

A SILENT AND DEADLY SOUVENIR OF HOME by Erin Loury

My story on Chagas disease is the article I am most proud of from my summer at the *Los Angeles Times*. I found the end result particularly rewarding because I had never heard of the disease before starting the story. The topic has many complexities, which I found both fascinating to learn about and challenging to convey.

The story idea came from another reporter who had adopted two kids from Guatemala, and was concerned about what some were calling “the new HIV from Latin America.” Researchers had touched off a controversy a month earlier by publishing a paper that compared Chagas to HIV. Some of the ensuing news coverage was a bit sensational or over-stated.

In my own story, I grappled with how to acknowledge the similarities between Chagas and HIV, as well as the important differences. I also wanted to communicate the impact of the disease in both Latin America, where it originates, and in the United States. The story proved particularly relevant to Los Angeles, not only because of the large Latin American population, but also because the city houses the only Chagas clinic in the country.

To build my understanding of the disease, I spoke to several people in medicine, research, public health, and health education. I’m glad I also had the opportunity to speak to a woman with Chagas, who graciously shared her story, and to attend a local health fair. Part of me wanted to describe every intriguing aspect of the disease in detail: how it spreads, how it affects the body, why it is so challenging to diagnose. My editor helped me find the right balance to make the story thorough without being overwhelming.

What I find most striking is how few people in the United States receive treatment for Chagas disease compared to the estimated number of cases. I felt my story had achieved something when a friend told me he saw it in the American Medical Association *Morning Rounds* briefing. Hopefully my story will play some part in helping doctors improve diagnosis and treatment for this often overlooked illness.

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CAMPAIGN 2012

Romney low-key on civil rights

In contrast to his father's active role in the '60s, he has said little on the issue.

By MAEVE RESTON

ANN ARBOR, Mich. — In 1963, an explosive year in the quest for civil rights, George Romney appeared unannounced in the mostly white suburb of Grosse Pointe and marched to the front of an anti-segregation demonstration to stand beside black leaders.

Letters from startled constituents poured into the office of the first-term Michigan governor, whose son Mitt was then 16. Supporters who had helped the elder Romney win his narrow victory the previous November said his actions made him "a double-crosser" and a "Ju-

das" to the people who voted for him. Their diatribes were sprinkled with warnings that they would work against him: "You are a 'dead duck' for 1964," one detractor typed above a newspaper photograph of a shirt-sleeved Romney walking shoulder to shoulder with civil rights activists.

Romney pressed ahead with an aggressive civil rights agenda that ultimately put him at odds with the leaders of his party. He refused to back Barry Goldwater as the 1964 Republican presidential nominee because, he told Goldwater in a letter, he was alarmed by indications that Goldwater's strategists "proposed to make an all-out push for the Southern white segregationist vote" and "exploit the so-called 'white backlash' in the North."

George Romney began [See Romneys, A10]



Lawrence Livermore National Laboratory

A BIOWATCH air sampler in the Washington, D.C., subway. This unit is a prototype of next-generation samplers intended to be more reliable, but the new technology has also shown problems in testing.

The biological defense system that cries wolf

BioWatch, the federal network of air samplers aimed at thwarting a terrorist attack, is plagued by false alarms and other failures.

By DAVID WILLMAN

DENVER — As Chris Lindley drove to work that morning in August 2008, a call set his heart pounding.

The Democratic National Convention was being held in Denver, and Barack Obama was to accept his party's presidential nomination before a crowd of 80,000 people that night.

The phone call was from one of Lindley's colleagues at Colorado's emergency preparedness agency. The deadly bacterium that causes tularemia — long feared as a possible biological weapon — had been detected

at the convention site.

Should they order an evacuation, the state officials wondered? Send inspectors in moon suits? Distribute antibiotics? Delay or move Obama's speech?

