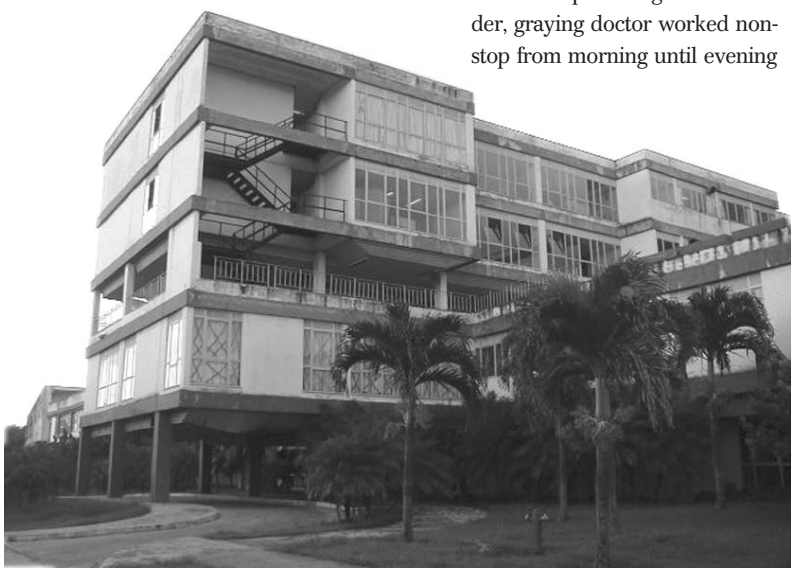
Cuba's Energetic AIDS Doctor

A tireless champion of both patients and public health, Jorge Perez Avila has withstood controversy and transformed the care that HIV-positive patients receive in Cuba.

| Sheri Fink, MD, PhD

IT'S NOT EASY KEEPING UP with Dr Jorge Perez Avila. On a sunny Monday last summer, the 57-year-old director of Cuba's national AIDS program seemed never to stop moving. He saw patient after patient, dispensed advice to numerous colleagues, met with 2 college students who arrived from Minnesota bearing a suitcase full of medical donations, had his own blood drawn to check his cholesterol, and bounded—2 steps at a time—up and down the staircases of the 5-story infectious disease institute he helped design. The slender, graying doctor worked nonstop from morning until evening without so much as a break for coffee until I insisted on buying him a drink. And he swore his recent cardiac bypass operation (the first time he had missed work for any illness) had slowed him down.



"His total dedication to his work and his love of the population come right out of his being," said Nancy Scheper-Hughes, professor of medical anthropology at the University of California at Berkeley, who first met Perez over a decade ago in Cuba. Since then, she has visited him several times and hosted speaking engagements for him in California. "He's a man that exudes both a wisdom and an empathy that his patients feel when they're in his presence."

While Perez is well respected at home and abroad, the national AIDS program he oversees in Cuba has been a target of both praise and sharp criticism. It has been praised because Cuba has the lowest prevalence of HIV in the hemisphere[1]—according to Ministry of Public Health statistics provided by Perez, only 4214 HIV-positive patients were detected between 1985 and July 2002. Criticism, though, has been directed at some of the controversial policies that Perez and others insist have contributed to keeping HIV infection rates so low.

"It's a strong version of medicine and public health that would be a problem for Americans to swallow," said Scheper-Hughes of policies such as mandatory commitment of newly diagnosed HIV positive patients to sanatoriums, sexual contact tracing, and the recommendation that pregnant women with HIV have abortions.

In his role as head of Cuban AIDS policy, Perez has led a campaign to change some of those policies. Dr Paul Farmer, professor of medical anthropology at Harvard Medical School and founding director of Partners in Health, a nonprofit organization providing health services to some of the world's poorest communities, has also worked closely with Perez. "His chief contribution in Cuba," Farmer wrote in an e-mail from Haiti, "was the development of a real national AIDS program that was based on his unique capacity to synthesize good clinical medicine with a public-health approach."

Perez ended up in public health and infectious diseases almost by accident. Born in 1945 during the pre-Revolution presidency of General Fulgencio Batista, Perez learned about politics at an early age. His father, a bus driver, was a communist who protested against the inequalities of the era and the government's corruption. He was taken into police custody and beaten. "Many people didn't have work," Perez said of those times. "There were many people who didn't eat."

Although he fell in love with medicine at an early age, teaching himself anatomy by "operating" on mice and frogs, Perez first aspired to be a cardiologist. The Cuban Revolution interrupted his plans. At age 14, Perez joined an armed rebel band living in the Cuban mountains and was groomed as a pilot. He quickly learned that he preferred the earth to the air. After the Revolution, he worked for a year teaching illiterate adults to read and then attended medical school at the University of Havana, graduating in 1973. He went on to study the effect of diuretics on cardiac patients, earning a master of science in clinical pharmacology from McGill University in Montreal in 1978.

Perez returned to Cuba expecting to work as a cardiologist, but a former professor recruited him to work at Cuba's Institute for Tropical Medicine instead. "I didn't much like the idea," he said, but his professor convinced him that well-trained researchers were needed to work in the institute, which was continuing to see tropical diseases brought into Cuba by Cubans returning from overseas or by people from tropical countries coming to Cuba to study.

