

# FOR THE Elimination OF Leprosy

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



The cemetery at Tichilesti, a leprosy hospital in southeast Romania dating from 1928, where more than 100 people are buried.

**MESSAGE**

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## Thoughts from a Cemetery

Recently, I stood under a hot sun in the cemetery of Romania's only leprosarium, Tichilesti. The leprosarium sits in a valley, surrounded by a forest of acacia and lilac. Birdsong filled the air.

More than 100 people are buried in the cemetery — a hundred different stories interred in the earth. Like many leprosariums I have visited over the years, Tichilesti is a world apart. It is set back from the main road, out of sight and out of mind.

During the country's Communist era, the hospital was not marked on any map. The authorities did not want to acknowledge the existence of leprosy, or those with the disease.

Before the development of a cure, the solution to the "problem" of leprosy was to round people up and isolate them in places such as Tichilesti. Guilty of no crime, they ended up spending decades of their lives segregated from the rest of the population.

Today, we have multidrug therapy. Gone are the days when people diagnosed with the disease were removed from society. But elderly survivors of those times live on in sanatoriums in Japan, Taiwan,

Malaysia, Ukraine, Colombia and elsewhere. And while science may have progressed, mistaken beliefs remain in people's hearts.

I have written about this before, but I regard the stigmatization of people affected by leprosy — of which state-sanctioned institutionalization was but one aspect — as a negative legacy of humanity. The suffering they endured must never be forgotten. At the same time, however, this negative legacy also has a positive side: people's powerful will to live in the face of adversity and despair, as well as the humanitarianism of doctors and nurses.

Representative of the latter is Dr. Rasvan Vasiliu, the medical director of Tichilesti. In the future, he would like to see some buildings there preserved as a museum and memorial. Places such as Tichilesti are part of our human heritage. We must ensure that the memories they contain — and the stories of the people already laid to rest — are not lost.

— Yohei Sasakawa, WHO Goodwill Ambassador

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# 'Leprosy Remains a Preoccupation'

Health ministers outline the various challenges leprosy still poses.

*The Goodwill Ambassador met with a number of health ministers or their representatives on the sidelines of the 67th World Health Assembly for an update on leprosy control activities in their countries. Their comments are summarized below.*

## **Dr. Jose Van-Dunem, Minister of Health, Angola**

You have a special place in our hearts for visiting our country at a very difficult time [in 2003] and going to the countryside to see the challenges we faced in implementing the program. We will never forget.



Leprosy remains a preoccupation. The situation is under control at the provincial level, but in some municipalities is not where we would like it to be. Now we have a clearer picture because we are setting up a program to municipalize public health. This will allow us to put more human resources into the field and give us greater control and supervision. We also have a team of Cuban doctors, nurses and epidemiologists helping us in 70 municipalities.

The drugs for treating leprosy are available free of charge, so we have a responsibility to do our best to fight the disease. We are working with the minister of social welfare and rehabilitation to tackle discrimination. But our main focus is the national program of dermatology and the training of young doctors and nurses to recognize the main dermatological diseases. If they have queries, they can send pictures via smart phone or iPad to professors and this is increasing the opportunities for early case-finding and for improving the prognosis for patients.

## **Dr. Enrique T. Ona, Secretary of Health, Philippines**

I have recently been to the island of Culion to inspect the recovery efforts from Typhoon Yolanda six months ago. I also visited the leprosy museum and archives supported by Sasakawa Memorial Health Foundation. In the Philippines, leprosy is not a serious problem, but it is still a problem. The number of new cases has remained unchanged for the past three to four years. Prominent dermatologists tell me that some cases are not



being diagnosed right away by general practitioners because they don't recognize the symptoms, so this is something we need to look at.

## **Professor Dr. Pe Thet Khin, Minister of Health, Myanmar**

Over the past four to five years, case numbers have remained the same. I have informed President Thein Sein that although we have eliminated leprosy as a public health problem, we are still finding some 3,000 new cases annually. The president knows about the situation and says he will support us in bringing down that number.



During 2013, I enjoyed productive discussions with senior figures working in leprosy for many years and received invaluable suggestions and recommendations. One issue is the future direction of the Yenanthar Leprosy Hospital in Mandalay. Is it to be a treatment center, a training center, a rehabilitation center or a combination of all three? And should it be a leprosy hospital or a general hospital that also takes care of patients with leprosy? I will take the experts' advice.