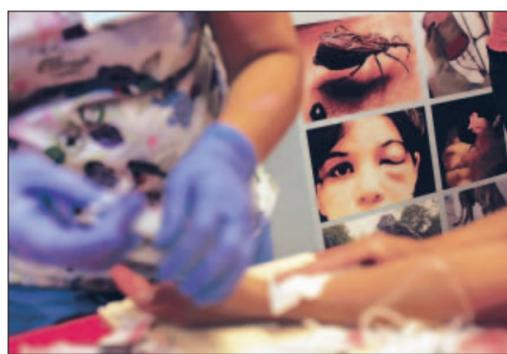
Another question loomed: Could they trust the source of the alert, a billion-dollar government system for detecting biological attacks known as BioWatch?

Six tense hours later, Lindley and his colleagues had reached a verdict: false alarm.

BioWatch had failed — again. President George W. Bush announced the system's deployment in

his 2003 State of the Union address, saying it would "protect our people and our homeland." Since then, BioWatch air samplers have been installed inconspicuously at street level and atop buildings in cities across the country — ready, in theory, to detect pathogens that cause anthrax, tularemia, smallpox, plague and other deadly diseases.

But the system has not lived up to its billing. It has repeatedly cried wolf, producing dozens of false alarms in Los Angeles, Detroit, St. Louis, Phoenix, San Diego, the San Francisco Bay Area and elsewhere, a Los Angeles [See BioWatch, A12]



MICHAEL ROBINSON CHAVEZ Los Angeles Times

A POSTER shows carriers and effects of Chagas' disease as a person gets a blood test at a health fair.

A silent and deadly souvenir of home

Chagas is a parasitic disease most often found in immigrants. It can go undetected for decades. But public awareness is growing.

By ERIN LOURY

The cryptic letter arrived a few weeks after Maira Gutierrez donated blood for the first time in 1997. The Red Cross had rejected her blood. It listed a phone number to call.

Gutierrez left a message, then waited three agonizing days for a reply, fearing she had HIV. The truth proved more confusing than reassuring: She had something called Chagas' disease, an ailment she'd never heard of, spread by a winged insect inconspicuously dubbed the "kissing bug."

A Red Cross pamphlet told her the parasitic affliction could be fatal — it could stop her heart. But doctors she consulted didn't know how to help her or treat the disease.

Physically, Gutierrez felt fine. After months of stress and unanswered questions, she decided to try to move on. But for more than a decade, the heavy knowledge that she carried a potentially deadly parasite hung over her.

Then, late one evening in 2008, her sister phoned, fran-

tic. Chagas' disease was on the news.

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Chagas affects an estimated 300,000 people in this country and about 13 million worldwide, chiefly in Latin America, where it is a leading cause of heart failure.

Most carriers in the United States are immigrants who acquired the disease in impoverished areas of Bolivia, Mexico or Central America, where kissing bugs inhabit the cracks and crannies of homes. The bugs nip [See Chagas, A20]

Polar opposites on saving bears

By KIM MURPHY

IQUALUIT, Canada — Doomsday predictions of the polar bear's demise tend to draw an Inuit guffaw here in Nunavut, the remote Arctic territory where polar bears in some places outnumber people.

People will tell you about the polar bear that strode brazenly past the dump a

month ago or the bear that attacked a dog team in the town of Arviat in November. Heart-rending pictures of polar bears clinging to tiny islands of ice elicit nothing but derision.

The move to protect polar bears is appreciated for one thing, however, and that's a hefty hike in the price for a dead one. Across Canada, prices for polar bear pelts have soared over

the last few years, with two at a June 20 auction in Ontario fetching a record \$16,500 each.

"Four years ago, we were lucky to get a thousand dollars for a 7-foot polar bear. Now, you can sell that 7-foot polar bear for between \$3,500 and \$4,000," said Frank Pokiak, chairman of the Inuvialuit Game Council in northwestern Canada. [See Polar bears, A11]

From the Taliban, poetry

By LAURA KING

KABUL, Afghanistan — War is an ageless poetic well-spring, yielding wrenching odes to the white heat of combat, the longing for lost loved ones, the dust of graveyards. Now a controversial new anthology unveils a collection of seldom-heard voices: those of Taliban fighters.

