

“With *The Kissing Bug*, Daisy Hernández takes her place alongside great science writers like Rebecca Skloot and Mary Roach, immersing herself in the deeply personal subject of a deadly insect-borne disease that haunted her own family. It’s a tender and compelling personal saga, an incisive work of investigative journalism, and an absolutely essential perspective on global migration, poverty, and pandemics.”

—AMY STEWART, author of *Wicked Bugs*

“The question *The Kissing Bug* investigates is timely: Who does the United States take care of, and who does it leave behind? Through the personal story of Hernández’s family and countless interviews that include patients and epidemiologists, the inequity of the healthcare system is exposed. Hernández writes to the heart of the story with immense tenderness, compassion, and intelligence. A riveting read.”

—ANGIE CRUZ, author of *Dominicana*

“Daisy Hernández introduces us to the most important bug you’ve probably never heard of. Authoritative and gripping at the same time, *The Kissing Bug* is a deft mix of family archaeology, parasite detective story, and American reckoning. A much-needed addition to the canon.”

—DANIELLE OFRI, MD, PhD, author of
When We Do Harm: A Doctor Confronts Medical Error

“In this wonderful story, Daisy Hernández describes how the bite of a kissing bug impacted the life of her beloved auntie and mentor. She dives into the fascinating history of the kissing bug disease and how it destroys the lives of the bitten, often poor immigrants who fall through the cracks of our for-profit medical industry. An engaging, eye-opening read for anyone looking to learn more about the human suffering caused by the collision of a parasite and years of neglect by the United States’ medical system.”

—KRIS NEWBY, author of *Bitten: The Secret History of Lyme Disease and Biological Weapons*

THE KISSING BUG

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THE
KISSING
BUG

*A True Story of a Family, an Insect, and
a Nation's Neglect of a Deadly Disease*

DAISY HERNÁNDEZ



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For Maya Durga

Any woman's death diminishes me.

—ADRIENNE RICH

There is a prayer in the act of writing.

—CHERRÍE MORAGA

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A WORD SHE WHISPERS

The New York City hospital is a black, cavernous mouth. I am six, and I am not afraid. Bolting from the elevator, I run down the corridor ahead of my mother and baby sister, my sneakers squealing on the clean floors. The doors are half-open. The doors are invitations. A cuarto here belongs to us. The room holds Tía Dora, my mother's sister, my auntie-mother.

A single window in the room stretches toward the ceiling, and Tía Dora is there with her pointy chin and thin face. The Spanish words tiptoe from her mouth. "Mi vida," she murmurs when she sees my mother.

Tía Dora rises onto her elbows. The gown sways on her small frame. She smiles at me with approval. My mother has combed my black hair into two ponytails. My sister, almost a year old, giggles in her summer dress. Outside the Manhattan heat licks our faces, but in the hospital, in my auntie's room, the cold air bites our ears.

The doctors have sewn a line of dark stars across Tía Dora's belly. Las cicatrices. And they have told her a word my mother whispers when she thinks I am not listening: Chagas.

...

No one in the hospital that day, or for many years after, told me that Chagas is a parasitic disease. Transmitted to humans by triatomine insects called kissing bugs, the parasite can often be eradicated with medication when a person is initially infected. Few people, though, are diagnosed and fewer receive treatment, which means the single-celled parasite *Trypanosoma cruzi* can spend up to thirty years in the human body, quietly interrupting the electric currents of the heart, devouring the heart muscle, leaving behind pockets where once healthy tissue existed. In the worst cases, the heart can eventually die.

The illness has come to be known in English as the kissing bug disease.

...

The corazón, the heart, is an accordion. It expands inside the rib cage, then squeezes. It belts out the familiar tune, the sacred thrumming that physicians in the early nineteenth century compared to a whip or, depending on the disease, a dog's tongue lapping. In 1836, Dr. Peter Mere Latham insisted that the musical movements of the heart could not be rendered in paragraphs. "It is useless to describe them," he wrote of the organ's varied sounds. A physician had to learn by listening directly to a patient's chest.

