



EPIDEMIC





OF SILENCE

Since 1989, the Thomas Street Health Center has been Houston's front line in the war against HIV/AIDS. Today, despite miraculous scientific advances, the center is busier than ever. With one in 250 Houstonians infected, is the epidemic over, **or have we just stopped paying attention?**

BY **MICHAEL HARDY**

PHOTOS BY **ALYSSA ORR**

When Oswaldo Gutierrez tells you the news, he will be careful not to use the words “infectious” or “disease,” even though what you’ve contracted is both.

H HE WILL TAKE YOU SOMEWHERE PRIVATE, maybe a vacant room off the hallway, unless of course you’re incapacitated from, say, a gunshot wound to the head, in which case he will come to you. Gutierrez will say that he works with the lab at Ben Taub Hospital and that a routine screening test came back positive. He will emphasize the hospital’s plan to run a confirmatory test, even as he knows, five years into this job, that there are only two or three false positives each month. If there are other people around, he won’t say the name of your disease out loud but will silently point to the word on his lab report: HIV.

And then he waits.

“You stay quiet,” says the handsome, preternaturally calm 37-year-old Mexican native whose family came to Houston when he was 14. “You don’t talk over them, you just stay quiet and let them get it out.”

Gutierrez, who has been through this process hundreds of times, says most of his patients don’t react in a dramatic fashion; they’re calm, almost as if they expected this but never wanted to face something so definitive as a test result. Then there are those to whom the news is a complete shock, those who burst into tears, like the woman Gutierrez recently diagnosed who had been married 30 years. Others worry openly

