

FOR THE Elimination OF Leprosy

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



A doctor explains the treatment for leprosy to a 21-year-old man diagnosed with the disease in Mato Grosso state, Brazil, in August.

MESSAGE

Looking to Brazil

Brazil is a country that has yet to eliminate leprosy as a public health problem. When I visited in August, however, the health minister gave me a firm pledge that Brazil would fulfill its commitment and achieve elimination by the end of the year.

According to the ministry's latest data, the prevalence rate of the disease was 1.27 per 10,000 population in 2014. The official figures for 2014 were 31,064 new cases detected and 25,738 cases under treatment as of December 31. As patients who have completed their treatment are not always immediately removed from the register, however, I learned that the true figure for prevalence is actually smaller.

During my stay I traveled to the states of Mato Grosso, which shares a border with Bolivia and has the highest prevalence rate of leprosy in the country, and Pernambuco, on the northeast coast. While in Mato Grosso, I visited the homes of leprosy patients in the vicinity of the capital, Cuiaba, and observed health personnel examine household contacts. I found the situation to be fairly serious.

In a relatively shortly space of time, several family members in each household were identified as suspected cases. Based on what I saw, one has to assume there are many more hidden cases in Brazil. It really brought home to me how important it is to examine the family of a person diagnosed with leprosy to see whether or not anyone else has the disease. The state governor is deeply concerned and we decided to organize a project for leprosy elimination involving the state health department, federal university and NGOs.

For now, I strongly hope that Brazil will achieve national-level elimination of leprosy by year's end, as per the health minister's comment to me. Should this happen, it will truly represent a major landmark in our long struggle against this disease.

Next will be to eliminate leprosy as a public health problem at state level and take measures to deal with so-called hot spots within states. I salute the health ministry for the efforts it is making and hope that it will strengthen its activities further.

— Yohei Sasakawa, WHO Goodwill Ambassador

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Momentum for the Last Mile

A leprosy dialogue in Brazil hosted by Novartis Foundation provides lots of talking points.

Putting leprosy back on the global agenda was one of the goals of a two-day leprosy dialogue organized by the Novartis Foundation and co-hosted by Brazil's Ministry of Health and the Nippon Foundation on August 6-7 in Brasilia.

With an estimated 3 million undiagnosed leprosy cases in the world today, the necessity to refocus attention on the disease is clear.* And it was no coincidence that the venue chosen for the dialogue was Brazil, which reported 31,064 new cases in 2014 and is the last major country yet to achieve the WHO's goal of eliminating leprosy as a public health problem.

Welcoming participants as well as those watching the live webcast of the first day's proceedings, Novartis Foundation head Dr. Ann Aerts said she was delighted to be able to show the region and the world some of the innovative and dynamic initiatives that Brazil was taking against leprosy.

In 2011, Brazil introduced a strategic action plan for the elimination of Neglected Tropical Diseases (NTDs) and poverty-related infections. As part of that strategy, in 2013 it launched a campaign for school-based de-worming and leprosy screening, and more diseases are being added each year.

"Putting leprosy together with other diseases benefits leprosy. It keeps the disease funded and visible," said the health ministry's Dr. Rosa Castalia, who also noted that disease control is taking place against the backdrop of a core government initiative to eliminate extreme poverty from Brazil.

Dr. Castalia announced that Brazil is closer to the elimination goal than official figures indicate. As data for the National System of Notifiable Diseases is input at the municipal level, this leads to delays in updating the information. As a result, patients who have been cured may still be in the system at year's end, when prevalence is calculated. The ministry is asking municipalities to tackle the issue, she said.

"We shouldn't worry that Brazil hasn't yet achieved elimination, but recognize that it is on the right track to achieve it sooner or later," said Dr. Ruben Santiago Nicholls of the Pan-American Health Organization. "There is a lot that other countries can learn from Brazil."

LOW AWARENESS

Presentations from some of Brazil's Latin American neighbors with comparatively few cases of leprosy showed the challenges countries face when the disease is not considered a priority. In Peru, awareness is low and there is a need to



Dr. Rosa Castalia: integration benefits leprosy.

train health professionals to be able to diagnose new cases. "Dermatologists ask if the disease still exists. They don't think of leprosy," said Dr. Valentina Guizado.

