EVERYTHING IS TUBERCULOSIS

THE HISTORY AND PERSISTENCE OF OUR DEADLIEST INFECTION

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CHAPTER 1

LAKKA

WHEN I FIRST VISITED LAKKA GOVERNMENT Hospital a few years back, I did not really want to be there.

Sarah and I were in Sierra Leone, a nation of nearly nine million people in West Africa, to learn about the country's maternal and neonatal healthcare systems. At the time, Sierra Leone had the highest maternal mortality rate in the world, with around one in every seventeen women dying in pregnancy or childbirth, and we'd traveled there to learn about and share stories of people affected by the crisis.[1]

So our trip was supposed to be oriented around the global maternal mortality crisis, not tuberculosis, and by our last day in Sierra Leone, I was exhausted and ill. (I possess a somewhat fragile constitution when it comes to health, and also when it comes to most other things.) But a doctor we were traveling with asked us to visit

1. Thanks to investments from Sierra Leone's Ministry of Health in deep partnership with other organizations, maternal mortality in Sierra Leone declined by more than 50 percent in the five years following our trip, a reminder that there is nothing permanent or unalterable about health inequities.

Lakka with him. He assured us that Lakka, a facility supported by the global health nonprofit Partners In Health, was basically on the way to the airport, and he needed to consult with the staff about a few cases.

At the time, I knew almost nothing about TB. To me, it was a disease of history—something that killed depressive nineteenth-century poets, not present-tense humans. But as a friend once told me, "Nothing is so privileged as thinking history belongs to the past."

When we arrived at Lakka, we were immediately greeted by a child who introduced himself as Henry. "That's my son's name," I told him, and he smiled. Most Sierra Leoneans are multilingual, but Henry spoke particularly good English, especially for a kid his age, which made it possible for us to have a conversation that could go beyond my few halting phrases of Krio. I asked him how he was doing, and he said, "I am happy, sir. I am encouraged." He loved that word. Who wouldn't? *Encouraged*, like courage is something we rouse ourselves and others into.

My son Henry was nine then, and this Henry looked about the same age—a small boy with spindly legs and a big, goofy smile. He wore shorts and an oversized rugby shirt that reached nearly to his knees. Henry took hold of my T-shirt and began walking me around the hospital. He showed me the lab where a technician was looking through a microscope. Henry looked into the microscope and then asked me to, as the lab tech, a young woman from Freetown, explained that this sample contained tuberculosis even though the patient had been treated for several months with

standard therapy. The lab tech began to tell me about this "standard therapy," but Henry was pulling on my shirt again. He walked me through the wards, a complex of poorly ventilated buildings that contained hospital rooms with barred windows, thin mattresses, and no toilets. There was no electricity in the wards, and no consistent running water. To me, the rooms resembled prison cells. Before it was a TB hospital, Lakka was a leprosy isolation facility—and it felt like one.

Inside each room, one or two patients lay on cots, generally on their side or back. A few sat on the edges of their beds, leaning forward. All these men (the women were in a separate ward) were thin. Some were so emaciated that their skin seemed wrapped tightly around bone. As we walked down a hallway between buildings, Henry and I watched a young man drink water from a plastic bottle, and then promptly vomit a mix of bile and blood. I instinctively turned away, but Henry continued to stare at the man.

I figured Henry was someone's kid—a doctor, maybe, or a nurse, or one of the cooking or cleaning staff. Everyone seemed to know him, and everyone stopped their work to say hello and rub his head or squeeze his hand. I was immediately charmed by Henry—he had some of the mannerisms of my son, the same paradoxical mixture of shyness and enthusiastic desire for connection.

Henry eventually brought me back to the group of doctors and nurses who were meeting in a small room near the entrance of the hospital, and then one of the nurses lovingly and laughingly shooed him away.

"Who is that kid?" I asked.

"Henry?" answered a nurse. "The sweetest boy."

"He's one of the patients we're worried about," said a physician who went by Dr. Micheal.

"He's a patient?" I asked.

"Yes."

"He's such a cute little kid," I said. "I hope he's going to be okay."

Dr. Micheal told me that Henry wasn't a little boy. He was seventeen. He was only so small because he'd grown up malnourished, and then the TB had further emaciated his body.

