

DIAGNOSIS

A Man Discovers He Has a Disease Most People Thought No Longer Existed

By Lisa Sanders, M.D.

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"Can you take a look at this?" the 50-year-old man asked his wife. Standing in front of the bathroom mirror in his home outside Asheville, N.C., he turned his head and touched an area on his cheek just in front of his ear. He could feel the smooth, slightly raised surface, but it was on the side of his face, in a spot that was hard for him to see. It was slightly pink, about the size of a 50-cent piece, with irregular borders. "Where did that come from?" his wife asked as she turned his head to get a better look. It didn't hurt, he told her. In fact, that whole part of his face, right up to the middle of his ear, was kind of numb.

He was fairly healthy over all. He quit smoking some 15 years earlier, and his job as a mason kept him moving. But he'd spent a lifetime worrying about his skin. He had a bad case of psoriasis that his dermatologist had only gotten a handle on a couple of years before when he started him on a new medication called Humira. Once he started the twice-monthly injections, the scaly lesions on his skin had practically melted away. He'd never had psoriasis on his face, though. He pointed it out to his dermatologist at his next appointment, but the doctor didn't seem worried about this new eruption. It would go away, he assured the patient.

The man found himself touching that spot constantly. And even though it wasn't that obvious, he couldn't help looking at it every time he passed a mirror. It didn't seem to be getting any bigger. But it wasn't going away either.

His wife was worried. She told him that at his age, it wasn't natural to grow anything new. He told her what the doctor told him — though he only half believed it himself — that it was nothing and would go away on its own. She was skeptical. When it was still there after six months, he decided he needed some answers.

Another Opinion

He brought it up again with his dermatologist, who referred him to a plastic surgeon. She wasn't sure what it was, either. She sent off a small piece of tissue cut from the pink spot. The biopsy showed that the tissue contained structures known as granulomas. These are benign collections of white blood cells, often characterized as the body's effort to wall off something perceived as foreign — a bacterium or an object — that can't be eliminated. There are a few diseases that can form these strange collections. Probably the most common is sarcoidosis, a somewhat mysterious inflammatory disease that usually starts in the lungs but can create granulomas anywhere in the body, including the skin. A second surgeon sent the man for a chest X-ray, and when it didn't show any lung involvement, he figured it probably was not sarcoidosis. He wasn't sure what it was. But it clearly was not a cancer.

The patient was relieved that he didn't have either sarcoidosis or some kind of cancer, but he still wanted to get rid of the pink patch on his face. This is not an unusual dynamic between a doctor and a patient. The patient comes in with something he would like diagnosed and treated. The doctor assesses the patient the way we are trained to do it — to first think about the most dangerous possibilities and then work our way down that list from deadly to annoying. Unfortunately, once we're sure it's not going to kill the patient, we can sometimes lose interest. But the patient is still stuck with his original problem.

Back to Square One

The patient went to see his dermatologist again. The dermatologist was also reassured by the pathology report. When the patient insisted on getting rid of the spot on his face, the doctor suggested that he get a second opinion from another dermatologist.

The patient made an appointment with Mark Hutchin, a young dermatologist he'd heard good things about. "I don't know what this is, but I want it gone," the patient told Hutchin. He went over the story of the sudden appearance of this strange spot and the weird numbness in that part of his face and the lower half of his ear. He hadn't noticed anything else and generally felt healthy. But he didn't like seeing that spot every time he looked in the mirror, and his wife was sure it was something bad.



Illustration by Cristina Daura

Something Odd

Hutchin examined the man carefully. What about this little bump, here on your neck? he asked the man. Oh, that's always been there, the patient told him. No, the doctor disagreed. I think this is new.

Before Hutchin started his training in dermatology, he spent two years in surgery, specializing in operations on the head and neck. His fingers recognized the bumpy linear structure he felt in the man's neck as some kind of swelling of the great auricular nerve — the pipeline carrying sensory information from the ear and surrounding skin back to the spine. If the swelling compressed that nerve, that would explain why the man's ear and face felt numb. The combination of this growth on the skin and the involvement of the nerve tissue suggested one disease in particular.

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A Scary-Sounding Diagnosis

“Have you ever heard of Hansen’s disease?” Hutchin asked the patient. When the man shook his head, Hutchin explained that it was the polite name for an old disease — leprosy. For the patient, the word immediately conjured ancient biblical images of sinners punished with this deforming disease. He pushed the images away. “Nobody gets leprosy anymore!” the man exclaimed.

It is a disease that has inspired revulsion for centuries. Those with visible evidence of the disease were often shunned and feared. It was thought to be both inherited and wildly contagious. We now know it is neither.

In the late 19th century, a Norwegian physician, Gerhard Armauer Hansen, identified the bacterium causing the disease, *Mycobacterium leprae*. It is a slow-growing cousin of *Mycobacterium tuberculosis* — the organism responsible for TB. *M. leprae* has an unusual need to reproduce in temperatures just below the average 98.6 of the healthy body, causing the organism to preferentially affect the skin of the face and the extremities — the coolest parts. The bacterium also prefers nerve tissue. Thus, the most recognizable characteristics of the disease historically have been numbness, loss of pigment and eventual loss of fingers, toes, ears, noses and eyes.

We now understand that Hansen’s is a disease easily fought off by a healthy immune system. Up to 90 percent of those infected with the bacterium will never come down with the illness. This man was at increased risk because his immune system was suppressed by the Humira he was taking for his psoriasis.

Trying to Confirm a Hunch

Still, leprosy is rare in the United States — with fewer than 250 new cases reported each year. It wasn’t clear how he would have been exposed to the disease. He hadn’t visited any endemic areas — those are primarily in Southeast Asia; he rarely left the area around Asheville. He hadn’t had any contact with armadillos — a natural reservoir for the disease in this country. Hutchin sent the man to have the nodule in his neck biopsied. If it was Hansen’s, then that nerve should be crawling with *M. leprae*. It was.

The first thing Hutchin told the patient was that Hansen’s was treatable with antibiotics. He put him in touch with the National Hansen’s Disease Program in Baton Rouge, La. The patient flew down to the clinic there and stayed in a dormitory for patients with the disease. He started on a regimen of two drugs he had to take every day. He went home after a few days. Treatment continued for a year, but the spot faded long before he was done with the pills.

He has never figured out how he was exposed to the bacterium and has never gotten the feeling back in his ear, but he’s glad that’s all he lost. Hutchin said it was because he took the problem seriously, even when his doctors didn’t. “If it had been somewhere else, maybe I would have let it ride,” the patient told me recently. “But it was on my face, and I wasn’t having that. I’m just too vain to let that go.”

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