In Bolivia, which saw 118 cases in 2013, it was a similar story in that many doctors don't know to suspect the disease. "When I took a course on leprosy, it lasted only 90 minutes," said Dr. Gilda Fernandez, the national leprosy program manager, whose program operates on a budget of just US\$14,000. "We need to train health staff to recognize leprosy, monitor contacts and involve community leaders," she said. "Unless we involve community leaders, we won't reach the marginalized."

From the floor, representatives of the Movement for the Reintegration of People Affected by Hansen's Disease (MORHAN) emphasized the importance of social policies in the fight against leprosy. "If we don't fight against discrimination, leprosy will remain hidden," said national coordinator Artur Custodio.

Concerning hidden cases, Dr. Claudio Salgado, vice president of the Brazilian Society of Leprosy, sounded a somber note. Speaking of Para state, where he has done leprosy surveillance work over a number of years, he said hidden endemicity was "extremely high" because basic health units had difficulty diagnosing the disease. He estimated that 4% of schoolchildren in the state have leprosy, which means that there are 80,000 cases yet to be diagnosed, he said.

Goodwill Ambassador Yohei Sasakawa attended the meeting and delivered one of the keynote speeches. He said he was delighted to partner with Novartis Foundation and the health ministry to make progress toward the "final mile" in leprosy.

While that final mile may take a long time to cover, events such as this generate momentum in the right direction, however challenging the remaining obstacles sometimes seem. ■

FOOTNOTE

* "The Missing Millions: A Threat to the Elimination of Leprosy" *PLoS Neglected Tropical Diseases* 2015 9(4)

‘Nobody Believed Her’

In Brazil's Mato Grosso state, people suffer because doctors don't recognize leprosy.

PROFILE:

Dr. Luciana Neder



Dr. Luciana Neder is a doctor specializing in leprosy at Hospital Universitario Julio Muller in Mato Grosso, Brazil. The state has the highest case detection rate of leprosy in the country.

How is the situation in your state?

Yesterday, I saw five cases of leprosy. Four people were already disabled by the time they came to me, including a child of seven who had lost some fingers and had a claw hand. There was a 40-year-old woman who had been looking for a diagnosis for three years. She knew that she had leprosy, but nobody believed her. She also had ulcers.

What's the problem?

Communities have access to doctors, but unfortunately many doctors don't recognize the disease because they don't know enough about leprosy. Leprosy is fundamentally a disease of the peripheral nerves with skin manifestations, but not always. You have to learn to examine the peripheral nerves, to examine the sensitivity. It's easy to diagnose someone with a skin patch; it's much harder without a patch when you have to look at nerve involvement.

Were you familiar with leprosy as a child?

No, only after I entered medical school. I did my residency at the Instituto Lauro de Souza Lima (a specialist dermatology and leprosy center in Sao Paulo) and saw leprosy patients many times. I wrote my doctoral thesis on leprosy.

What drew you to specialize in the disease?

The disability that it leaves behind; the after-effects.

Are your fellow health professionals interested in leprosy?

No, because it is not a specialty that makes money for them as consultants. It is not profitable for doctors.

If you had to persuade them, what would you say?

You have the power to change the course of someone's life, especially a child, when you make a diagnosis. If you don't act at this moment, that child will have complications that will affect the rest of his or her life. As a doctor, you can make a difference.

What needs to happen now?

We need to train doctors and healthcare staff at the very local levels — the basic health units, the primary health care units — to identify and treat leprosy patients. That way, you cover most of the cases. Difficult cases can be referred to referral centers. If you train doctors at the periphery of the health structure, you will reach most of the population and then you will improve the diagnosis and treatment. ■

HERITAGE

SUNGAI BULOH'S 85TH ANNIVERSARY

An international symposium on the preservation of heritage and the collective memories of communities affected by leprosy was held on 14 August 2015 at the National Leprosy Control Center at Sungai Buloh, Malaysia. Previously known as Sungai Buloh Settlement when it opened in 1930 as the largest leprosarium in the British Commonwealth and the second largest in the world, Sungai Buloh marked its 85th anniversary this August.

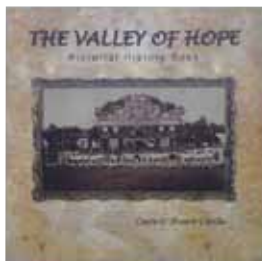
To commemorate the anniversary, Sungai Buloh Hospital is opening a gallery that will feature the lives of former patients and medical artifacts. A project of the Ministry of Health and the Department of National Heritage,

the objective of the gallery is to tell the life stories of the patients, correct misperceptions about the disease and preserve the history of the settlement.

