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The Protection Racket

And the band plays on

By Wyatt Olson

A quarter century after the advent of AIDS in America, Professor William Darrow's sense of urgency about one thing remains undiminished: This state, this country, isn't doing enough to stop the disease.

Although new treatments have made AIDS less deadly, a vaccine remains chimerical, and prevention efforts are flagging. We are as far from eradication today as we were 25 years ago. Last summer, Darrow, putting the considerable heft of his reputation as a groundbreaking AIDS researcher on the line, called for a "state of emergency" in South Florida. He called on Florida health officials to begin kicking in the state's own money for prevention. Nothing happened.

"We have known about the serious problem of HIV disease in South Florida for at least the last decade," says Darrow, a professor at Florida International University and a medical sociologist. "If you want to have a good program of public health, someone has to pay for it. Right now, the story line is that underfunded programs don't work."

Darrow is uniquely qualified to understand the implications of the disease. Back in 1981, he was a member of the scientific team with the Centers for Disease Control and Prevention (CDC) that first cracked the mystery of an ailment killing gay men. For the past ten years, as a professor at FIU's school of public health, his research has focused on the spread of the HIV virus in South Florida, particularly among gay men and minorities.

Ignorance and "safe-behavior fatigue" are the great enemies of prevention, AIDS specialists say.

"Few people seem to be interested in AIDS," Darrow declares. For those too young to remember the epic saga of AIDS in the 1980s, the disease can seem abstract or a relic from the past now that death rates have declined. For some new immigrants in America, HIV/AIDS simply wasn't discussed publicly where they came from. Others, however, who might have taken the disease seriously in the past have grown more complacent, wearied of keeping a constant vigil.

Still, HIV/AIDS remains a scourge. South Florida has long possessed higher-than-average rates of HIV/AIDS cases, and things are only getting worse. Much worse. According to CDC statistics released in November, Broward County led the nation in new AIDS cases in 2004, with 58 cases for every 100,000 people — up from fourth place in 2003. That's higher than Miami-Dade County. Even higher than New York City. Florida's overall rate jumped by 24 percent in one year, but Broward rose a staggering 49 percent.

Broward's minority population is especially affected, with the rate of AIDS three times as high for black men and twice as high for Hispanic men and women than it is for white people. Darrow's researchers found that less than a quarter of Broward's minority population living in the neighborhoods hardest-hit by the disease even know that the county is a high-risk place.

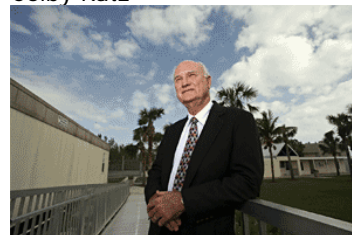
There's also been a recent upsurge of HIV infections among the county's gay men. Among white gay men, the jump has been a whopping 139 percent from 1999 through 2004.

This might seem like an auspicious time to redouble prevention measures. But the opportunity is passing us by.

If the past quarter century has been a war against AIDS, then Broward County has done fairly well caring for its wounded: those infected with HIV or who have developed AIDS. But this is a Bush-era war. When it comes to prevention, we've been scrimping on the body armor.



Colby Katz



FIU Professor William Darrow helped solve the riddle of AIDS in the early 1980s, but he hasn't been able to solve the dilemma of dwindling dollars for HIV prevention.



Carmen Letizia, HIV-positive for 20 years, takes thousands of dollars of antiviral drugs a month to keep the disease at bay.

Almost all money used for prevention in Broward County comes from federal grants through the Florida Department of Health. The level of those funds, however, has remained stagnant for many years, even as the amounts needed for treating people already infected has increased.

"Patient-care dollars certainly increase because we're continuing to deal with a larger and larger population living with HIV," says George Castrataro, assistant director of the state's health department in Broward County. "The number of people living with HIV might be 16,000 right now, whereas it was at 10,000 a few years back. To care for 16,000 versus 10,000 people is a huge increase."

Without a vaccine, however, prevention is the only way of eradicating HIV and AIDS. "We certainly put a lot of money into treatment once somebody becomes positive, but not a lot of money is put into prevention," says Kathleen Cannon of Broward House, which provides an array of services for those with AIDS or at risk of contracting the disease. "If we just continue to Band-Aid this, we're not going to get anywhere as a nation. There's not enough right now in prevention, and I don't know if there will be more in the future."