The kissing bug disease tampers with this music, and doctors cannot explain why most people live with the parasite without any symptoms, while 20 to 30 percent of those infected suffer

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cardiac problems. To date, doctors cannot predict whose heart will be spared. Unless the infection is caught early, there is no cure. In a few infected people, like my auntie, the parasite strikes not the heart but the esophagus and the colon.

The Centers for Disease Control and Prevention (CDC) estimates that about three hundred thousand people with the kissing bug disease live in the United States. They are, like Tía Dora, immigrants. Close to six million people are currently infected, mostly in South America, Central America, and Mexico, and every year, more than ten thousand people die from the disease.

Tía Dora did not know these harrowing figures or that the parasite can be transmitted from a woman to her baby during pregnancy. In the United States, women are not routinely screened during pregnancy for the kissing bug disease, though each year more than three hundred babies may be born infected. My auntie also did not know that blood banks in the United States now screen people for the parasite the first time they donate. Fortunately, the disease does not spread like the common cold or Covid-19. Most people are infected from direct contact with a parasite-carrying kissing bug.

Formally called American trypanosomiasis, the disease is also known as Chagas after Carlos Chagas, the Brazilian doctor who discovered it in 1909 and was twice nominated for a Nobel Prize. The World Health Organization classifies Chagas as a neglected tropical disease. Others in that category include leprosy, sleeping sickness, and river blindness—afflictions the world has largely forgotten as they affect mainly poor people in countries beyond the borders of the United States and Western Europe.

Daisy Hernández

The *New Yorker* has called the kissing bug disease the “red-headed stepchild” of vector-borne diseases—those caused when insects transmit pathogens—because even among the neglected, it has long been ignored.

...

I did not know any of this as a child. I only knew the hospital room that summer and Tía Dora with her pointy chin and the Spanish consonants in her mouth and how often the word Chagas made my mother sigh. I also knew that I wanted my auntie’s love and suspected even then the impossibility of that desire.

IN SEARCH OF MY
FAMILY'S STORY

PALABRAS

In the seventies, Colombia's civil war remained tucked away in the mountains. Airplanes flew from Bogotá without exploding in the sky, and no one worried about being kidnapped for hefty ransoms. At the Palace of Justice, the Supreme Court judges, staffers, and cafeteria workers did not think of dying at the hands of the military or the rebels. All that would come later.

Tía Dora grew up with her parents—my grandparents—in Quiroga, a neighborhood on the south end of Bogotá. The houses looked like multicolored boxes stacked in the corner of a room, and the sidewalks curved toward stores that sold arepas, buñuelos, and glass bottles of Coca-Cola. The hills rose beyond the roofs, high and sepia-tinged, sprouting one-room homes constructed of wood and tar paper creating, at times, the impression that poor families were building in the direction of heaven. My abuelos, from the town of Ramiriquí, a few hours outside the capital, would probably have lived in the hills if it had not been for a government program that granted them a house in the city.

The family house had a front yard with two banana trees. A window in the living room looked out onto South Thirty-Third Street, and Tía Dora and my mother and their brothers and

sisters—they were a family of eleven children—filled that living room over the years with gossip and a radio that played vallenato songs. The house had three bedrooms and accommodated itself to the size of the family. Beds were shared, pillows christened communal. Occasionally, another family rented a room so my grandparents, once farmers and now city folks without jobs, could earn extra cash. Behind the main house, rooms were built for two of my uncles and their wives and young children. The hens had their coop in the backyard, where they huddled in the cold and laid their generous eggs and, at night, surely dreamt of the campo.

