ito (Ambassador of Japan to Ethiopia); Abayneh Gijo (Federation of Ethiopian Associations of Persons with Disabilities)

Despite the rainy season, the morning of the opening ceremony was blessed with sunshine and blue skies. ENAPAL members looked a bit tense and joyful at the same time. Following the planting of a commemorative tree, Goodwill Ambassador Sasakawa joined Minister of Women and Social Affairs Ergogie Tesfaye and Minister of Health Lia Tadesse for the honor of cutting the ribbon. During a brief tour of the building, guests heard about how the building will be leased to an educational institution.

Awareness-raising through media

Goodwill Ambassador Sasakawa spoke at a press conference and appeared on an Ethiopian Broadcasting Corporation (EBC) television program. He called for correct knowledge of leprosy and urged households to implement skin checks, especially for children, in order to increase the likelihood of early detection.



WHO Goodwill Ambassador for Leprosy Elimination Yohei Sasakawa speaking at a press conference in Addis Ababa, Ethiopia.



WHO Goodwill Ambassador Yohei Sasakawa spreading correct knowledge about leprosy as a guest on an Ethiopian Broadcasting Corporation (EBC) television program.



At the opening ceremony for ENAPAL's new building, the day's honored guests worked together to plant a commemorative tree. Takako Ito, Ambassador of Japan to Ethiopia, holds the shovel.



Tefsaye Tadesse, Managing Director, ENAPAL

To construct this building, we relied on the strength of ENAPAL and the power of God. I would like to express my gratitude once again to all of you. Regarding how we will use the rental income, 44% will be used for activities that support persons affected by leprosy, 26% for operating expenses, 20% for investments, and 10% for contingency planning.



Yohei Sasakawa, WHO Goodwill Ambassador for Leprosy Elimination

ENAPAL is the strongest people's organization of persons affected by leprosy in the world, and ENAPAL's actions encourage persons affected by leprosy in all countries. I urge ENAPAL to embrace a leadership role. I am confident that you have the capacity, unity, and passion to do so.



Dr. Ergogie Tesfaye (Minister of Women and Social Affairs), Yohei Sasakawa (WHO Goodwill Ambassador), and Dr. Lia Tadesse (Minister of Health) prepare to cut the ribbon at the opening ceremony for ENAPAL's new building.



Dr. Boureima Hama Sambo, WHO Country Representative for Ethiopia

The operation of this building will bring social and economic benefits. I believe that it will become a symbol of the restoration of dignity. We absolutely can eliminate stigma and discrimination. The World Health Organization will continue to take action based on the Global Leprosy Strategy.



Dr. Lia Tadesse, Minister of Health

The Ministry of Health will allocate 50 million birr to the fight against leprosy. The training of health care workers and other professionals is especially important. We will cooperate as much as possible toward a world without leprosy.



Kefyalew Bekele, Chairperson, ENAPAL

We will use the rental income from this building to support persons affected by leprosy to rejoin society.



Takako Ito, Ambassador of Japan to Ethiopia

The Sasakawa Leprosy (Hansen's Disease) Initiative is working with ENAPAL and others toward a world without leprosy. The completion of this building is having a great impact on persons affected by leprosy and people around the world. I hope that the building will become a symbol of friendship between Ethiopia and Japan.



Dr. Ergogie Tesfaye, Minister of Women and Social Affairs

Stigma and discrimination against persons affected by leprosy can be eliminated through our own efforts. The fight against leprosy and support for those who are affected is the responsibility of the government, and we will provide technical and financial support. ENAPAL's efforts can serve as a model for other organizations and governments.

INITIATIVE NEWS

Second phase of Don't Forget Leprosy campaign includes support for 2nd Global Forum of People's Organizations on Hansen's Disease

The Sasakawa Leprosy (Hansen's Disease) Initiative is supporting the 2nd Global Forum of People's Organizations on Hansen's Disease as part of the second phase of the Don't Forget Leprosy campaign. As was done at the time of the 1st Global Forum in the Philippines, the location and dates of the event were selected in relation to the International Leprosy Congress (ILC). This year, the ILC will take place in Hyderabad, India, Nov. 8-11. The 2nd Global Forum will be held Nov. 6-8.

In July, the Initiative opened a selection process for choosing people's organization representatives to join the 2nd Global Forum's Organizing Committee. By vote, representatives from the following six organizations were selected: MORHAN (Brazil, Americas); IDEA Ghana (Ghana, Africa); ENAPAL (Ethiopia, Africa); IDEA Nepal (Nepal, Asia-Pacific); HANDA (China, Asia-Pacific); APAL (India, Asia-Pacific). The Organizing Committee held an in-person meeting in Bangkok, Thailand, Sept. 4-5, to discuss the Forum's theme and program. Preparations are now underway for a program focused on strengthening

and maximizing the role of people's organizations in order to restore the dignity of persons affected by leprosy.



Organizing Committee for 2nd Global Forum.

The Initiative is inviting applications from organizations and individuals who can share "good practices" related to

building on the capacity of an organization, social inclusion, or partnerships with other stakeholders. From among the applicants, organizations and/or individuals selected by the Organizing Committee will be invited to be speakers at the Forum and the ILC.

Apply to share a "good practice":
<https://bit.ly/shf-good-practice>



¹ The title of the event reflects concerns and recommendations expressed by the African and Latin American/Caribbean assemblies at the time of the 1st Global Forum: "Hansen's disease" is used instead of "leprosy" and "People's Organizations on" is used instead of "Organizations of Persons Affected by."

Don't Forget Leprosy campaign's updated logo emphasizes "leave no one behind"

The Sasakawa Leprosy (Hansen's Disease) Initiative has updated the "Don't Forget Leprosy" logo in conjunction with the start of the campaign's second phase. The updated logo incorporates the "leave no one behind" principle that informs the United Nations' 2030 Agenda for Sustainable Development. The campaign shares the Agenda's imperative to combat inequalities and discrimination. The further we spread the "Don't Forget Leprosy" message, the more likely it is that no one affected by leprosy will be left behind.



**SASAKAWA
LEPROSY**
HANSEN'S DISEASE
INITIATIVE

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