Yet there's little sense of urgency, Darrow argues. For the past five years, he has headed a project called Reach 2010, funded through a grant from the CDC. The project's goal is to slow the spread of HIV in Broward County among African-American, Hispanic, Haitian, and Caribbean islanders in Broward. Its emphasis is primary prevention — keeping someone from becoming positive in the first place.

"We're trying to run a community mobilization project," Darrow says. "I thought if you took two sticks and rubbed them together, sparks would fly and before you know it, you'd start a fire. Well, we're still rubbing our sticks, but *nobody* seems to be very interested."

With the advent of pharmaceutical drug cocktails that have helped reduce the death rate from AIDS, the epidemic has somewhat faded from the headlines. Asian bird flu? That's new, scary — sexy — even if it remains remote for the time being. HIV? Hmm, is that still a problem?

Just before World AIDS Day on December 1, Darrow sent out an op-ed piece to local newspapers, urging George Bush's administration to get serious about fully funding HIV prevention work. "Reversing trends in HIV transmission in South Florida requires a long-term commitment to disease prevention," he wrote. No one published the article.

As one local newspaper reporter recently told a Reach 2010 employee looking for coverage, "Call me when you've got a cure."

The monetary cost of the AIDS epidemic is in the billions of dollars, but the human price is incalculably high.

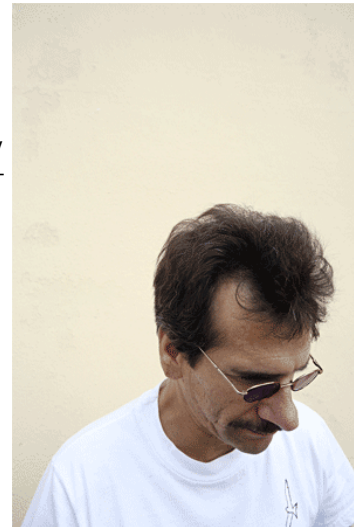
Carmen Letizia lives in a crowded efficiency apartment south of downtown Fort Lauderdale, from which his entry door opens toward a busy street. In the middle of his Formica kitchen table is a bowl-sized plastic jar with an orange lid that holds the daily regimen of antiviral drugs he takes every day.

Letizia has a long face and puffy hair that has ceded some territory to his forehead after 46 years. He's ultraslim, a result of the AIDS wasting condition that robs the body of muscle.

He's gregarious, though, with a snappy sense of humor — a trait perhaps heightened after living with HIV for more than two decades. When the subject of preventing HIV infections is raised, he laughs and says, "If they'd had more of it 20 years ago, I wouldn't be in this position today. Nobody was talking about having condoms while having sex."

A volunteer at the Broward House, Letizia gives the county a high grade for its work with HIV/AIDS, but it hasn't been enough. "The problem is, people don't care about the disease anymore. It's been around for years and years and years. A few beers and a couple of joints and people don't care; they'd rather have sex with anybody. The bar crowd won't have protective sex because they don't like wearing condoms."

Letizia learned for certain that he was HIV-positive in 1985, although he suspected it long before that time. He didn't exactly live an austere life up until then, but it probably was in comparison to the years that followed.



The chances of getting HIV infection vary widely among Hispanic subgroups, says Guillermo Prado, an AIDS researcher at FIU.



Kenneth Obiaja and Claudia Uribe (following) are among the few researchers remaining with the prevention-oriented Reach 2010 in Broward after the federal government slashed funding.

"The devastation was like, 'Oh my God, I'm going to die,'" he recalls. "I became an IV drug user in 1986. I was on self-destruct." He lived on, though, even as friends and acquaintances died while taking AZT, the first treatment found for the disease. He didn't start taking medication until the late 1990s, and the first regimen he took had such intense side effects that he ended up using a wheelchair for two years.

But he's tolerated far better a new course of pills he began a couple of years ago. Sitting at his kitchen table, he lifts the pill pot. "Before, I was taking seven pills three times a day," he says. "Now, I take six pills once a day in the morning." The pills cost several thousand dollars a month, he says, and are paid for by the federal government because he's on full disability.