The youngest of the girls, Tía Dora grew up on a merry-go-round of women's hands—of sisters, cousins, comadres, and cuñadas—and maybe, for that reason, she spent years referring to one of her oldest sisters as Mamá. Or perhaps Tía Dora knew the truth, knew exactly who her mother was, but loved her doting sister so much that she could think of no higher compliment than Mamá. As a child, she watched her older sisters make melcocha, a kind of molasses taffy. They heated the molasses, then waited for it to cool enough so they could pick it up and twist the melcocha into figure eights on the table, cut it into pieces, and hand it out to friends, primos, neighbors, whoever happened to walk by the front door.

Tía Dora had a predisposition toward joy. Her father's drinking did not bother her. She poured the cheap liquor down the drain and never blamed him. The sound of a brother coming home drunk at night and yelling at his wife pinched her ears. But men were men. They swung at each other and drank too much and still there they were.

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Or maybe my auntie could afford to be generous since she planned to have a different future. By her late twenties, she was teaching elementary school children in the mornings, and in the evenings, working towards her bachelor's degree. She paid for the classes from her earnings, and she planned to be the primera: the first girl in the family to graduate from college. She carried herself as if she were made from copper, as if she was important, necessary even. One year, she saved her money to buy knee-high boots and Jackie O–style sunglasses. She gossiped with her *cuñadas* and nieces about men's faces. “*Me encantan los hombres con bigotes,*” she'd say because she thought facial hair on a man delightful, though by all accounts she had no boyfriend.

...

The first time I met Tía Dora I was eight months old. My mother had been living in New Jersey six years by then, having left Colombia for work in the textile factories that dotted the towns along the Hudson River. She had been in the States long enough to marry a skinny Cuban exile, procure a green card, and give birth to me. She bundled me in a pink winter onesie, and we flew together from New York City to Bogotá, where Tía and the other aunties cradled me and changed my diaper and fed me formula. They had a crib ready for me, and over it they hung an enormous handmade doll with an obedient face and long braids the color of canela.

The second time we visited Colombia, I had acquired language. I was three. It was the summer of 1978, and Mami and I arrived in Bogotá to find Tía Dora embracing the fashion of the women's movement. She had cut her long wavy hair into a

bob and wore blazers, a scarf around her neck. She looked like a woman who expected to work on Wall Street. Her handbag, thin and boxy, suggested a briefcase.

If the family stories are true, Tía Dora sat with me and the aunties one day, all of them chattering and laughing, and she decided to humor the other women, her older sisters and the cuñadas.

In Spanish, she whispered to me, “Say: puta.”

I must have given her a dubious look. The word felt new to my ears, but she insisted. “Putá!” I cried to my mother and the aunties and the aunties married to my uncles.

My mouth latched on to the word. Puta, puta, puta. The word felt good and hard like carrying a knife between my teeth.

The women screamed in mock horror, then howled with laughter. I had called everyone in the room a whore.

...

If Tía were alive to read this, she would insist she never taught me vulgarities. “No fue así,” she’d chide. “Fue una broma. You’re making it sound so serious. It was funny.”

But I was three and already negotiating with my auntie’s ideas about language and transgression.

...

Tía Dora’s sickness began with a swelling.

Around 1979, her belly inflated under the blouses she wore to teach at the local elementary school. She thought she was bloated.

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She drank her mother's herbal teas. Nada. The discomfort persisted for a day, then another. Her belly stretched. In the shower, she would have looked down and seen it: her growing abdomen.

Her brothers teased. They knew women who got knocked up. "Tell us! Who's the father?"

Tía Dora scowled, then laughed. She was not pregnant. She had barely kissed a man. She waved her brothers away. After another day or so, she ran a fever. The ice cubes melted on her forehead and the towels grew moist, soaking the heat from her body.

At the hospital in Bogotá, La Clínica Fray Bartolomé de las Casas, the nurse handed Tía Dora a baby-blue nightgown with a pattern of stars. A pain must have torn through her body. Tía turned to her sister and begged, "Pray the rosary for me."

The nurses looked at my auntie's belly. It was not the first time they had seen a woman pregnant and young, unmarried and terrified. They told Tía's sister that it was most likely an embarazo ectópico, the baby growing in her fallopian tubes.