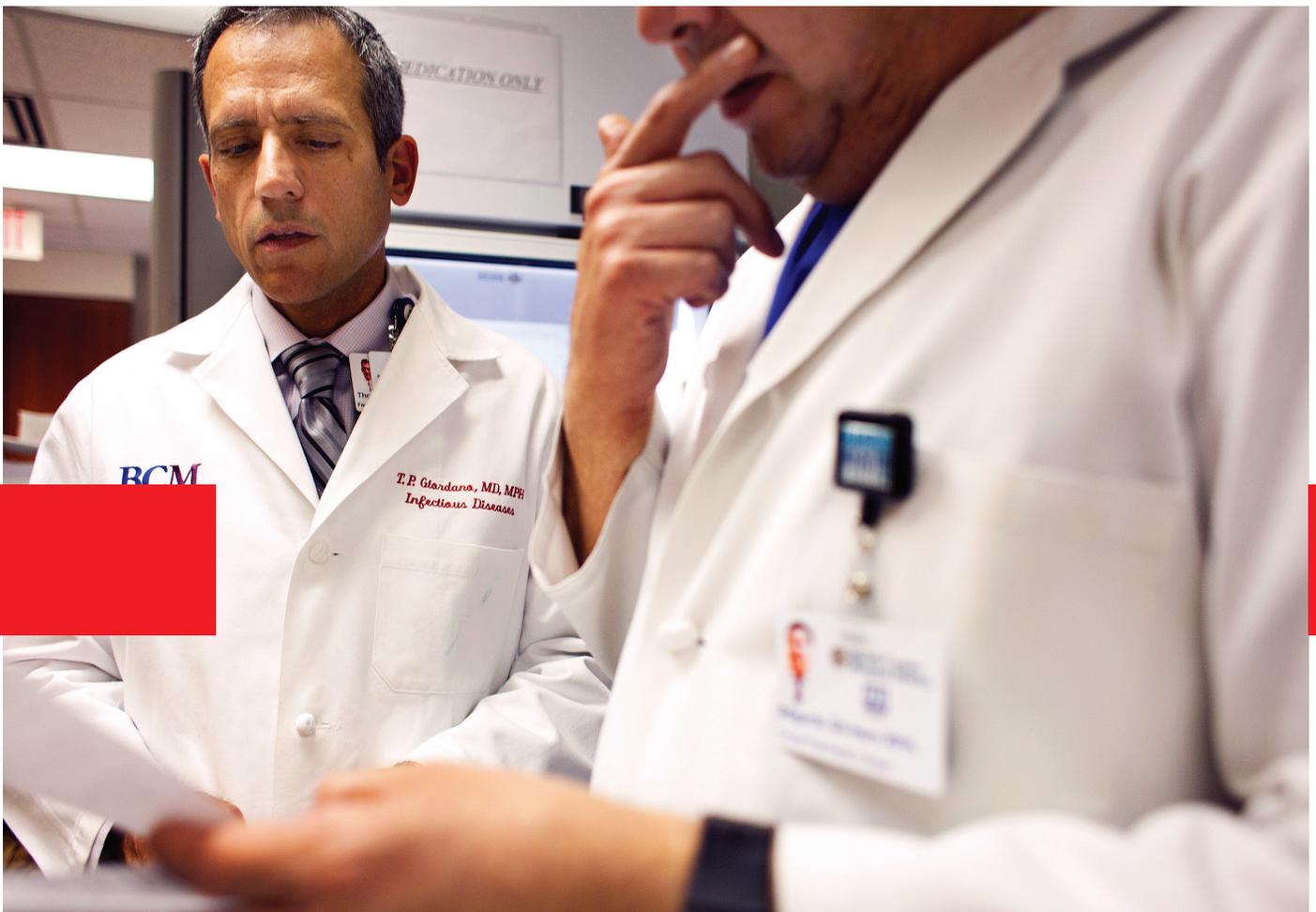


about how to tell their family and friends. Because unlike tuberculosis or hepatitis or smallpox, this infection carries with it something else; something that’s been part of the HIV experience since the epidemic began more than three decades ago. Every year fifteen thousand Americans die of a disease so treatable it should be killing no one, and 1,400 Houstonians contract the virus that causes that disease. Upwards of 1 in 250 of us are now HIV-positive. “Nobody wants to say they have HIV,” says Gutierrez. Which is a major reason so many people do.

ON A RECENT THURSDAY, a woman newly diagnosed with HIV paid her first visit to a Harris Health System HIV/AIDS clinic called the Thomas Street Health Center, having been sent there by a service linkage worker, which happens to be the odd title Ben Taub gives to what Gutierrez does. (Harris Health operates Ben Taub, Lyndon B. Johnson Hospital, and 42 other medical facilities around the county.) Of all such clinics in Harris County, the one at 2015 Thomas Street is the largest, treating a quarter of the city’s 22,000 HIV-positive residents, and of all the volunteers at Thomas Street Health Center, perhaps none is more powerful a mentor than Carolyn Watson. A middle-aged African American woman with colorful rings on her fingers, her hair swept up into a neat bouffant, Watson was on this day paged by a screening clerk after the clinic’s newest patient had broken down into sobs. She quickly found the woman, sat down across from her, and then, for just a few moments, held her tongue, letting her weep.

“Look real close,” she finally said. “On the 24th of April this will be 10 years for me.” The woman stared at the strong, healthy, HIV-positive woman before her. “Yes, you *can* live,” Watson continued, as if in conversation. “You’re still human. You still have all your body parts. There is hope and there is life.”

Watson always emphasizes the positive in such meetings, and not only because an HIV diagnosis, even now, means an endless number of doctor visits and a lifelong commitment to



antiretroviral medicine that costs an average of \$25,000 a year (although most qualify for subsidies). She emphasizes the positive because she's been there, and because she knows what it's like to feel simultaneously afraid of how a disease will kill you and what your neighbors will whisper as you waste away.

Left untreated, HIV leads to full-blown AIDS; with medication, it can be a burdensome aspect of an otherwise healthy life. But treatment entails acknowledgement. "Keeping secrets is not going to help us educate people," Watson said recently, reflecting on her experience working with new patients. "It's not going to help break the stigma."

Watson says that all the Thomas Street volunteer mentors—longtime patients who provide support for new arrivals—hear the same questions over and over. How will the newly diagnosed tell their family and friends? Their co-workers? Medication has brought the virus under control, but not the negative attitudes associated with it, attitudes perhaps more prevalent in Houston than elsewhere, and which help explain why, according to a 2010 White House report on AIDS, the Houston-Baytown-Sugar Land area is the eighth-hardest hit area of the country.