Now a Christian, Letizia says he's clean and sober and doesn't have sex with anyone. Abstinence isn't on religious principle alone. "I could get infected worse because there are different strains of HIV," he says, "and there's other things I could pick up."

While he's personally hopeful, Letizia does lament the public's weariness over the disease. "I think the AIDS epidemic is on a back burner," he says. "People are fed up with AIDS, AIDS, AIDS — they don't want to hear about it."

Just back from Amsterdam over the holiday break, Darrow sits in his tiny office in Trailer 7, the home of Reach 2010 headquarters. The walls are covered with watercolor paintings by his 6-year-old son, Dreis.

Darrow seems a bundle of nerves, though he confesses to feeling jetlag from the trip back from Holland, where his wife, Susan, is from. Every few minutes, he repositions himself in his desk chair. His restless demeanor isn't what you'd expect after seeing him portrayed by Richard Masur in the 1993 HBO film *And the Band Played On*, based on Randy Shilts' book that traced the spread of the disease. Masur, chunky and bearded, was as laid-back as a cartoon bear as he tracked down answers to the riddle of AIDS.

The real Darrow has a shock of white hair, pinkish-hued skin, and an academician's build. His sense of humor is dry, and one quickly gets the sense that he doesn't suffer fools gladly. Much of his career, however, has depended upon the skills needed by good interviewers: empathy, self-control, and a quick mind.

Darrow's lifetime work as a sex scientist was launched quite unintentionally. While a senior majoring in economics at the University of Connecticut in 1961, Darrow met a recruiter looking for young graduates to join a project to eradicate syphilis in the United States. John Kennedy had just been sworn into office, and the winds of social change were blowing. Sure, Darrow thought, that seems like a good idea, and he was off to work for the New York City Department of Health.

By his own account, his first forays in his job as a venereal disease investigator were dicey. He's still embarrassed when he recalls acting as an "arrogant bureaucrat" one time by relentlessly pressing a 38-year-old gay man with syphilis to admit that he'd had hundreds of sex partners. He drove the man to tears.

In the early 1960s, the CDC, then called the Communicable Disease Center, began working toward the eradication of syphilis. Darrow joined that effort, under the tutelage of Raymond Forer, a sociologist who had recently set up the first social/behavioral science unit at the CDC, which was partly established to study sexual behavior.

"The program was to introduce the idea of behavioral research into public health and communicable disease control," Darrow says. "Had more to do with people than microbes." The work as a "cub sociologist" inspired him to get a master's degree in the field in 1967. He ultimately received a doctorate from Emory University studying medical sociology; his dissertation examined how the use of condoms affects the spread of venereal disease.

Through the 1970s, Darrow investigated the source and spread of a penicillin-resistant strain of gonorrhea by interviewing prostitutes and their sex partners. In 1977, he joined a CDC team studying the incidence and prevention of hepatitis B among gay men in five cities, including Miami.

"I went to bars and clubs and bathhouses as part of my work," Darrow says. "I knew about these underground activities, and some sociologists were writing about them, some weren't."

So when the CDC began hearing about cases of immune deficiency among gay men on both coasts in the early '80s, the agency tapped Darrow for the Task Force on Kaposi's Sarcoma and Opportunistic Infections. (Kaposi's sarcoma is a type of cancer that affects many AIDS patients.)

Today, more than a generation since AIDS first appeared in America, it's sometimes hard to grasp how little was known about AIDS in the early years. In fact, most Americans weren't even aware of the problem for the first couple of years that the team



Details

Who / What:

AIDS

News Category:

Education

Health

investigated what was initially called gay-related immune deficiency, or GRID.

At that point, the only thing the CDC team knew was that the malady was affecting only gay men. Darrow and others suspected it was a sexually transmitted illness, but others believed it might be caused by an environmental agent in bathhouses, perhaps by breathing in something, as was the case with the 1976 Legionnaires' disease. Some in the National Cancer Institution suspected the cause was tainted "poppers," drugs used to enhance sexual experience.