Another challenge is the social rehabilitation of people cured of leprosy, as they are not always accepted by society or even by their own families. There are 1,000 acres of land in Mandalay that were given to people affected by leprosy some 20 to 30 years ago; they can work the land themselves or rent it out to other farmers. Currently, the government is in dispute with the farmers the land was originally taken from and we are looking to find a solution. The future direction of the hospital depends on how we resolve the issue.

## **Dr. Jarbas Barbosa, Vice Minister of Health, Brazil**

We believe the Bangkok Declaration [signed following last year's International Leprosy Summit in July], is an important tool for countries not to forget leprosy. It is totally unacceptable that in 2014 a person suffers from this disease and the possibility of disability.



Last week, Brazil finalized the data for 2013. All the indicators showed improvement, except

for the incidence of leprosy in children under 15. The reason for this is the campaign to de-worm schoolchildren and exam them for leprosy. The campaign, which is about to begin again, involves not only the ministry of health but the ministry of education, churches, NGOs and other stakeholders.

Out of several million schoolchildren who examined themselves, 250,000 reported something. Of these, 3,000 were sent to see a doctor for further examination. Out of this number, 300 were newly diagnosed with leprosy. What is good about the campaign is that children talk about leprosy with their families. It's important to take a family approach.

**“What is good is that children talk about leprosy with their families.”**

We are moving forward. In Brazil, leprosy is again on the table. It is a priority. Our new minister of health, Dr. Arthur Chioro, has the same commitment to leprosy as his predecessor.

In July, Brazil is hosting this year's meeting of heads of state of the BRICS nations (Brazil, Russia, India, China and South Africa). Following that meeting, there will be a meeting of BRICS health ministers. The focus will be on neglected tropical diseases — with an emphasis on leprosy.

**Dr. Seif Seleman Rashidi, Minister of Health, Tanzania**

The low prevalence rate makes case detection a challenge. Because health workers don't see many patients with leprosy, they are losing experience of diagnosing cases. There is a need for more education to improve case detection. At the same time, there is also a need to build up the capacity of communities so that they recognize the symptoms and visit clinics. This dual approach is how we will achieve control of leprosy: through intervention on the part of health services and through intervention on the part of the community. Another important area is to support those with disabilities — and those who make the crutches and other tools that people with disabilities need in their daily lives.



**Dr. Félix Kabange Numbi, Minister of Health, DR Congo**

Leprosy is a very big challenge, but your support has made a difference to our efforts. The problem is now significantly reduced. If we can mobilize the resources, it will be possible to make even further progress. We know the areas where leprosy remains; we just need the resources to mount a campaign.



**Dr. Alexandre Manguela, Minister of Health, Mozambique**

Mozambique has made great progress in recent years. The economy is growing; the quality of life is improving; the fight against poverty is gathering pace. We want to use the country's natural resources to improve the quality of life. I spent some time in Japan in the 1980s; I learned a lot and improved my technical capacity as a doctor. I will do my best to see that young health professionals go to Japan to be exposed to a professional environment, so as to improve services in Mozambique. I am working with colleagues to revamp the country's leprosy program and create a new roadmap. We still need your support; together, we can beat leprosy.



**Mr. Zhang Yong, Deputy Director-General, Bureau of Disease Prevention and Control, National Health and Family Planning Commission, China**

China has made strides in prevention and control. The rate of infection is now low, but we still see new cases — around 900 in 2013. The government attaches great importance to raising awareness of leprosy, promoting treatment and eliminating discrimination. Every World Leprosy Day, the health minister participates in events. However, there is still a long way to go to root out discrimination. ■





# Praise the Lord

A Romanian pastor has a special bond with his congregation.



Romica Nedelcu is ministering to his small flock at the Baptist church at Tichilesti, Romania's only leprosy sanatorium, as he does every Sunday. Casually dressed – as casually as most of his congregation – he sits at a desk decorated with a flower plucked from in front of the 75-year-old church that morning.

If Romica looks very much at home among the residents of the sanatorium, it is because he used to be one himself. These are old friends and neighbors who have a shared experience of leprosy. “We are like family,” he says.

Born in 1944, Romica entered Tichilesti in 1956 at the age of 12. His mother, who preceded him there by four years, burst into tears at finding him marked by the same disease. Romica, for his part, was glad to be reunited with her.

Coming to Tichilesti signaled the end of his formal education. He passed the time playing chess and backgammon, going fishing and watching TV. Occasionally, with the doctors' permission, he was allowed out to visit his father.

As he grew into manhood, he lived from day to day, not knowing how long he would remain



Romica takes the service on a recent Sunday in May.

at Tichilesti or when his treatment would end. He began drinking, smoking and playing around. “I had several girlfriends,” he admits.