DR. ELIZABETH CHIAO, a specialist in infectious diseases at the Baylor College of Medicine, came to Houston in 2004, having spent years at New York-Presbyterian Hospital, a national leader in HIV/AIDS treatment. When Chiao first arrived at Ben Taub, she was shocked by the state of her patients' health. "I saw so many things that I hadn't seen before—I mean advanced, *advanced* AIDS," Chiao said. "I just assumed that everywhere was like New York, where everyone was pretty healthy. Here, people were still dying of AIDS."

And in higher numbers. Although the first HIV cases appeared in New York and California, the geography of the epidemic has shifted. Increasingly, the virus's victims are concentrated in the 17 states of the South—including Texas, which has the country's 12th-highest percentage of HIV-positive residents. Chiao

speculates that the shift can be attributed, at least in part, to the stronger taboo against homosexuality below the Mason-Dixon line. "The stigma here is really profound," Chiao said. "You hear about it almost every day from a patient, either in a comment about how they can't talk to their family, or how people won't talk to them at work anymore, or how their family won't help them."

"My son kept [his HIV] a secret from me for eight years," said Jackie Wear, who first came to Thomas Street in 1993 with her 20-year-old son Rusty, who had developed full-blown AIDS. A relentlessly positive woman with a passing resemblance to Ann Richards, Wear, or Miss Jackie as she's known at Thomas Street,



soon became a volunteer at the clinic, and then a full-time employee. She continued to work after her son succumbed to AIDS in 1998, and in 2005 founded the well-regarded mentor program in which Watson and others participate.

"That's what's killing people," Wear said flatly. "Secrets?"

WHEN IT WAS FOUNDED IN 1989, at the height of the epidemic, Houston's Thomas Street Health Center was the first freestanding HIV clinic in the country. It's housed in a former hospital for Southern Pacific Railroad employees, a stately, 103-year-old Mediterranean Revival pile nestled in a quiet residential neighborhood in the Fifth Ward. (A tile mosaic of the railroad's logo still marks the building's original entrance.) But beyond the fanciful façade once lay decay so advanced it posed a danger to patients. When the clinic first opened, only the bottom floor was suitable for human habitation, and even there the peeling paint and soiled carpeting bespoke years of neglect. "It was a dull, drab, stinky, horrible building," recalled Carolyn Barrett, Thomas Street's nursing director from 1989 to 2000. "It was depressing."

Dr. Wayne Shandera, who co-authored the 1981 Centers for Disease Control article detailing the first cases of what the world would soon know as AIDS, began working at Thomas Street soon after it opened, and he still has an office there. He remembered worrying that a patient with CMV retinitis, a common AIDS-related infection that impairs vision, might fall into the building's open elevator shaft.

One way of understanding the battle against AIDS in the years since is to look at the ways Thomas Street itself has evolved. Melvia Ramirez, who began working at Thomas Street in 1991, had a first impression reminiscent of Dante's description of limbo in *The Divine Comedy*. "Patients were sitting in the waiting area, sitting on the floor, falling down," Rodriguez remembered. "You'd see patients come in, and a few months later they were gone. When I walked in here my first day, I said, 'Lord, you sent me here, and you must have sent me for a reason.'"

Jackie Wear has a vivid recollection of her initial impression too, during her first visit in 1993. "I remember walking through the front door," she said. "They were in the midst of remodeling, and it was the most dreary, ugly, messed-up place. And I was like 'Oh my God, my baby's here.'" But her revulsion didn't prevent her from becoming a volunteer. "It was very traumatic—people were dying," Wear said. "They posted a list of the dead in the break room."

Sick people came to Thomas Street in droves, but the clinic had precious little to offer when it first opened. John Tuttle, the manager of a Houston auto repair shop, was diagnosed HIV-positive after catching the virus in what he described as a "moment of indiscretion." He had about two years to live, he figured, if his friends' deaths were any indication, although he also knew several people who'd committed suicide after receiving their diagnoses. "It was a scary time," he said. "The doctors had no idea—you might as well write your will and forget it in 1988."