"First, we had to find the cases," Darrow explains. "What does the San Francisco case have in common with the case in New York and the case in Los Angeles? The evidence started coming in, and it was our job to put it all together and explain what the hell was going on to whoever was interested."

For Darrow, the only nonmedical doctor in the unit, the *aha!* moment came only after the partner of a hospitalized man in L.A. quietly took a CDC field doctor aside and advised, "You asked my partner all kinds of questions about his sexual activities — what he did, where he went — but you didn't ask *who* he was having sex with. You probably don't know this, but two or three of the people who are in the same hospital were his sex partners."

Darrow quickly rushed from Atlanta to L.A. to question as many ill men — some near dementia and death — about their sexual partners. By the time he was done in the spring of 1982, Darrow had found sexual ties among 40 men in ten U.S. cities.

"We only included people in this network if one person named the other and the other named him back," he recalls. In the center of that fatal version of connect the dots was a French-Canadian flight attendant named Gaetan Dugas who could be sexually linked with 40 of the first 248 gay men diagnosed with GRID in the United States.

In the network diagram presented to his colleagues, Darrow had designated Dugas as "O," which stood for a sexual contact who lived "Out of California." But his fellow scientists began referring to him as Patient Zero, a designation that would eventually lead to a widespread myth.

"There's a conventional wisdom that he started the whole epidemic, but that's not true," Darrow says. "Nobody said he was the first case. You had a few people in L.A. who had AIDS. They didn't have sex together, but they had sex with this guy, so he was important. He linked it. That was the whole idea of social networks, which I happened to know about then and is now a big thing in disease control."

Evidence that this was a sexually transmitted illness strongly suggested that a virus was at the heart of this new plague. "We tried to convince our colleagues, the medical community, and we were hoping we could convince the new administration that they had a real big problem on their hands."

How did that go? "Not well," Darrow mutters. "It's still not going well." The CDC had earned its reputation by researching epidemics and then bringing them under control with vaccines. "They were very successful with smallpox and polio," he says. "They were good at vaccine-preventable diseases. But dealing with condoms, sexual behavior — boy, that was going to be tough. Still is. Sex and morality and all that. It's very contentious. Politicians don't like to get involved in that kind of thing."

Darrow's job on the task force had been primarily researching the spread of the disease. But as the '80s ebbed on, the sociologist became impatient with the CDC's approach. Darrow implored his superiors for an aggressive approach to prevention. "I said, 'I'm glad to help you guys out, but there's a time when we're going to have to do something. We need to intervene. We need programs to discourage high-risk behavior.' The CDC people, they'd say, it's our job to do the research. It's up to someone else to do interventions and develop the public health programs."

The CDC did launch a series of public service announcements called America Responds to AIDS in 1987, but Darrow recalls arguing with CDC officials. "It's not for gay men, and it's gay men you have to worry about."

It wouldn't be until after Darrow got to FIU in 1994, however, that he'd actually get a crack at ground-level intervention.

Twelve women and three men sit around the horseshoe shape of dark brown folding tables in one of several English-language classes sponsored by Hispanic Unity, a Hollywood agency that aids Spanish-speaking immigrants. It's a Wednesday morning, and Spanish chatter from adjoining rooms seeps easily through the thin sliding doors that partition them off.

Lining the walls are charts chock full of pronouns, adjectives, conjunctions, and every other part of speech you can throw at English-language neophytes.

But for about an hour this morning, they won't be thinking about subject-verb agreement and the like as the instructor turns the class over to Magaly Alvarado, who, until funding cuts, was part of the Reach 2010 project. Dressed in a light-blue pants suit, Alvarado is in charge of the organization's HIV/AIDS education outreach program. She's accompanied by Teresa Hidalgo, a medical doctor with a stocky build and serious demeanor, who also works for Hispanic Unity.

Alvarado jots down the category, *Origen*, on the whiteboard in front of the class. "Where does HIV come from?" she asks in Spanish. The group quickly identifies homosexuals as the originators of the disease, and several argue that it all started when some men had sex with monkeys. As Alvarado gently dissects this myth, one student finally admits that, yes, the idea is fairly ridiculous once you really think about it. But that's what she's heard, she reiterates.