Sungai Buloh was also known as

stories and eliminate prejudice and misunderstanding. The book, which was paid for by the Sungai Buloh Settlement Council, is a valuable record of the settlement's 85-year history and its distinctive culture.

The one-day symposium heard presentations from Japan, Malaysia, the Philippines and Taiwan. It also gave participants the opportunity to go on a heritage tour of



Read the book, take the tour: tools for appreciating Sungai Buloh

“The Valley of Hope” and a pictorial history book by that title has been published by Care & Share Circle, a group of volunteers who work with the remaining residents to tell their

the settlement — the brainchild of the residents' descendants. As Dr. Arturo C. Cunanan from the Philippines noted, “Entering the settlement is like walking into an open air museum.”

What Are We Waiting For?

Actions can be taken now to tackle delays in diagnosis and reduce transmission.

The priority today for global leprosy activities is to reduce transmission. There are actions that can be implemented now that will help achieve that. However, reducing transmission to zero will need further research to develop accurate diagnostic tests, well-organized chemoprophylaxis and effective vaccines to prevent leprosy.

Leprosy surveys in many countries continue to find considerable numbers of undetected and untreated patients in the community due to delay between the onset of symptoms and detection. This delay in diagnosis increases the risks of nerve damage and disability for patients as well as contributing to ongoing transmission.

Leprosy surveys continue to find considerable numbers of undetected and untreated cases.

There are two specific actions that all programs should now develop that can tackle this problem of delay in diagnosis: active management of contacts and focal approaches to leprosy control. They need not be costly and they could be integrated with other Neglected Tropical Disease (NTD) programs.

One effect of this will be to increase new case detection numbers. As the Goodwill Ambassador observed in his Message (Issue #74, June 2015), this is a positive sign of improved leprosy control because of the existing hidden cases, and it will contribute to reducing transmission.



Examining a contact in Mato Grosso state, Brazil

But the key to monitoring progress is not in the numbers of new cases detected but in monitoring reduction in disability (WHO Grade 2 Disability) in new cases, as proposed in the current WHO Global Strategy for 2011-2015.

Let us consider these two actions in more detail:

1. Active Contact Management

Contact management is an integral part of the current global leprosy strategy and is described in detail in the WHO operational guidelines.

Coverage of contact management needs to be improved, however. It should be monitored by looking at the number of contacts identified as well as the percentage of contacts examined.

Other activities can be conducted with contact management to give added value. There is the opportunity to improve community awareness through education and counseling. Contacts can be made aware of the signs of leprosy and how to seek help in the future. The index cases are important assets in the process.

Chemoprophylaxis with single-dose rifampicin can be simply added when good contact management is in place. This is also an opportunity to give positive messages to change attitudes to leprosy and those affected by leprosy by showing that the disease is not only curable, but preventable.

2. Focal Leprosy Control

Maps of the distribution of leprosy over the years show a progressive shrinking of leprosy into focal pockets. This can be seen in both global and national maps of leprosy or by using Geographical Information Systems (GIS).

It no longer makes sense to have a national program that uniformly provides leprosy services to every part of the country in the same way, whether or not they have new leprosy cases.

Maps can identify discrete focal areas where there are a higher number of new cases so that more active approaches to leprosy control can be used.

These more active approaches would include focal awareness campaigns, strengthening capacity of the local health care staff, case-finding activities, and even selective surveys in communities and schools. Community volunteers, people affected by leprosy, and community and religious leaders can also be encouraged to support the local control efforts.

Maybe there could be focal immunization as was used in smallpox control or mass chemoprophylaxis as is used in other NTD programs. But that is for the future; there is still much that can be done now. ■

AUTHOR:

W. Cairns Smith



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Don't Neglect Brazil

The country offers fertile ground for pilot initiatives that can benefit the world at large.

AUTHOR:
Duane Hinders



Duane Hinders is Country Representative, Netherlands Leprosy Relief, Brazil.

In recent years, it has become increasingly difficult to find international non-governmental partners and donors willing to work in Brazil. From a purely economic point of view, this is logical given that Brazil has the seventh largest economy in the world and a high tax burden from which to address social needs.

When comparing whether to support a smaller country in Africa or Asia or a continental behemoth like Brazil, organizations must make rational choices about the allocation of scarce resources. Large-scale international events, such as the 2014 FIFA World Cup and the 2016 Summer Olympic Games in Rio de Janeiro, lend even more credence to international perceptions that Brazil needs little external support to tackle basic public health problems.

