Welcome to the Peripheral Nerve Podcast, the official podcast of the Peripheral Nerve Society. I'm Camila Pupe, professor of neurology at Universidad Federal Fliminense, Rio de Janeiro, Brazil.

And I am Wilson Marques Jr, full professor of neurology at Universidad de Sao-Paulo-Ribeirão Preto. This is the very first episode of our special Leprosy Awareness series where you explore the science, history, and the clinical aspects behind one of the most misunderstood diseases of all time: leprosy.

In this episode, we'll take a deep dive into the history, stigma and current epidemiology of leprosy and we, we are honored to have as our guest, an outstanding physician and public health leader, Dr. Vera Andrade.

Dr. Vera Andrade has dedicated her career to Leprosy Advocacy, working with national programs and international organizations such, such as the World Health Organization. And welcome Vera. It's a pleasure to have you with us.

Thank you. Hello, fellow neurologists. It's a great pleasure to be here with you. Thank you so much for making space for this important conversation about leprosy — a disease that begins exactly where your expertise lies: in the peripheral nerves. I hope this dialogue helps us share knowledge, broaden our perspectives, and strengthen our joint mission to care, prevent disabilities, and promote dignity for those affected by leprosy.

Let's start by going back in time. When people hear the word leprosy, they often think of fear exile, or even biblical imagery.

Why do you think this image persists and how has history shaped our collective perception of the disease?

Oh, well thank you Camila. A very interesting question to start with. It's a sensitive topic. You know, since the Middle Ages, leprosy has been associated with impurity and divine punishment, leading to the forced isolation of patients as a way to control transmission around the world.

As a result of course, people have linked leprosy to fear and rejection. The spread of the disease, and the image of dread that came with it, became deeply rooted in centuries of institutional exclusion. For example, in Brazil, back in 1920, people with leprosy were forced by law to live in isolation, you can believe it? Taken away from their homes and loved ones.

It was a painful time marked by fear and exclusion. It forced this idea that leprosy was a contagious and disfiguring disease with no chance of being cured. Leprosy is a hidden disease for the general population — without positive media coverage, voiceless, with no space for complaints. It lacks strong images and success stories, so fear has taken their place.

Our challenge has been to replace this negative image with accurate information, solid science, and respect of human rights. Although we have made efforts to change this perception, fear and rejection persist, but we believe with specialized and qualified care, knowledge, and respect, we can offer hope and finally overcome the stigma — treating not only the disease itself, but also the shame that continues to surround it.

It’s unbelievable right, professor Wilson?

Okay, thank you. Vera. Could you highlight by both moments in the global response to leprosy, whether medical social or political, that's changed how the disease is approached today?

Definitely. Most big advances have been about the germ and how to treat it. Mycobacterium leprae was identified in 1873, you believe? 1873. By Norwegian physician Gerhard Armauer Hansen, becoming the first bacterium proven to cause disease in humans. The Mycobacterium leprae grows very slowly, doubling only every 12 to 14 days, and it cannot grow easily in artificial medium until today.

That’s why most of the major advances in fighting leprosy have focused on understanding this bacterium and developing effective treatments. As you know, in 1839, the German physiologist Theodor Schwann described the cells that now bear his name — Schwann cells — which protect the nerves in the peripheral nervous system. These are precisely the cells where the leprosy bacillus first takes hold, beginning its attack in the peripheral nerves and causing the characteristic damage associated with Schwann cell destruction.

1940s – Sulfone drugs. Specialists recommended dapsone (a sulfone), the first therapy that convinced the world leprosy could be cured.

Early 1980s – Shepard’s mouse-footpad model. Dr. Shepard succeeded in multiplying M. leprae in a mouse’s footpad, opening the way for drug-resistance testing. In 1980, multidrug therapy. The WHO-recommended MDT regimen combined dapsone, rifampicin, and clofazimine, dramatically shortening treatment and slashing transmission.

Thank you so much, Vera, for this historical point of the leprosy, but in your view, how has the stigma around leprosy evolved over the years? What are the sum of the most common myths and misconceptions that still persist in communities?

Well, Camila, the stigma is quieter today, but it has not vanished.

Any visible disability still provokes fear. Many people still believe leprosy is contagious an incurable. Myths persist about heredity, the danger of touch, and family exclusion. In some countries a diagnosis can still mean abandonment, job loss, or a child leaving school. Medical progress is real, but social and institutional stigma demands constant education.

Wow. Thank you. That's terrible. You have been involved with community-based approaches of leprosy care. Could you share an example where a local education engagement helped reduce stigma and improve the outcomes?

The most striking example was the opening of Brazil’s former leprosarium in the late 1970s, when compulsory isolation was finally banned. I worked when the leprosarium disappeared. I know this very well. This is a very sad period. Patients who had never set foot outside the hospital could suddenly visit a bank, walk in town, or live with family again. Communities welcomed them; stigma did not block this reintegration.