Denounced by some as propaganda by the enemy in America's longest war, hailed by others as a rare window on a largely hidden world, the verse assembled in "Poetry of the Taliban" is by turns bombastic and introspective, dark and mirthful, ugly and lyrical — and perhaps above all, surprising in its unabashedly emotional tone.

"I stoned him with the stones of light tears / then I hung my sorrow on the gallows.... / It might have been the wine of your memory / that made my heart drunk five times."

The collection's compilers, a pair of European re- [See Poetry, A6]

Iowa draws crowd

Thousands visit the floating museum on its first day. CALIFORNIA, A21

Complete Index A2

Weather: Clearing. L.A. Basin: 80/62. A28

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JULIAN FINNEY Getty Images

Serena Williams wins Wimbledon

The U.S. star claims the title for the fifth time, over Poland's Agnieszka Radwanska. SPORTS, C1

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Treatment can keep effects of Chagas at bay

[Chagas, from A1] at faces and lips while people sleep, and drop feces laden with the parasite *Trypanosoma cruzi*. The parasite can enter the open wound and circulate in the blood, attacking the heart, colon or esophagus.

No one is predicting an epidemic in this country, but disease experts are trying to increase awareness, testing and treatment of Chagas, which can affect sizable swaths of the population, particularly in states like California, with a large Latin American immigrant population.

The effort is needed because the disease can linger undetected for decades, making it difficult to diagnose. Symptoms can be as subtle as an irregular heartbeat or shortness of breath.

Two-thirds of those who become infected never develop complications. But for about 30% of those who contract Chagas' disease, it can cause serious illness, often silently ravaging the heart muscle. Most American physicians don't think to test for it, potentially denying life-saving treatment to thousands.

The disease can trigger strokes and heart failure in people as young as 30. "Your heart just turns into a big, ineffective bag," said cardiologist Sheba Meymandi, director of a Chagas treatment program at Olive View-UCLA Medical Center, the only one of its kind in the nation. About 1 in 100 Latin American immigrants whom the center tests has the disease.

Insects carrying the parasite live throughout the southern half of the U.S. But there have been only nine confirmed cases of people contracting the disease from insects in this country since 1955.

Still, says Meymandi, "This is not an exotic dis-

ease. This is a prevalent disease that is treatable in our community. And until people think about it, we're not going to make inroads."

Kissing bugs are suspected of having infected two Los Angeles high school students recently. Meymandi treated the 17-year-olds, who tested positive for Chagas after donating at school blood drives. Neither is of Latin American descent or has ever traveled to the region. But both spend time outdoors mountain biking or golfing, and Meymandi thinks they acquired the disease locally.

Los Angeles County currently has no Chagas public education program, but officials say they might create one if there are increased signs that the disease is being contracted locally.

The federal Centers for Disease Control offers free drugs to treat Chagas. But they receive just 50 or 60 requests a year for the medications, suggesting that thousands of cases go untreated. "Most healthcare providers don't think of Chagas' disease when they see someone who might be at risk," said Susan Montgomery, a CDC epidemiologist.

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Gutierrez, 39, of Mission Hills grew up in the small mountain village of El Congo, El Salvador, with no running water or electricity. She lived with her grandmother until age 8, then immigrated to Lynwood with her younger sister to join her parents, who had already fled their homeland's civil war.

Working as an administrative assistant at Universal Studios introduced Gutierrez to the man who became her husband, Daniel, who works there as a landscaper. It was also through her job that she learned of



Photographs by MICHAEL ROBINSON CHAVEZ Los Angeles Times

CARDIOLOGIST Sheba Meymandi, center, directs a Chagas' disease treatment program at Olive View-UCLA Medical Center, the only one of its kind in the U.S.

Chagas. She tested positive for the disease during a random screening after a 1997 workplace blood drive.

The Red Cross brochure that Gutierrez received explained that kissing bugs spread the disease in places of extreme poverty, hiding in thatched roofs and cracked walls. Looking at the brochure's photos, Gutierrez flashed back to El Congo: "Oh, my God, that's exactly where I lived."