At 27, Romica came to the realization he was heading down the wrong path. It happened at 9.30 on May 9, 1971. He had come back from the city of Constanta, where he had been treated in hospital for a stomach complaint, and began to read the Bible. “I had been forced to read the Bible before,” he said, “but for the first time the Word entered my life. I knew I had to change my ways.”

**Romica believes God gave him leprosy and that through leprosy he found God.**

## A PASTOR IS BORN

He began assisting the elderly minister at the Baptist church. Eventually, he was taking the service himself. “God put in me the ability to preach the Gospel,” Romica says.

He also settled down. He met his future wife through an introduction and after a three-year courtship they married and set up home in the nearby town of Braila, when he was 34. They have two sons and a daughter.

Religion was strictly controlled during the Communist era, but the church at Tichilesti continued to function. “I can't speak for the Communists, but I expect they felt that a church operating in such a secluded location wouldn't have much influence.”

Even so, the secret police occasionally came calling—once because letters containing Bible passages that Romica had sent anonymously to senior Communist Party officials were traced back to him.

Romica believes God gave him leprosy, and that it was through leprosy that he found God. “If I had not got leprosy, I probably would have stayed in the city without God in my life.”

Concerning the Bible's portrayal of leprosy as a disease of the unclean, he says he is careful not to use leprosy as a symbol of sin, “because that doesn't have relevance to the people here.” He goes on: “Jesus didn't discriminate against people with leprosy. He was there for everyone. I am the same.”

He says he is not ashamed of leprosy nor tried to conceal his history of the disease. It has given him an affinity to feel the pain of others, something he believes that everyone in Tichilesti has.

“I am fulfilling my purpose in life,” he says. “It's a miracle.” ■

## A Visit to Europe

The Goodwill Ambassador travels to Geneva for the 67th World Health Assembly and visits a Romanian leprosy hospital by the Danube Delta.

### SWITZERLAND (May 19-23)



With Dr. Emma Guzman as she holds the Sasakawa Health Prize

I always value my visits to Geneva during the World Health Assembly. One of my purposes this year was to sustain the momentum generated by the Bangkok Declaration. This was the declaration endorsed by 17 leprosy-endemic countries at last July's International Leprosy Summit in Thailand, when they agreed to renew their commitment to achieving a leprosy-free world at the earliest. The summit was called to inject fresh energy into leprosy control activities in the face of stagnating annual new case numbers.

At the summit, I announced that the Nippon Foundation pledged a maximum US\$20 million for projects that would improve efforts to tackle leprosy for a period of five years from 2014. As I made the rounds in Geneva, I urged health ministers of the relevant countries to submit proposals for consideration if they had not already done so, while also asking the WHO's regional directors to encourage the countries in their regions to take advantage of this opportunity to strengthen and refine their

anti-leprosy efforts.

Some three-and-a-half years have elapsed since the adoption of the historic UN resolution on elimination of discrimination against people affected by leprosy and their families. Since then I have been organizing a series of regional symposia on leprosy and human rights to explore ways of implementing the Principles and Guidelines noted in the resolution.

Following symposia in the Americas, Asia and Africa, the next gathering is scheduled for the Middle East and will take place in Morocco this autumn. Meeting with Morocco's director of epidemiology and disease control, Professor Abderrahmane, I was gratified to hear him say that the symposium comes at a good time for Morocco. "Human rights have a big place in our constitution," he said, referring to the new constitution that came into effect in 2011. He also told me that the Ministry of Health had just signed a Memorandum of Understanding with the National Council for Human Rights in order to collaborate on addressing stigma in relation to HIV, leprosy, mental illness and other diseases. "I think this is a good context for Morocco to host the event," he said.

### I urged health ministers to submit proposals for funding consideration.

Another of my initiatives marks its 10th anniversary next January when Global Appeal 2015 to end stigma and discrimination against people affected by leprosy is launched in Japan. I am hopeful that the International Council of Nurses and its member associations will endorse next year's appeal. As the ICN is headquartered in Geneva, I had the chance to meet its president, Dr. Judith Shamian, and chief executive director, David C. Benton, for a productive discussion.

Nurses represent the largest body of medical professionals in the world; they are also very close to the community. I am convinced that their backing for the Appeal would represent a huge step forward for our efforts to break down the remaining barriers of >>



Calling on Hima, Tichilesti's oldest resident

discrimination.