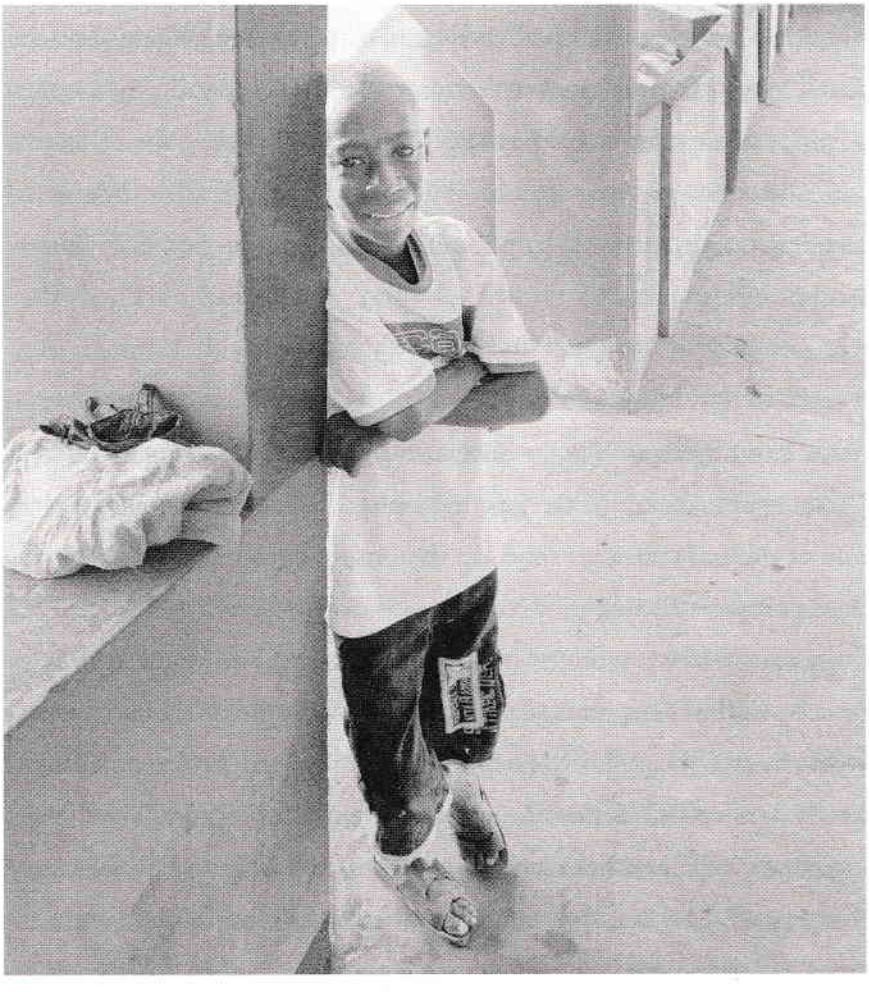
"He seems to be doing okay," I said. "Lots of energy. He walked me all around the hospital."

"This is because the antibiotics are working," Dr. Micheal explained. "But we know they are not working well enough. We are almost certain they will fail, and that is a big problem." He shrugged, tight-lipped.

There was a lot I didn't understand.

I saw Henry again as we were getting ready to leave. He was standing near the entrance to the hospital, and I asked him if I could take his picture. He said yes, and I photographed him a few times.

We scrolled through the pictures together. I tried to communicate that I was smiling from behind my mask. Henry wore no mask—his bacterial load was low enough that he posed no infection risk to others. As we chatted, I realized I was looking at him differently than I had when I believed him to be the son of a staff member. He no longer reminded me of my nine-year-old son; now he was an emaciated young man. When he looked up at me, I saw



yellow clouds in the whites of his eyes—a byproduct of the liver toxicity that frequently accompanies the treatment he was on. I noticed swelling on one side of his neck—which I would later learn is a telltale sign that TB has infected the lymph nodes. I asked him if he took medicine every day.

"Yes," he said. "I swallow them. Also they inject shot."

"Is that scary?"

His big eyes got bigger as he nodded.

Henry told me that the injections burned like a fire under

his skin, and that the medications had many side effects, but the worst one was hunger. Active tuberculosis severely suppresses appetite, causing stomachaches and generally inhibiting the ability to eat, and once treatment commences and the infection begins to lessen, hunger roars back, which is a good sign—but only if one has enough to eat.