CONTRAST TUTTLE'S EXPERIENCE with that of a newly diagnosed patient—say, the woman who had been married for 30 years. In the halls of the now-orderly, businesslike, clean, and well-stocked Thomas Street clinic, you get the sense that an HIV diagnosis, at least these days, is just the first in a well-re-

hearsed and tightly-coordinated series of steps designed to efficiently shepherd patients through a heavily-subsidized and frequently successful treatment program. Before he even introduces himself to new patients, Gutierrez has already started the paperwork to enroll them in the national Ryan White program or the county's own financial assistance program, and has made a doctor's appointment for them either at a private clinic or one of Harris Health's facilities—usually Thomas Street.

The efficiency begins with the diagnosis. Since 2008, Harris Health has performed "opt-out" HIV tests on every blood sample drawn from patients between the ages of 16 and 64. Prior to instituting this policy, known as the Routine Universal Screening for HIV program, a patient had to check a box to request an HIV test; now you have to check a box if you *don't* want one. (A similar program is in place at Memorial Hermann.) With 10,000 people a month coming through the emergency center at Ben Taub alone, almost half of whom get their blood drawn, that's a lot of HIV tests—305,680 to be exact, leading to 841 new diagnoses in the five years since the program began. (Using a CDC statistical model, Harris Health estimates that 230 infections have been averted because of the program.)

At that point, said Harris Health HIV testing project coordinator Ken Malone, who directs the RUSH program, patients are typically counseled extensively in order to help them under-



stand the various treatment options. "HIV is such a serious disease that you have to have someone talk to you about it," Malone said. "Because there's so much to it. You can't just say, 'Oh, you're HIV-positive, and we have lots of services.' That does not work—nobody will access your services. It's that simple."

Gutierrez follows up the counseling by calling the patient at home to remind them of their doctor's appointment, then calls again afterward to make sure they actually went. If someone can't find transportation, he'll show them how to get a bus pass or taxi voucher. "It seems extravagant, but you know what—it's efficient, and they get here," Malone said. "It's only seven miles from Ben Taub to Thomas Street, but it might as well be 700 sometimes. If they can't get there, or you haven't impressed on them that this is really important to their future health, then they aren't going to come. When you have a disease that is communicable, you want to make every effort to get them treatment."

So yes, things have changed dramatically since 1989. Still, the more time you spend there, the more you realize how much *hasn't* changed. Despite the near-certainty that a patient who complies with their treatment regimen will go on to live a rea-



sonably normal life, thousands still decline to follow any regimen at all. As of now, 80 percent of all HIV-positive Americans are aware of their status, but only 37 percent of those are in regular care. Only a third have ever received a prescription for anti-retroviral medication. And only a quarter have a suppressed viral load—the ultimate goal of HIV therapy.

To even begin to figure out why, you have to understand that other epidemic, the epidemic of silence, the one that tricks patients into believing that their only option is to accept the stigma, keep the secret, deny, and do nothing.

CONSIDER THE 19-YEAR-OLD MAN who, after learning he was HIV-positive, gave Gutierrez a wrong telephone number and skipped his doctor's appointment. Two years later, he showed up in the Ben Taub emergency center with a case of *Pneumocystis carinii* pneumonia, one of the most common, and deadliest, AIDS-related diseases. When asked why he hadn't been getting treatment, the man told Gutierrez that he didn't see what the big deal was. After all, he said, there were always drugs he could take. "That's what I told you two years ago," Gutierrez remembered saying. "Now you're coming back with opportunistic infections and a CD4 count of God knows what. Just by the fact that you stopped that care, you cut down like ten years of your life. If you continue not to take care of your health, you're going to die."

And then there was the homeless woman with a crack cocaine problem to whom Gutierrez delivered a diagnosis in 2011. On top of all the other services—doctor visits and transportation and free meds—Gutierrez personally secured housing for her at a shelter run by Sisters of Serenity, a Christian outreach ministry, and got her into HIV treatment at Thomas Street. But the woman eventually relapsed and returned to the streets. "Sometimes it's frustrating with patients," Gutierrez said. "If someone tells me I have a disease that can kill me, I'd want to do as much as possible. And if someone's offering all these resources, I would jump on that opportunity. Some of these people I just want to slap around, like, 'What's going on with you?'"