Origins of the disease aside, Alvarado learns that most students here, some middle-aged, don't understand the basics of how HIV is transmitted, that it is spread only by contact with infected blood, semen, breast milk, or vaginal secretions.

As she continues to talk about transmission of the virus, she sees panic in some faces over a subject they perhaps had given little thought to before.

"Calm down," she coos. "I know it sounds like I'm creating a crisis in your lives, but there are solutions. You have to be conscious about what you're doing. It's not who you are; it's what you're doing."

Still, the mention of abstinence as one possible means to prevent infection prompts a 40-something woman with short hair and a husky build to sputter. "No, impossible," she declares. "There's no way to be abstinent, no, no, no."

Shortly after the presentation is done, Alvarado and Hidalgo walk across Johnson Street back to their office.

"When we first ask what they know, we look for the level of the people in the room," Alvarado says from the small cubicle space she shares next to Hidalgo. "That way, we can approach them in a different way. If they have no knowledge, you have to speak in a much simpler language. This was a medium-level group."

Hidalgo interjects: "We never, in my experience, have found a high level. Low to medium, that's it."

Preventing HIV anywhere in America is a tough task, and tackling the job in a place as diverse as South Florida is even harder. Here, the challenges in reaching immigrant communities are layered: language and cultural barriers that are divided yet again by country of origin, family makeup, and plain personality.

"When we talk about preventing HIV in Hispanics, I don't think there's one program that works across the board for all Hispanics," says Guillermo Prado, an assistant professor at FIU's public health school who specializes in HIV prevention in minority families. Baby-faced with a dark goatee, Prado is young and energetic. He's currently involved in a project looking at the most effective ways to prevent Hispanic adolescents from engaging in risky sex and using drugs, the two greatest risk factors in infection.

"The research out there shows that HIV rates and drug-use rates are not the same for all Hispanics," he says. "We know that certain Hispanic subgroups are at risk. Puerto Ricans tend to use intravenous drugs at higher rates, so they're at higher risk of HIV. Hispanics are a very heterogeneous group."

Research has consistently shown that enculturation, which is the process of an immigrant's assuming the values of his new country, plays an important role in HIV and drug use. Ironically, in South Florida in particular, the more encultured a teenager becomes, the greater his chance of risky behavior.

"What we've started to believe," Prado says, "is that it's not so much that the adolescent becomes subsumed in the American culture per se that puts them at risk; it's that they also lose the values of their country of origin." That's nothing new, of course, for a country that's been attracting immigrants for a few hundred years, but there's a twist here.

"The reason we believe this is such a risk factor is that their parents tend to be older, and coming to an area like Miami where Hispanics have political and economic power, they really don't need to speak English. They don't tend to gain American values." Meanwhile, the kids Americanize quickly, which heightens a cultural mismatch that affects family communication and can, Prado says, lead to risky behavior.

Haitian immigrants also face a readjustment in thinking about HIV when they arrive in America, says Edele Firmin, the HIV/AIDS outreach worker at Minority Development & Empowerment, a Fort Lauderdale agency that serves the Haitian community.

"To be honest, it's the newer immigrants that are more motivated about prevention, more open," says Firmin, who sports chin-length dreadlocks and round, black-rimmed glasses and speaks with a distinctive Creole accent. "When I recently had a focus group here, they were so shocked, the new immigrants, that there were Haitians living here who were not willing to disclose their status when they find they're HIV-positive."

But Firmin knows that many of those same Haitians will clam up as the realities about AIDS in America become clear. Many immigrants send money home, sometimes supporting an entire family. Some Haitians learn that they have a lot to lose in America by disclosing their HIV status, whether that's a job, spouse, or the support of friends.

By 1987, Darrow had been studying the transmission of HIV for more than five years, but he'd grown frustrated that he couldn't work directly on preventing the spread of the disease. His bosses at the CDC kept telling him they wanted him to work on vaccine studies, telling him that a vaccine was "just around the corner." Fifteen years later, there's still no vaccine.

Darrow transferred out of the infectious disease branch in 1987, taking charge of a section that developed intervention programs and community pilot programs, although at times he was called upon for AIDS research projects.