Years later, a young TB survivor told me about the hunger. I was at Lakka again, sitting in the immense shade of a mature mango tree, one of the only pleasant spots on the hospital grounds, which otherwise comprised patches of red clay and overgrown shrubbery. Three long, rough-hewn wooden benches were moved throughout the day to keep in the mango's shade. On the bench opposite me sat a young woman—we'll call her Marie—hunched forward, knees on elbows. Marie was so thin when she arrived at the hospital that she'd been unable to walk, and her chest X-ray revealed hardly any healthy lung tissue at all. She was five feet, three inches tall, and when she'd arrived at Lakka, she weighed less than seventy pounds.

Marie told me she dreamed night and day of eating as she recovered her health, that she thought of making mud soup and eating sticks. She thought about how crunchy they would be, imagining them as overstuffed with rich, soft nutrients inside. She could not think of anything but food, all the time.

Almost apologetically, a nurse sitting beside us said, "We feed everyone three times a day. Big meals. But it is not enough." Not nearly enough, in fact, but the nurse explained that even three meals a day strained resources, because food was not considered to be an

essential aspect of tuberculosis treatment, and so there was no funding for food. Some people became so hungry, she told me, that they left the hospital and stopped taking their medication, which increased the likelihood that the TB bacteria within them would continue multiplying, eventually developing resistance to first-line treatments. But they simply could not live with the hunger.

In Henry's short, beautifully written memoir, he referenced hunger many times. He called Lakka "a place where hope and despair intertwined. . . . I found myself in a world where food was scarce, water was rationed, and clothing was inadequate for the chilly nights."

After I first met Henry, I asked one of the nurses if he would be okay. "Oh, we love our Henry!" she said. She told me he had already gone through so much in his young life. Thank God, she said, that Henry was so loved by his mother, Isatu, who visited him regularly and brought him extra food whenever she could. Most of the patients at Lakka had no visitors. Many had been abandoned by their families; a tuberculosis case in the family was a tremendous mark of shame. But Henry had Isatu.

I realized none of this was an answer to whether he would be okay.

He is such a happy child, she told me. He cheers everyone up. When he'd been able to go to school, the other kids called him *pastor*, because he was always offering them prayers and assistance.

Still, this was not an answer.

"We will fight for him," she told me at last.

CHAPTER 2

COWBOYS AND ASSASSINS

AFTER I RETURNED FROM LAKKA TO MY home in Indianapolis, I began reading about the history of tuberculosis, which seemed to pop up everywhere from fashion to warfare to human geography, and I found that I simply could not shut up about the disease. Someone would mention New Mexico, and I'd jump in: "Did you know that New Mexico became a state partly because of tuberculosis?" Or, if a conversation turned to World War I, I'd respond, "Did you know that tuberculosis sorta kinda but not really caused World War I?" Or perhaps at a neighborhood Halloween party, I'd confront a ten-year-old dressed as a cowboy: "Did you know tuberculosis helped give us the cowboy hat?"

Which it really did, by the way: In the 1850s, a young man named John was living in New Jersey, working as a hatmaker, when he started coughing up blood. John visited the doctor and learned that, indeed, he had consumption. According to the prevailing wisdom of the time, his only real chance of survival was to head West.

The American West has long been associated with escape and

freedom and last hopes. "West is where we all plan to go some day," Robert Penn Warren wrote in *All the King's Men*. "It is where you go when the land gives out and the old-field pines encroach. It is where you go when you get the letter saying: Flee, all is discovered." And it is where consumptives went to extend their lives.

In the nineteenth and early twentieth centuries, it was commonly accepted that consumption could be effectively treated by dry air, which made a kind of sense—consumptive lungs seemed wet, and so did the humid, stagnant air in big American cities like New York and Baltimore, where consumption flourished. People fled to Arizona or New Mexico or California, which came to be known as the "land of new lungs." As one brochure boldly promised: "Come West and live."

Several cities, including Pasadena and Colorado Springs, were essentially created for consumptives and their families. But it wasn't only desert air that was mythologized. Doctors also recommended island air, or mountain air, or forest air, or Italian air. The justification for the so-called "travel cure" varied, except for one constant: Consumption thrived in cities, and so the solution must be rural. (This worldview was not unique to Europe and the U.S., although it was centered there. The Japanese poet Masaoka Shiki also traveled with consumption in the hopes of improvement.)

Now, our hatmaker John did not travel all the way to the West Coast, but instead headed from his home in New Jersey to the rough frontier town of St. Joseph, Missouri. It's hard to see how St. Joe's humid, stultifying air could be viewed as TB-friendly, but John ended up settling there for a while, and—wonder of wonders—began to feel better. For reasons we still don't fully understand,