In the 1980s, alongside MDT, Brazil decentralized care: new cases were no longer automatically hospitalized, and long-term residents gradually moved out. It echoed the mental-health reform that closed life-long asylums. Bringing leprosy into everyday primary-care clinics humanized treatment, and living side by side replaced fear with familiarity.

Thank you, Vera. It's a shock for us nowadays to think about it. Uh, on a personal, level, what inspired you to dedicate your professional life to leprosy work? Were there any moments that particularly moved or challenged you?

Yes, I remember that well. This is a little bit a piece of my life. My driving force has always been to ease the suffering of people with diseases.

During night, I sit in the leprosarium. I heard patients groan in never-ending pain and wondered what more could be done. Of like the at in baus Sao Paulo, I realized that the new treatment innovation could realize pain and prevented disability. At that time, we only have sulfone therapy, which was already showing cases of resistance.

And this time I realized that I needed to study deeply and that the therapeutic innovations, such as treatment of Ministry of Health was beginning to recommend MDT regimen, rifampicin and clofazimine combined with dapsone, could open a new page to relieve pain and prevent disability. This is the start of my life. I start in laboratory state after study of infectious diseases. I do my residence in a middle. Hes and I work with labs as an infectious disease doctor. I dedicated myself intensely to learning. And during that period, I had the opportunity to take a specialization course in communicable disease and in epidemiology of disease in Paris at Claude Bene Hospital.

Where the proof show were the very scientists who developed MDT regimen is still induced today. It was then that I established a professional relationship with this group, and I had the chance to bring a study on the operational implementation of the new treatment in the leprosarium. This is a good chance in my life. I was in the good place and a good time and with very special people. It was a remarkable experience that directly influenced Brazil’s decision to adopt the treatment, implementing the decentralization manner with near total coverage about 10 years later. Those were the best ways. We saw millions of patients cured because they were diagnosed on the early stage of disease and received effectively a good special treatment.

We lived through two decades of hope.

It's amazing Vera.

Oh, thank you. This is a very beautiful history of life.

Thank you.

But nowadays, even in countries where leprosy is still a huge problem, leprosy is often absent from medical curriculum and training. What strategies could we adopt to inspire students, doctors, and researchers to care about neglected diseases like this one?

Oh, well, yes. Let's talk about that. We have tried, we, we have tried everything, uh, for the last 40 years. We have really tried everything, appeals to the Ministries of Health and Education—yet leprosy remains on the sidelines. Patients suffer and professionals who choose this field are often marginalized.

As long as neglected disease equals low academic prestige and scarce funding, progress stalls. Today, after decades, I finally speak with neurologists like you; the gap is so wide that a nerve disease kept us strangers until now. We must embed leprosy content in core curriculum, fund research, and especially highlight its relevance to neurology, infectious disease, dermatology, and public health.

Vera, you are absolutely right and because of this, these episodes of podcasts have been done. So now let's shift to the present moment.

What does the current global epidemiological landscape of leprosy look like? Are there any country or regions we should be paying closer attention to?

Oh, it’s a lot. More than 140 countries still report cases in 2025. India, Brazil, and Indonesia account for over 75 percent of the global burden. In Brazil, hyper-endemic areas include Mato Grosso and vulnerable groups such as Indigenous peoples, quilombola communities, and residents of crowded urban settlements. Several African nations also report high incidence. Wherever poverty and social exclusion persist, leprosy remains active.

That's terrible again. There is often a discrepancy between reported numbers and actual disease burden. What are the main challenges with today's surveillance systems and how can we improve detection and reporting?

Oh, let me start by saying, underreporting is it still serious.

It's only this year, for example, India made leprosy a notifiable disease. Only this year! And India was reported as the first country with most cases of leprosy in the world. However, the situation is worse, because the most serious problem with leprosy is underdiagnosis, as many health professionals do not know about the disease and do not recognize its early signs, and the population is also unaware of its symptoms. We need more robust training in primary care, point-of-care tools such as rapid or immunological tests, and robust information systems. Sustainable programs at all levels of government are rare; control efforts have never been taken fully seriously. Decentralization of diagnosis, supported by qualified and effective training of professionals, associated with community-based health education based on neurological symptoms in addition to skin manifestations, are essential actions to break this cycle of invisibility. You can count, you can count the doctor and the professional who knows to the neurological symptoms of leprosy.

Thank you, Vera. And again, because of this, this podcast series is so important for all of us and all of, uh, physicians around the world. But how did the COVID-19 pandemic do you know, impact leprosy care, especially when it comes to new diagnosis, follow up and treatment continuity.

Okay, let's go there. But it's still, uh, it’s a sad history, the COVID-19. The pandemic disrupted every service. Diagnoses plummeted, treatments were paused, and community outreach stopped. Hidden transmission and late disabilities increased. Federal and state programs are trying to catch up, but progress is very, very slow.

Thank you. Uh, despite the availability of multidrug therapy, leprosy transmission continues in some areas. Why is that — and what are the key barriers to elimination? Why some countries were able to control the disease and in others, sometimes not so poor, the disease is still out of control?