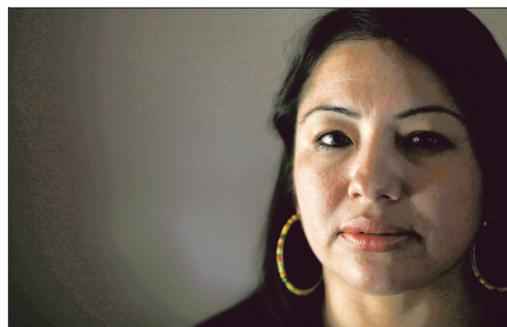
Her doctor referred her to a specialist, who told her Chagas was untreatable, Gutierrez said. She was confused and angry — no one could tell her what to do. Eventually, she stopped asking.

For the next decade, Chagas crossed her mind whenever her health flagged, when her daughter was born two months early, when delivering her son required a lengthy recovery.

After her sister called about the Chagas news story in 2008, Gutierrez learned of the Olive View Center and contacted Meymandi. The doctor performed heart tests and started Gutierrez on an anti-parasitic drug. She took the pills three times a day for three months, a grueling regimen that sapped her appetite. She lost 20 pounds.

As with nearly everyone who undergoes treatment, she wasn't cured, but her parasite count and the risks of serious complications were greatly reduced.

After her treatment, Gu-



MAIRA GUTIERREZ, who was born in El Salvador, went untreated for years after her Chagas diagnosis.

tierrez began speaking at medical conferences about Chagas from a patient's perspective. "People think it's not here," she said.

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Experts agree that Chagas needs more attention, but a recent editorial in the Public Library of Science's journal *Neglected Tropical Diseases* sparked controversy by labeling Chagas "the new HIV/AIDS of the Americas." Peter Hotez, the paper's lead author and dean of the National School of Tropical Medicine in Houston, noted that both are chronic diseases spread by blood, require toxic medications and disproportionately affect the poor.

But Chagas is not a virus and cannot be sexually transmitted. And there is little patient advocacy to draw attention and funding to the

illness. "This is a forgotten disease among forgotten people," Hotez said.

Caryn Bern, a visiting global health expert at UC San Francisco, said the comparison to HIV is overblown and sensational. And Meymandi worries that the association will create additional stigma for immigrants with Chagas.

In the southern U.S., kissing bugs carrying the parasite can infect raccoons, dogs and, on occasion, people. The blood-borne disease also passes from mother to child in utero 5% to 10% of the time.

Since 2007, the American Red Cross has screened all new blood donors for Chagas. Unlike Gutierrez, donors who test positive today receive disease information and treatment guidance from the outset. But the Red Cross has found that most do not check in with a doctor

'This is a forgotten disease among forgotten people.'

— PETER HOTEZ, dean, National School of Tropical Medicine

as instructed.

A more effective approach, Meymandi says, is working with *promotoras* — trusted Latin American community members who provide health education through churches and schools. They also organize neighborhood health fairs, where Meymandi and her staff collect blood samples for Chagas testing. Attendees who test positive almost always come in for treatment, Meymandi said.

At a recent fair at Emmanuel Covenant Church in Northridge, several dozen people advanced through rows of wooden chairs, fanning themselves with health brochures. Mara Barajas of Pacoima sat at the Chagas table while a nurse swabbed the crease of her elbow, then pushed a thin needle under her skin. Barajas' 4-year-old son, Justin, covered his eyes.

The 40-year-old, who emigrated from Mexico 12 years ago, had never heard of Chagas' disease but still wanted testing. "It's good to know," she said.

Chagas screening can be a hard sell for some. Gutierrez persuaded her family to get tested — everyone but her sister, whose late-night phone call finally led Gutierrez to treatment. Gutierrez said her sister fears that receiving a positive test result would "eat you up alive."

For Gutierrez, the disease's shadow remains, if more faintly. "You kind of forget that you have it until someone brings up the subject," she said.

She's determined to lead a normal life but also talks with her husband about their finances, their kids' college education and when he could remarry — just in case. "I don't know how much time I have," she said. "It could be 50 years, but I'm not sure."

erin.loury@latimes.com

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Thursday July 19th 1:00PM to 3:00PM
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Wednesday July 11th 5:00PM to 7:00PM
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