In the hospital room, Tía Dora lay in bed, and her sister paid thirty pesos to have a rollaway bed brought in so she could stay the night. They recited the rosary together: Bendito es el fruto de tu vientre. Blessed is the fruit of your womb. Then, Tía Dora felt a chill. "Tengo frío," she said to her sister. "Give me my coat." She pointed at an empty chair. Her sister prayed harder. It was one thing to have a fever and another to lose your mind.

Gloved hands wheeled Tía Dora into an operating room. She might have kept her eyes open and watched the light above the nurse's face, the honey-tinted halo. She would have heard the instruments tinkling on the tray, the unwanted music of paper rustling, latex gloves snapping into place, the hum of orders being

issued. She could not have heard the blade, its silver face pressing into her belly.

After the exploratory surgery, the doctors told her sister, “Tiene los intestinos de diez personas.”

My auntie’s large intestine had dilated, widened, begun to go loose inside her body. She had enough of a large intestine for ten people. The doctors offered a colostomy bag. It would get her through her last year of college, and when she graduated, a colostomy bag hung from the side of her belly. The doctors believed she might live a year, maybe two. No one suspected a parasite.

...

The women in my family decided to save Tía Dora. That is not how they told the story later. They credited the men: one particular doctor and also the husband of another auntie who knew of a clinic in Manhattan for poor people. But it is clear that my mother and my aunties made a decision: Tía Dora would not die. They shipped colostomy bags to Colombia. They paid for her flight to the United States in the winter of 1980. They asked my father if he would be so kind as to pick up Tía Dora at JFK.

In the car that night on the way to the airport, my father’s skinny fingers gripped the steering wheel. A Cuban, he had curly hair and bushy eyebrows, and he wore a flannel button-down shirt under a thin jacket. He was a man who refused winter. Now, he was also irritated, tense, and short-tempered probably because he felt nervous, afraid even. Driving made him uncomfortable. The responsibility of it frustrated him.

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My mother sat next to him, a rag doll of a woman, and like a muñeca, she was consistent and quiet. Papi, a jack-in-the-box, grumbled about the traffic and why we had not left earlier and did Mami have money for the tolls, but like a doll, my mother was steady in her moods—her half smile, her nonjudgment. She answered his questions and looked out the window at the black road ahead of her.

I was five years old, and my mother had stuffed me into a coat so heavy and snowball-resistant that my arms could move only up and down. The mittens on my hands were as puffy as pillows. But I was enjoying having the back seat to myself. My sister, Liliana, had stayed home with someone. She was still new, only four months old, and I did not quite understand that she was a permanent addition to our family. The world had always been as it was at that moment in the car: the rag doll and the jack-in-the-box and me.

I was the only one thrilled about the drive. I loved airports. I loved the balloons people brought for those who arrived and the flowers too. I loved running around the grown-ups, squeezing between their bodies. I loved how people hollered the names of sisters and cousins, and how they cried and hugged. Every arrival was a premio, a prize someone deserved.

My mother hated the airport.

Two years earlier, on our way back from Colombia, agents at JFK had opened our bags. The men picked through my mother's panties and socks. They tasted the arequipe and the hard candies too. Later, she complained to her sister: "¡Hasta los pañales!" Even the diapers were suspect.

At the airport that night, my mother worried that the immigration men would not let Tía Dora through, and so while I

ran around the waiting area, Mami stood with my father and all the women and men, everyone in winter coats and heavy scarves, and monitored the doors and tried not to think of the worst. She watched sisters and abuelas and couples arrive, but no Tía Dora. Maybe they had detained her. Maybe she'd gotten sick during the flight. Maybe they had simply refused her entry.

The crowd thinned. My father grew irritable. Where was she? He still had to drive us all back home, and it was the middle of December and the roads just awful.