Well, great question. It brings up three or four important issues. Why transmission continuous, what are the main barriers to elimination, why some countries have made progress while others have not. Well, leprosy is still spreading in Brazil, unfortunately, leprosy is still a serious public health problem in Brazil. The disease continues to spread, especially through people with a high number of bacteria in their bodies who haven’t been diagnosed or treated.

When cases are found in children under 15, it shows that the infection is recent and that the chain of transmission is still active. This is very worrying. Red flag.

Secondly, main challenges: Late diagnosis. Many people are diagnosed too late. Leprosy still causes permanent physical disabilities, called Grade 2. You can’t believe, 7 to 10% of new cases in Brazil has PDG2. That means people already have visible problems like claw hands, foot drop, open sores on their feet, or eye damage that can cause blindness. Lack of training in primary care. Many health workers don’t know how to examine peripheral nerves, so they miss the early signs of the disease.

Poor living conditions Leprosy is more common in places where people live in poverty and face social difficulties, with leprosy being more related to living in crowded places, which increases the risk of transmission, of course, a fact greater than hunger, as occurs with tuberculosis.

Weak, weak, very weak surveillance. When health systems don’t follow up on contacts or actively search for cases, the disease spreads silently.

One important solution is to train primary healthcare workers to examine properly peripheral nerves. This can maybe help find cases earlier, prevent disability, and stop the spread.

But you ask me why were some countries able to control leprosy? These countries made leprosy a top priority in public health, of course. They invested in early diagnosis, treated all cases, stopped transmission, trained health workers, and educated the public. They also kept strong surveillance systems and included leprosy services in regular health care.

But success wasn’t just about health programs. It also came from better living conditions, economic and social development, better education, and strong political leadership. Where governments acted quickly and made long-term plans focused on fairness, leprosy became rare or disappeared completely.

Why is leprosy still out of control in some not-so-poor countries? In some countries, leprosy continues because it’s not treated as an urgent issue. Health workers may not be trained, diagnosis comes too late, and the disease stays invisible in public policies. Without political will, proper funding, and strong community support, it’s very hard to stop transmission.

Finally, I belief, leprosy can be controlled — but only when early diagnosis, full treatment, and social justice go hand in hand.

You are absolutely right Vera, but from a public health standpoint, what interventions have been most effective in reducing disability and transmission? Are there any community driving models that should be scaled up?

Yes, yes, yes, Camila.

Models that blend primary care, especially in Brazil, popular education, and inter-sectoral support work best. In Mato Grosso, the state Public Health School and the Brazilian Leprosy Society has already offered medical specialization courses to more than 60 leprologists after a gap of 40 years. 40 years without a medical specialization course in Brazil! The Mato Grosso Free of Leprosy program—backed by the State Audit Court—combines door-to-door contact tracing, smart dashboards, and rehabilitation. Scaling up such initiatives and putting leprosy on the public-policy agenda are urgent.

Well, you have worked extensively in international collaboration. In your view, what should be the role of institutions like the World Health Organization and non-governmental organizations today and how can you ensure that local voices remain central?

That is very important.

The WHO sets norms and builds global consensus. NGOs once brought innovation, field presence, and advocacy to Brazil, but few remain. Solutions must spring from local realities. That means investing in community leaders, practicing active listening, and forging horizontal partnerships. Without that, we risk repeating top-down mistakes detached from daily life.

Vera, uh, we are going to the final question, and I have to say that I learned so much from you, and that was absolutely a very nice lecture about someone that, uh, really worked on the years and years during the Leprosy history. So, uh, some people still believe leprosy is a disease of the past.

What do you say to them, and why is it still so relevant to talk about leprosy today?

Well, I'm very sorry to say leprosy still exists, still excludes, and still scars lives. It is invisible only to those who refuse to look. Talking about it is a collective responsibility: no one should be forgotten. Curing the infection is just the beginning—the bigger task is keeping the public alert to its signs and symptoms and reminding everyone that it is both curable and preventable.

Thank you, Vera.

Thanks so much, Vera. Your insights truly brought both clarity and urgency to this talk and called us neurologists to participate in this process. Thank you very much again.

Well, thank you. Thank you. I want to sincerely thank you for the opportunity to speak with you. And my fellow neurologists. It was a true joy to share a topic as important as leprosy. We need all neurologists with us. Leprosy is a disease that starts precisely where your expertise is: the peripheral nerves. I hope this exchange brings us closer together in the mission to identify the disease in its early neurological phase, treat it with dignity, and prevent disability. Let’s keep moving forward — with science, listening, and shared commitment.

Thank you very much.

Thank you, Vera. So you can find links to relevant papers, global reports, and more in the show notes. And visit www.pnsociety.com to learn about the Peripheral Nerve Society and its working education, research, and the advocacy. Well, we'll back next month with another powerful conversation. Until then, stay curious, stay compassionate, and stay connected.