"I tried to start and guide this effort to get CDC and state and local health departments involved in interventions in health promotion in the absence of a vaccine," he recalls.

Darrow left the CDC in 1994, primarily because his wife had had enough of his workaholic ways. He landed a professorship at FIU, a location that made his wife happy because of the Miami airport's direct flights to Holland. Since then, he's coauthored a number of peer-reviewed articles concerning HIV and gay men living in South Beach.

Darrow saw a chance to increase HIV prevention work in a Clinton administration initiative intended to eliminate health disparities among minority groups. Out of that was born Darrow's Reach 2010 Coalition to Reduce HIV in Broward's Minority Communities, which was to receive just under \$1 million a year until 2007.

The project contracted with several community organizations, including Hispanic Unity and Minority Outreach & Development, to work on prevention outreach and education.

"The difference between our plan and others in Broward County is that we were going out to the community and looking for residents who are at risk and delivering them prevention messages specifically at their houses, laundromats, houses of worship — wherever they hang out," says Claudia Uribe, the project coordinator, a serious young woman with long dark hair.

Unlike most prevention efforts, Reach 2010 meticulously measures whether its outreach is actually having an effect. Kenneth Obijaja, the research coordinator, whose desk is surrounded by stacks of interview notes received from outreach workers, says that the data doesn't point toward the kind of behavior changes they'd expected. But with funding cuts, he adds, "We haven't been able to spread our wings as wide as we'd have liked."

"The problem is that just about all the money currently being spent in South Florida to prevent HIV infections is federal," Darrow says. "Few Florida general-revenue dollars, if any, are used to prevent HIV infections, unless you count the matching funds the state legislature puts up to support Gov. Bush's 'It's Great to Wait' teen pregnancy prevention program."

The health department's Castrataro, a young man with a shaved head and buffed physique, admits that prevention money has been and will likely remain flat. That has meant shifting prevention money among certain groups with rising HIV rates.

Tallahassee's way of dealing with the static funding, Castrataro says, has been to instruct local health departments to "be more creative, be more efficient, find new opportunities to use what you have to address everyone's needs without hindering any one population."

One casualty of low funding was local prevention plans. The state had mandated that local health departments, in partnership with community-based organizations, produce three-year prevention plans tailored to meet the needs of the groups most affected by HIV. Last year, the state stopped requiring the plans, which it had never sufficiently funded in the first place. (Castrataro says his office is developing a five-year plan anyway.)

With moribund state funding and the CDC slashing money to Reach 2010, Darrow called on the health department and others to declare an AIDS "state of emergency" in South Florida.

"A visible and viable coalition — and not just me and a few others — should call for a 'state of emergency' to address the AIDS situation in South Florida," Darrow says. "We should have a plan of action prepared to present with it that is credible, realistic, and worthy of support."

But Castrataro says that's unwarranted. After targeting prevention funding among blacks in Broward County for about a decade, he says, statistics show that HIV rates among that group have steadily declined. "The health department doesn't tell agencies what to do," he says, "but at that time we couldn't provide data to support the declaration of emergency."

The trouble with moving a finite amount of prevention money among at-risk groups, however, is similar to the carnival game in which you swing a mallet at toy gophers popping their heads out of holes: There's always another one jumping up elsewhere. So too is the case with beating back HIV infections in Broward. Just as the rates have gone down among blacks, infections among gay men — and Hispanics to a lesser degree — have risen, leaving the county with little overall improvement.

"It's very hard to have a persistent effort to try to deal with AIDS in South Florida," Darrow says.

After decades in the field, Darrow laments the current state of public health. "You can't make profit out of public health," he says. "It's a waste of taxpayers' money in a lot of people's minds, so it's not being supported."

For example, instead of increasing AIDS programs, the National Institutes of Health actually endured cuts for AIDS-related prevention of about \$12 million last year.

Darrow mentions the disease that's galvanized the media recently, Asian bird flu. It may or may not become an epidemic, but he's pessimistic that the country, particularly South Florida, with its burgeoning population from around the world and strained health-care system, could handle such an outbreak.

"Sooner or later," he warns, "we're going to have to deal with piling people on top of each other, with a public-health infrastructure that's in decline."