When discussing Hansen's disease or other Neglected Tropical Diseases (NTDs), however, few countries bear the burden that Brazil does. Despite a strong and decentralized public health system, nearly 90% of all new cases of Hansen's disease in the Western Hemisphere are Brazilian.

Few organizations that deal with leprosy and other NTDs maintain a presence in Brazil.

With only 20% of the hemisphere's population, it also has virtually all cases of schistosomiasis and visceral leishmaniasis as well as the majority of trachoma, leptospirosis, dengue fever, malaria and Chagas disease. There are even pockets of onchocerciasis and lymphatic filariasis that still need attention. Nevertheless, few organizations that deal with leprosy and other NTDs maintain a presence in the country, and donors rarely include it as a priority nation.

INCOME INEQUALITY

Along with the geographical and climatic factors that favor these diseases, there is also the factor of inequality that skews any discussion on Brazil. Despite an improving GINI coefficient*, there are still only four countries with a more inequitable distribution of income in the world.

Nearly 11% of the total population — 22 million people — live on less than \$2 per day, and these are the ones disproportionately affected by diseases of poverty. Although each disease has unique pockets of high-burden areas throughout the country, there is a greater risk for those living in the impoverished northeast, the Amazon River

basin and in communities of indigenous peoples that dot the national landscape.

POTENTIAL IMPACT

Regardless of the regional and economic disparities that contribute to a major disease burden akin to Asia and Africa, most aid organizations see only the middle-income, BRICS reality of Brazil. However, even if one discards the possibility of direct interventions and social development projects, there are still a number of important opportunities for international NGOs, universities and donors to have an impact for the world at large:

- Brazil offers a unique combination of multiple tropical diseases and a number of highly skilled researchers. This has led to a number of joint research projects over the years, especially with large universities in the south and southeast. However, the range of committed researchers and scientists goes well beyond the federal public universities and allows for engaging studies closer to the endemic leprosy and NTD areas. The combination of institutional capacity and persons in need of new health tools and services makes it a very attractive national partner;
- The variety of NTDs and high level of regional and urban poverty allow for cross-cutting initiatives that take a holistic view of the individuals affected. Netherlands Leprosy Relief and other ILEP/NNN** members have been working on approaches to work transversally for improved social inclusion, quality of life and access to services;
- Brazil offers fertile ground for pilot initiatives and testing of new diagnostic tools and vaccines that could be scaled up within Brazil and expanded to other countries in need. While it may be possible to outsource the rollout phases to the Brazilian government, support for innovative strategies is often welcomed locally even as an initial testing ground.

Despite the crushing need of direct support in many regions and communities of Brazil, there is not likely to be a large-scale return of international NGOs and donors to the public health arena.

However, the country offers important conditions for the development of new approaches, research, training courses and technical tools that can benefit its own population affected by Hansen's disease and other NTDs as well as those in many other countries across the world. ■

FOOTNOTES

* An economic measure of income inequality.

** International Federation of Anti-Leprosy Organizations/Neglected Tropical Diseases Non-governmental Development Organizations Network

Leprosy's Front Line

Hidden cases of leprosy in the community remain a stumbling block to rooting out the disease, the Goodwill Ambassador finds on a recent visit to Brazil.

BRAZIL (AUGUST 4-14)



Watching as Cicero examines a family contact

One in seven of all new cases of leprosy in the world are found in Brazil. For some years, Mato Grosso state has had the highest new case detection rate in the country. In August, I visited Cuiaba, the state capital, to see for myself something of the challenges Brazil faces in combating leprosy.

The Sucuri district health center is about a 20-minute drive from the city center and serves a community of around 5,000 people. There I met Cicero Frasa de Melo, an experienced nurse who works as coordinator for the state health department's leprosy program.

I observed him examine a number of local residents who had been invited to the health center for a checkup. Using hot and cold test tubes, followed by a pin prick test, he looked for impaired skin sensibility and also examined the peripheral nerves for signs of thickening.

Of four people I saw him examine, one required further testing and another had the diagnosis confirmed by a doctor. The latter patient, a 21-year-old man, was told he had to take medication for 12 months but would be able to live a normal life. Arrangements were made for his family to be examined too.