An important item on my Geneva agenda each year is to attend the award ceremony for the Sasakawa Health Prize. Given each year for innovative work in public health, the prize this year went to the Leprosy Control Foundation, Inc./ Hubert Bogaert Institute of Dermatology and Skin Surgery in the Dominican Republic.

Established in 1963, the foundation has played a major role in tacking leprosy in the republic and treated more than 13,000 patients. Collecting the award was Dr. Emma Guzman, who said the prize will be used to benefit those most in need. To Dr. Guzman and all her colleagues I offer my heartiest congratulations.

I also met with Dr. Margaret Chan, the WHO's director general. In extending my term as Goodwill Ambassador for another two years, she expressed the hope we would be able to visit Brazil together one day. I would very much welcome the opportunity.

### ROMANIA (May 26)

Romania's Danube Delta in the southeast of the country is home to 300 species of birds and 45 species of freshwater fish and is on UNESCO's World Heritage List. Less well known, but also part of our heritage, is the leprosy hospital at



The sign at the entrance to the hospital.

Tichilesti in the delta region, where the River Danube empties into the Black Sea south of the border with Ukraine.

A sign on the road from Tulcea, a city some 40 kilometers away, indicates the turn-off for "Tichilesti Hospital." A five-minute drive down a narrow road that cuts through rolling countryside brings one to the entrance. Only then does the facility properly announce itself: "Tichilesti Hospital – Leprosarium."

Strictly speaking, Tichilesti no longer functions as a leprosarium. No new cases of leprosy have been recorded in Romania in recent years and residents are free to come and go. In 2005, with the assistance of European Union funding, part of the hospital was turned into an old people's home to help integrate Tichilesti into the community. More recently, it has also been accommodating patients with psychiatric problems.

Tracing its origins back to a monastery that cared for people with the disease, the current leprosy hospital dates from 1928.

When once there were as many as 200 patients under treatment for leprosy, there are just 16 persons affected by leprosy resident at Tichilesti today, ranging in age from their 50s to their 80s.

Greeting me at the entrance was Dr. Rasvan Vasiliu. He has worked at Tichilesti since 1991. Dr. Vasiliu studied under a renowned Romanian dermatologist, Dr. Pavel Vulcan, who shaped Dr. Vasiliu's approach. "His attitude really impressed me and was a kind of guideline for me in my life. He wasn't just a professor or doctor but a human being. For him, the people at Tichilesti were normal human beings, just as he was. This was the most important thing I learned from him," he said.

It was Dr. Vasiliu who showed me round Tichilesti. Its white-washed buildings were



Dr. Rasvan Vasiliu





The pace of life is relaxed at Tichilesti.

bright against the backdrop of forested hills and a clear blue sky.

Here and there I stopped to chat with residents, who I found sitting outside on benches passing the time of day. Maria was dressed in her finest and had a red flower behind her ear. In her 70s, she was diagnosed with leprosy at 15 and has lived at Tichilesti ever since. Long a widow, she joked that she was looking for a rich husband. “I can’t wait any longer. You’ll do!” she said. Her son and daughter-in-law live in the next village. “My daughter-in-law is wonderful. She is as beautiful as this flower,” she told me.

Tichilesti has two churches, Orthodox and Baptist. The pastor of the Baptist church is a former patient. Romica, who had delivered a sermon the previous day, had stayed overnight especially so that he could meet me. I told him that he was the first pastor I had met who was also a person affected by leprosy.

Close by the Baptist church I met Domnica. Her mother Iona was a resident from 1941 until her recent death and Domnica herself was born here. She lived in Tichilesti until she was 13 before starting school and later getting a job. Now she is retired and lives on a pension. She told me that she used to come and stay with her mother every month, and still spends 10 to 15 days a month at Tichilesti. “My heart is here,” she said.

I visited another lady, also called Maria. She has five children, 11 grandchildren and two great grandchildren. She was listening to religious music on her radio. “I have been sustained by the love of God,” she tells me. “I have been a widow for 11 years, but I am fortunate.” She said that she appreciated my visit because it was an opportunity to meet someone new and chat about different things. “Usually, we just talk to the same old people.”



Domnica: “My heart is here.”

Tichilesti’s oldest resident is Hima. She lives in a cottage up a hill, and negotiates a flight of steps each day to reach the main part of the hospital. She arrived in Tichilesti a month shy of her 18th birthday. On June 6, she turned 86. Of the 160 people receiving treatment when she first came, she is the only one who is still here.