The doors opened again. Tía Dora took a tentative step out, and the corners of my mother's lips collapsed. Her sister's face had thinned. How much weight had she lost? Already, she looked like a young woman about to die.

...

In the back seat of the car, Tía and I studied each other. I did not have my mother's worry. I did not know that grown women could become sick and die. If anyone had asked, I would have said my auntie looked like all the grown women I knew except she was flaca. Also, someone in Colombia had stuffed her into a ruana and coat. I sensed a kindred spirit. An auntie who did not get to dress herself. An auntie who was coming to live in our apartment in Union City, New Jersey.

...

In Colombia, Tía Dora had her mother, three sisters, and several cuñadas. In Jersey, she had my mother and Tía Rosa who

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my father eventually nicknamed Radio Auntie since this auntie talked all the time. Radio Auntie had a bundle of hair that looked like black cotton on top of her head. She was the oldest auntie in Jersey, the one who had no children of her own but whom Tía Dora had once called Mamá.

Over the next six months, Radio Auntie ushered Tía Dora onto buses and subways. She and my mother fed her papas rellenas. They learned that Columbia-Presbyterian Medical Center in Manhattan had specific days and times when any patient would be seen, regardless of whether the person could pay. They shuttled Tía Dora across the Hudson River to the hospital. They helped her get in and out of the hospital gown and met with Dr. Alfred M. Markowitz. The surgeon had strong eyebrows and thinning silver hair carefully groomed away from his face. He looked crisp and alert in his suit underneath his white coat, the kind of man that made you think of a clean piece of paper.

The doctors in Colombia had not suspected the kissing bug disease but Dr. Markowitz did. In an article in the *New York Times*, years after his death, he was celebrated as an old-school physician-teacher who quizzed his residents, on the spot, about obscure medical conditions. This may explain how Dr. Markowitz diagnosed Tía Dora with the disease, because only in a few number of cases does the parasite attack the gastrointestinal system, making it so that the large intestine begins to lose its shape. Food starts to collect in the colon. The person's belly begins to swell. A man can, as Tía Dora did, appear pregnant. Without intervention, toxins can seep from the intestines and kill the person.

Dr. Markowitz explained that Tía Dora would need several abdominal surgeries. My mother, anxious and worried, asked

how much it would cost. In Colombia, if you didn't have health insurance, you had to save your earnings before a doctor would perform a procedure. "We'll have to raise the money," Mami said quickly, imagining the expense, and she thought about asking a local Spanish radio station to make the announcement that our family needed many thousands of dollars to save my auntie's life.

"Don't worry about the cost," the doctor said.

The women in my family did not know how hospitals took care of patients who did not have insurance. They did not know about Medicaid. They did not know the phrase *indigent patients*. They believed the doctor himself would pay for the surgeries. They insisted our family had been blessed.

...

In New Jersey, my mother and Radio Auntie and Tía Dora made audio recordings for my grandmother in Colombia. Tía told her mother about the doctor and the nurses and the hospital but didn't mention an interpreter. She had studied English and apparently understood more than she could speak. Or maybe no one needs an interpreter when a priest comes to offer last rites.

"I got scared," she whispered into the cassette recording, describing the day of her first surgery, but she did not lose faith, she assured her mother. Then, Dr. Markowitz came to her room. "He spoke to me in such a sensitive way. All in English."

He wanted to be clear with her. "I am asking for luck for you and for me," he said. "If I make a mistake in any way, I ask for forgiveness."

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She assured him that he possessed all her forgiveness, all her gratitude.

So many doctors filled the operating room that Tía Dora lost count of them. Some were residents. One a cardiologist. Another an anesthesiologist. And then she was asleep and the men busy slicing open her belly.

When she woke from the first surgery, Tía spoke in English. She meant to say that she wanted to see Dr. Markowitz, but “Por favor, quiero ver el Dr. Markowitz!” collapsed in the translation, and she cried, “Please I like Dr. Markowitz!” She cried it repeatedly until he appeared and clasped her hands.