From the health center, I accompanied Cicero on two home visits to examine household contacts of existing patients. At the first house was a man under treatment who was living temporarily with his sister and brother. His sister, brother and brother's daughter were all examined. To general dismay, both the man's sister and his 20-year-old niece were diagnosed with the disease.

Next we visited the home of a 17-year-old boy who had been diagnosed with leprosy two weeks earlier. His father, mother and two brothers were

all examined. This too resulted in a disturbing outcome: all three males exhibited signs of leprosy; only the mother was leprosy free. Cicero said it was likely that the father had infected his sons.

In the space of a few hours, I had seen at least half-a-dozen cases diagnosed. If concerted efforts are made at early detection, no doubt many more new cases would be found. Contact tracing is very important and it is essential that those who do not display obvious signs of the disease, such as skin patches, are examined by a doctor or nurse trained to recognize nerve impairment.

Mato Grosso's governor, Pedro Taques, made his concern plain. He told me that agribusiness has made Mato Grosso a wealthy state, but that one thing made him ashamed — the high rate of leprosy — and he wanted to address this during his term. "It will mean more to me if the rate of leprosy goes down than if the rate of soybean production goes up," he said.

In the 40 some years I have worked for leprosy elimination, traveling to more than 120 countries, I can say from experience that the commitment of leaders is absolutely essential to getting something done. I could see that commitment in the governor and told him I would assist in his state's fight against leprosy. I was also impressed by a state assemblyman, Dr. Leonardo Albuquerque, who was equally determined to do something about Mato Grosso's leprosy burden.

The international network IDEA (Integration, Dignity and Economic Advancement) has a branch in Mato Grosso. I went to a meeting in the grounds of a local church. The group has about 15 members affected by leprosy, but not all attended because they were embarrassed over their appearance. "The biggest challenge we face is disability," their leader Alzira Rodriguez told me. "Some people with leg ulcers worsen their condition just by going to and from the health center for treatment," she said, adding that "some doctors don't want to examine us."

From Mato Grosso I traveled to Pernambuco state in Brazil's northeast, another state with high endemicity of leprosy. On arrival in Recife, I was given a briefing by the state health department, where officials explained to me how they have ramped up efforts against the disease. Central to this has been the Sanar Project, a program introduced in 2011 to tackle Neglected Tropical Diseases in the state in an integrated way.



Mato Grosso Governor
Pedro Taques

(Left) Hospital Mirueira residents Maria (seated) and daughter Zelma; an art class at an IDEA meeting in Mato Grosso



Indispensable too has been the cooperation between state and municipal health authorities, with a focus on cities that are high priorities.

While in Recife, I visited Hospital Geral Mirueira, a former colony hospital in the outskirts of Recife. Opened in 1941, it has been home to many leprosy patients over the years. At its busiest, there were 500 patients living there. It was like a small town back then, with places of worship, a library, a theatre, a band, a radio station and newspaper. Patients raised chickens and pigs and grew their own food.

Today there are just 15 people left in residential accommodation, not including some two dozen bed-ridden cases, while the hospital sees around 200 leprosy outpatients a month. From 2001, it has also started accepting drug addicts as in-patients.

Dr. Jose Carlos Rosa told me that the hardest challenge is to help those who have been cured, but still bear physical — and emotional — scars, to reintegrate into society. “It is difficult to tell someone they have been cured when they have suffered impairment and disability,” he said.

A member of staff has been preserving residents’ stories, aware that as the remaining residents die their histories will die with them. She also has some books written by patients. This is truly a precious resource for posterity.

Touring the grounds, I was shown a room containing some 2,000 patient records. I called at the orthopedic department, chatted with some in-patients, and met some of the permanent residents. One man told me he had lived at the hospital for 43 years. “I arrived at 27 and have been here ever since. I spent my prime here,” he said.

In the afternoon I attended a meeting organized by the local branch of the Movement for the Reintegration of People Affected by Hansen’s Disease, or MORHAN. Their leader ran through the history of suffering of those affected by leprosy in the state — how they were separated from their families and forced to live in the colony hospital, how children born to parents there were taken from them, and how inmates had had to assume some nursing duties because of discrimination by health workers. Summing up the situation of people affected by leprosy today, he said, “What is required is that the rights of all Brazilians are respected. Everyone has the right to live equally in society.”