When she first arrived, she was in such pain that she couldn’t leave her bed. Now she is a spry octogenarian. “It’s because I thank God every day that I am able to get up every morning and have been able to live healthily to this great age.”

I wondered what life was like under the Communist regime of Nicolae Ceausescu, which ended with his overthrow in 1989. According to Dr. Vasiliu, while leprosy was not talked about during the Communist era and the hospital’s existence was not acknowledged, the residents were provided for by the state and received the necessary food and drugs. “They were never abandoned,” he said.

“The big change today is in the mentality. Before, the gates were closed and there were very few visitors — and absolutely no foreigners. Now, the gates are open.”

I understand that Dr. Vasiliu has worked hard to remove any misunderstandings about leprosy among the public, giving interviews to the media over the years and dispelling myths about the disease. From talking with the residents, it was clear to me how much he and his staff were appreciated for the care they provide and what they have done to normalize life at Tichilesti.

Before I left, Dr. Vasiliu thanked me for visiting and said that it had been like a festival for residents and staff alike. “I hope you will become our ambassador and tell the world about us.” I am happy to do so. ■

# Interrupting Leprosy Transmission

Novartis, NLR announce collaboration on preventative treatment.

On June 10, Novartis Foundation for Sustainable Development and Netherlands Leprosy Relief (NLR) announced they would be collaborating with national leprosy programs and other partners from the International Federation of Anti-Leprosy Associations (ILEP) to interrupt the transmission of leprosy.

The newly announced collaboration, known as the Leprosy post-exposure prophylaxis project (LPEP), aims at introducing preventative treatment for contacts of newly-diagnosed patients to decrease their risk of developing leprosy.

While unanswered questions remain about how leprosy is passed from person to person,

it is recognized that close and frequent contact with an individual who is infectious increases the risk of transmission.

In recent years, the case detection rate of leprosy has leveled off at around 220,000 to 250,000 new cases annually. As a way to break this impasse, Novartis is looking to shift the focus of anti-leprosy activities to interrupting the transmission of the disease through preventative treatment.

Operating at several sites across Asia, Africa and Latin America, LPEP aims to provide evidence of the impact of post-exposure prophylaxis on case detection rates and its feasibility as a strategy to prevent leprosy transmission.

## LEPROSY VACCINE

A vaccine for leprosy is being developed by American researchers and is set for toxicology tests toward the end of 2014 and for Phase I clinical trials in human volunteers by 2015, SciDev.Net reports. The project is led by the Infectious Disease Research Institute (IDRI) and the American Leprosy Missions

(ALM). For the clinical testing phase, they have partnered with the Philippine-based Cebu Leprosy and Tuberculosis Research Foundation. For the past 12 years, the ALM has invested US\$4 million in the endeavor to develop the leprosy vaccine and a new diagnostic test for the disease. ■

## FROM THE EDITORS

### BROTHERS IN ARMS

Last month saw the passing of two men who had been leading lights in the movement to restore the dignity and human rights of people affected by leprosy in Japan.

Michihiro Ko, the president of Zenryokyo, the All-Japan Hansen's Disease Sanatoria Residents' Association, died at the age of 80 on May 9. Born in Fukuoka Prefecture, he developed symptoms of leprosy at 17 and was sent to Oshima Seishoen, a leprosarium on an island in Japan's Inland Sea. As general secretary of Zenryokyo from 1995 (and president from 2010), he campaigned tirelessly to improve conditions for Japan's sanatorium residents and was active in the movement that saw the overturning of Japan's Leprosy Prevention Law in 1996. At the time of his death, Mr. Ko was working on an appeal against the government's plans to cut back the number of personnel at sanatoriums, arguing that this posed a danger to the lives of the remaining elderly residents, many

of them living with disabilities.

Yuji Kodama, who died of lung cancer on May 11, was also a key figure in championing the rights of people affected by leprosy. Born in 1932, he displayed symptoms at 7 and was sent to a sanatorium in Tokyo. He was later transferred to Kuryu Rakusenen in Gunma Prefecture. An activist and poet, he led the fight for compensation from the central government for its decades-long policy of isolating those with the disease.

Following a legal challenge mounted by Mr. Kodama and a group of plaintiffs, the Kumamoto District Court ruled in 2001 that the policy had been unconstitutional and those who suffered under it should receive an apology and compensation. Just before he died, he was able to attend the opening in April of a museum he had campaigned for: a reconstruction of a detention facility showing the appalling conditions in which sanatorium residents were held for disciplinary reasons.

## FOR THE ELIMINATION OF LEPROSY

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