Why AIDS would be so stubbornly resistant to the efforts of modern medicine is a deep, complex question only partially answered by society's attitude toward the disease and its victims. "The demographics of HIV have shifted over the last few decades," said Thomas Giordano,

Thomas Street's medical director, "from a population that was largely gay, white, working, and educated to more of an urban, poor, minority population." The disease is increasing among the old, as they find their sex lives reinvigorated by the advent of Viagra and other drugs. At the same time, AIDS is on the rise among the young, who weren't alive for the huge public education initiatives of the early '90s.

Still, AIDS victims come from every walk of life, from every generation, race, and economic background. And sometimes they seem to have nothing in common save the reluctance to admit that their disease is a disease.

I SPOKE TO CAROLYN WATSON in Thomas Street's first-floor chapel, a chapel that at the height of the AIDS epidemic held several memorial services a day. Now it's usually empty, a good place to reflect, and on that recent Thursday she was reflecting on the tearful woman. After the woman dried her eyes, Watson had told her the story of how she herself nearly died of AIDS in 2002. She had been a rater technician with the Hartford Insurance Group at the time she became ill, and spent a year going to specialists in



hopes of discovering what was wrong—receiving, in the process, two colonoscopies, a liver biopsy, a bone density test, and several erroneous diagnoses of bronchitis. Finally, unable to breathe and a hundred pounds thinner than she had been the year before, Watson ended up at the Ben Taub emergency center. When her blood test came back, a doctor stopped by to speak with her. "He asked me if I knew Magic Johnson," Watson said. "I didn't know what he was talking about."

When he told her that she had advanced AIDS, Watson passed out from the shock. She spent the next week and a half drifting in and out of consciousness. (She now believes she contracted HIV from a heterosexual affair in the '90s, when she was between marriages. Watson's second husband, whom she had married before learning her HIV status, stayed with her through her extended hospitalization, although the two later divorced.) At one point, the family was told that Watson might not live through the night. Eventually, she emerged from her semi-conscious haze, began treatment, and slowly started to improve. As if the year hadn't been hard enough, in December her mother and brother both died within the space of a week. Then Watson discovered that Hartford had eliminated her old position; if she wanted to return to work she would have to apply for a new job and move to San Antonio.

If it weren't for regular hospital visits from a fellow member of New Bethel Baptist Church, Watson said, she doubts she would have survived her *annus horribilis*. When at last she got out of the hospital, she began going to Thomas Street for treatment; she also returned to her church, where she took to the pulpit one Sunday to speak about her ordeal. "I said, 'You guys can either love me or reject me,'" Watson remembered. "Really, I was scared, because I didn't know whether they were going to accept me. Even though the pastor said it was okay, I still didn't know how the rest of the church would react. And it worked out—there was a good response." Since then, Watson has been invited by several other Houston churches to speak about life with HIV. Now retired, she spends her time singing in the church choir, attending the women's support group at Thomas Street, and mentoring on Thursdays. She has never kept her HIV a secret and has even discussed her condition on local TV. "I stopped being scared a long time ago," Watson said.

FOR OVER A YEAR, Oswaldo Gutierrez had been trying in vain to reestablish contact with the homeless woman he had diagnosed with HIV and sent to the shelter. Then, a few months ago, someone walked into Ben Taub asking if she could see a Mr. Waldo. "Nobody knew who she was asking for at first, because nobody calls me Waldo," Gutierrez said, laughing. "But she remembered me—it was amazing." The woman was still apparently living on the streets, but appeared to have put on weight since the last time Gutierrez saw her, which he took as a good sign. They went into his office, where they sat and talked for two hours. The woman said she had family in Killeen, but that she didn't want to be a burden to them. Home was a trigger for getting back on crack cocaine, she said, and she preferred being homeless. Right then, Gutierrez made a doctor's appointment for her at Thomas Street, and because she had lost her ID card, as homeless patients often do, he gave the woman a voucher to get a new card from Project ID. When they parted, Gutierrez embraced her. "She's a hugger," he said.

A few weeks later, the woman showed up at the Ben Taub emergency center complaining of pain in her stomach and a cough. Gutierrez wasn't there when she arrived and only found out about her visit the following morning. By the time he went to check on her, she was already gone. ❧

