

India renews its fight against leprosy

In 2005, officials declared that they'd vanquished the disease. They were wrong.

BY APOORVA MANDAVILLI

Three years ago, Siddamma's mother-in-law developed pale patches on her arms. But Siddamma, 32, did not get along with her, and did not pry. A year or so later, she noticed that her husband had similar marks on his back — but he was on a rare visit home from herding goats, so she was reluctant to raise the issue. She suggested that he see a doctor, and left it at that.

Then, one day in 2017, she returned home from work and saw her son Lingappa, then 9, crying. He told her he couldn't go back to school because the other boys were making fun of the ulcers on his face. That did it, Siddamma said: "I have only one son."

Eventually she brought him 50 miles from Mudumal, where the family lives, to Mahabubnagar, a city of 200,000 in the southern Indian state of Telangana. A dermatologist in the town referred Siddamma to a specialized clinic, where a doctor diagnosed the boy with leprosy. "I didn't know anything about it before then," Siddamma said.

Leprosy is the result of infection with *Mycobacterium leprae*, a close cousin of the bacterium that causes tuberculosis. The disease has been around for centuries, but because it cannot be cultured in the lab, its mysteries remain unsolved.

Leprosy often starts off with the sort of discolored, numb patches that appeared on Siddamma's family members, or with tiny nodules under the skin. Left untreated, the bacteria slowly destroy nerves and muscles, eventually leading to the deformities associated with the disease and to permanent disability.

The disease has all but disappeared from most parts of the world, thanks in part to a yearlong multi-drug treatment, donated by the pharmaceutical company Novartis. In 2005, India declared that leprosy was no longer a problem in the country. But that announcement was premature: According to the World Health Organization, India harbors 60 percent of the world's cases, with more than 100,000 new diagnoses each year.

As India's health officials concede, the prevalence of leprosy was low in 2005 not because fewer residents were being



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infected, but because the government stopped trying to find them.

"Sometimes the program managers start making less effort, so they get less cases, so that they can say that prevalence is going down," said Dr. Anil Kumar, who has led the country's leprosy program since 2015.

There is no blood test for the disease, and scientists aren't entirely sure how it is transmitted. Contact with infected people is one way, but not a certain one: Siddamma's younger daughters also became infected, but an older daughter, and Siddamma herself, remained unaffected.

"Does genetics play a role? Maybe," said Dr. Paul Fine, an epidemiologist at the London School of Hygiene and Tropical Medicine. "Does prior immune status play a role? Maybe." Nutrition, access to health care and socioeconomic status all might be involved, he said: "We frankly don't know."

"A LOT OF COLLATERAL DAMAGE"

Clarity or no, the World Health Organization has long made the elimination of leprosy one its goals. In 1991, the organi-

zation announced that by 2005 leprosy would be "eliminated as a public health problem," meaning that there would be fewer than one case per 10,000 people.

The odds were long — the deadline had been deferred once already — but "sometimes you put intentionally targets which are rather aspirational," said Dr. Erwin Cooreman, team leader of the organization's Global Leprosy Program.

"We don't talk about it. And because we don't talk about it, we don't know who's got leprosy and who doesn't."

But the subtleties of that aspiration were lost on most people in India.

"People actually just completely misunderstood it," said Dr. Diana Lockwood, a leprosy expert at the London School. "For them, elimination means no cases."

People infected with the leprosy bacterium may not show symptoms for 20 years. Meanwhile, they still can infect others, who in turn may remain symp-

tom-free, and infectious, for years. Reducing the number of visible cases of leprosy is a start toward eliminating the disease, but it is hardly the end.

Still, health officials in India took the goal of elimination seriously, and by 2005 the number of symptomatic cases dropped to less than one case per 10,000 people. Then the country dismantled most of its leprosy programs and redirected its resources to more urgent priorities such as AIDS and tuberculosis; public awareness of leprosy plunged.

But out of view, the bacterium remained active. The number of infected, disabled people remained low for nearly a decade, and then began to rise. The disease was being detected way too late, generating "a lot of collateral damage," Dr. Cooreman said.

Leprosy causes distinct deformities and imposes a heavy social stigma. Indian law forbids people with the disease from working and traveling in public. One returning patient at the Mahabubnagar clinic, a well-educated man in his late 20s, had not told anyone in his family, not even his mother, because he was



Left, bandaging a leprosy victim in Hyderabad, India. Above, a house at a colony for people with leprosy in the city of Mahabubnagar. India harbors 60 percent of the world's cases of the disease, with more than 100,000 new diagnoses each year.

terrified that the news might leak to his neighbors. People with the disease sometimes exile themselves to leprosy "colonies" — there are 700 or so in the country — where they interact only with one another and beg for money.

The stigma, in turn, makes the disease harder to detect and eliminate. "In countries like India, people from all classes get leprosy," said Ashim Chowla, who heads a nonprofit agency called Lepra. "But because of discrimination and prejudice, we don't talk about it. And because we don't talk about it, we don't know who's got leprosy and who doesn't."

FIGHTING MISINFORMATION

Organizations such as Lepra help people with the disease fight for government benefits. Pressured by the organization, India's Supreme Court ruled in September that the government must end discriminatory laws, conduct regular surveillance to detect new cases, provide treatment to everyone who needs it and promote awareness of leprosy as a curable disease. "We work to make leprosy a disease of no consequence, which is what it should be," Mr. Chowla said.

The organization runs 26 local clinics in India including the one in Mahabubnagar that Siddamma visited with her son. On one hot day in February, the staff tested three new cases and fol-

lowed up with 17 previously diagnosed ones: men and women, children and older adults, rich and poor.

The awareness campaigns are key to combating the myths and misinformation that surround leprosy. Mr. Chowla recalled a tribal woman he had met in Chhattisgarh, a locus of the disease in northern India. The woman's fingers were clawed, a signature effect of leprosy. But she saw no point in visiting a doctor. The disease was an intergenerational curse, she said: Her grandmother once had boiled frogs in a fit of annoyance at their loud croaking, and the frogs had taken revenge on her, the granddaughter.

Mr. Chowla had leprosy as a child; he thought the hairless patch on his left arm was magical and dared his friends to plunge sharp objects through his numb skin. He has been cured for decades, but doctors still shrink from him when they hear about his diagnosis. "Just because my mum was clever enough to get me to a dermatologist, and the dermatologist was clever enough to diagnose me, I got cured," he said.

Dr. Kumar, the head of India's leprosy program, has taken steps to raise awareness of the disease and combat the stigma around it. On World Leprosy Day — Jan. 30 — he encourages the leaders of the more than 600,000 villages in the country to talk about the disease.