This visit to Brazil opened my eyes anew to the challenges it faces and the impact of leprosy on people’s lives. The country has my unwavering support in its efforts against the disease. I am ready to assist in whatever ways I can. ■

‘YOU HAVE TO COMPLETE THE TREATMENT’



The driver of my vehicle in Mato Grosso told me he once had leprosy. When small patches began to appear on his body in 2000, he quickly sought treatment and was cured without suffering any lasting after effects. “You have to be diagnosed and treated promptly. If you leave it, it only gets worse,” Admilson Luiz Da Silva told me.

“Some Brazilians won’t mention they have leprosy. But I believe that when you

have the disease, it’s wrong to say nothing. Because of the medication, your skin can turn darker; there can be side effects. But you have to complete the treatment.

“I told my family, my friends — everyone. I was never once discriminated against. My family has been examined; no one else has the disease.”

Are people getting the message about leprosy, I wanted to know.

“There isn’t enough publicity. More should be done. Not everyone reads newspapers.

“TV is best. Everyone watches TV. If something about leprosy aired at the same time each day, that would be great.”

Novartis Extends Drug Donation

Pharmaceutical company guarantees MDT drug security through 2020.

Novartis has renewed its pledge with the WHO to extend its donation of multidrug therapy (MDT) for treatment of leprosy for a further five years through 2020. Novartis has been donating MDT since 2000, taking over from the Nippon Foundation, which paid for the drugs between 1995 and 1999.

The extension by Novartis forms part of the company's commitment in 2012 to the London Declaration on Neglected Tropical Diseases.

This five-year agreement includes treatments worth more than US\$40 million and up to US\$2.5 million to support the WHO in handling the donation and logistics. Overall, the drugs are expected to reach an estimated 1.3 million patients during the next five years.

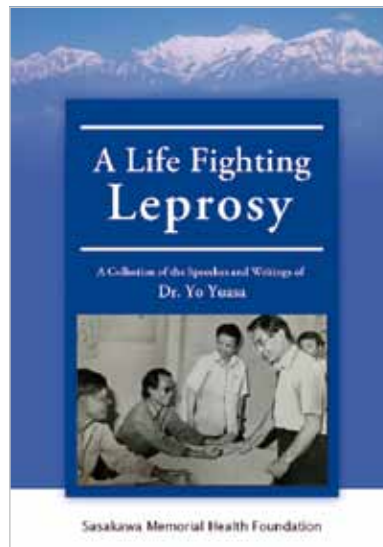
Since 2000, Novartis has donated more than 56 million blister packs valued at approximately US\$90 million through the WHO, helping to treat more than 6 million leprosy patients worldwide.

NTD TEACHING GUIDE

American Leprosy Missions has developed a teaching guide to address cross-cutting issues common to many Neglected Tropical Diseases and other health conditions. The package contains three sets of materials: *Ten Steps: A guide for health promotion and empowerment of people affected by Neglected Tropical Diseases*, the *Ten Steps Executive Summary* and *Ten Steps Summary Card*. The materials can be downloaded for free at www.leprosy.org/ten-steps.

'A LIFE FIGHTING LEPROSY'

A collection of the speeches and writings of Dr. Yo Yuasa, former medical and executive director of Sasakawa Memorial Health Foundation between 1975 and 2005, and advisor until 2012, is now available online at www.smhf.or.jp/e/hansen/publications/. Free copies of *A Life Fighting Leprosy* are also available in book form. ■



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FROM THE EDITORS

I AM ALZIRA

How does a person like to be identified? Alzira Rodriguez is clear about how she *doesn't* like to be identified. "I don't want to be known as a 'former leprosy patient'. We don't refer to a 'former TB patient', do we?" she remarked to the Goodwill Ambassador when he met her recently in Brazil.

Continuing in this vein, she added: "I don't like it when people refer to me as 'Alzira — you know, the one with deformed hands.' I just want to be known as Alzira."

Alzira is the leader of a branch of IDEA (Integration, Dignity and Economic Advancement) in Mato Grosso state. She is — and the description may not please her — a person affected by leprosy. Cured of the disease, she continues to live with its physical

after-effects as well as the prejudice and discrimination.

Until such time as society sees only the person and not the disability or the disease from which it sprang, Alzira continues to work for a better quality of life for those who have experienced leprosy; for greater awareness and understanding of Hansen's disease among the general public and health professionals; and for an end to stigma and discrimination.

She does so as a member of IDEA, an international human rights and advocacy organization comprised primarily of people like her; she does so as a person affected by leprosy, she does so as the mother of six children, she does so as a friend and neighbor. Above all, she does so as Alzira.