Perez poured his energy into his new specialty, undertaking additional training in Great Britain and the United States and working in several countries in Africa. In 1983, Perez watched Fidel Castro make an appearance at the Institute for Tropical Medicine and predict that a mysterious illness, later known as AIDS, would be "the disease of the century." Castro tasked the institute's physicians with stopping its spread in Cuba. Almost immediately, they moved to protect Cuba's blood supply, ordering the destruction of all blood products that hadn't originated in Cuba, banning the import of blood, and testing the country's own blood donations. These actions may have prevented hundreds or thousands of needless infections, the likes of which other countries that didn't implement such ideas suffered. Perez read what he could about the emerging disease and sent colleagues overseas to train with those who knew more about it.

However, Cuba could not escape the epidemic. Two years later, it had its first AIDS patient, a man who had returned from living in Mozambique. Perhaps because of Perez's kind, calm manner and his unusually close rapport with patients, he was chosen by the Ministry of Public Health to break the bad news. The patient had been admitted to the hospital 2 to 3 months previously, but doctors hid his diagnosis from him. Others warned Perez the man would kill himself if he knew his diagnosis. Perez disagreed—not if he told him the right way. "This is not the end of life," he remembers telling the man.

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Dr Perez with Pedro Mas, former director of the Cuban Institute of Hygiene, in Ocho Rios, Jamaica, February 2002. Photo by Arachu Castro.

Cuba began instituting mandatory HIV testing of at-risk communities, such as the many soldiers and others returning from abroad; tracing the sexual contacts of infected patients; and, beginning in 1986, committing all those who tested positive to sanatoriums.

A delegation from the American Public Health Association

Opposite: The Institute for Tropical Medicine.

Fast Facts on the Cuban Health System's Response to HIV/AIDS

August 1983: Cuba participates in Pan American Health Organization workshop in Washington, DC, and creates a national commission on AIDS.

1983: Cuba's National Commission bans importation of blood products, destroys existing stocks, begins production of blood products in Cuba, and creates an epidemiological surveillance system for the detection of clinical manifestations of AIDS (Pneumocystis carinii pneumonia [PCP] and Kaposi's sarcoma).

December 1985: Dr Jorge Perez Avila participates in the diagnosis of Cuba's first HIV-positive patient, a heterosexual man returning from work in Mozambique.

End of December 1985: Cuba designates US $2 million to develop a national AIDS program and decides to purchase 750 000 diagnostic testing kits, install enzyme-linked immunosorbent assay (ELISA) readers at all blood banks, and train professional personnel in their use.

January 1986: National HIV laboratory opens.

April 30, 1986: Santiago de las Vegas HIV/AIDS Sanatorium opens. There is mandatory confinement of all HIV/AIDS patients, who are treated with interferon and transfer factor.

May 1986: All blood donors and those who have spent time in Africa since 1981 are screened for HIV. First Cuban AIDS patient dies.

June 1986: HIV/AIDS prevention campaign begins. Testing is recommended for those working in the tourism industry.

September 1986: All those who have worked in Africa since 1975 are tested for AIDS.

December 1986: Cuban HIV test begins production. Ninety-nine HIV-positive persons are detected over the year: 57 international workers, 22 of their contacts; 3 blood donors, 1 child, and 16 others (no hemophiliacs).

1987: Cuba begins production of the Western blot HIV test. An HIV test is now mandatory for pregnant women in the first trimester (abortion recommended for positive test), all hospitalized patients, patients with sexually transmitted diseases, and prison inmates.

1988: National Center for AIDS Patients is created at the Institute of Tropical Medicine. Azidothymidine (AZT) therapy is begun.

1989: Recombinant HIV test is started. Work to isolate HIV begins.

1993: Cuban scientists begin sequencing HIV and developing a vaccine against HIV.

December 1993: Outpatient treatment option for patients with HIV/AIDS is initiated.

1995: HIV-positive pregnant women are given AZT to prevent mother-to-child transmission.

1996: Phase I trial for the first Cuban candidate vaccine against HIV begins.

1998: National Center for HIV/AIDS and STD Prevention opens.

2001: Patients are provided treatment with generic antiretroviral medicines produced in Cuba.

Source. Information was derived from the written version of a slide presentation, "History of the HIV/AIDS infection in Cuba," provided by Dr Jorge Perez Avila.

visited the Cuban sanatoriums in 1993 and was impressed with the way patients were treated and the guaranteed high-protein, high-calorie diet—full of foods such as beef, ice cream, and milk—that they were guaranteed.

"It was unheard-of on the outside," said Julie Feinsilver, a member of the delegation and author of the book *Healing the Masses: Cuban Health Politics at Home and Abroad.* At the time, Cuba was suffering economic devastation in the wake of the fall of the Soviet Union, its major supporter. Cubans refer to the time as the "special period." But the government kept health care, including HIV prevention and treatment, a priority.

Still, the sanatorium approach drew the ire of many in Cuba and worldwide, including Dr Jonathan Mann, an American epidemiologist and founder of the World Health Organization's Global Program on AIDS. Mann, who died in 1998, crusaded for the protection of the basic human rights of those at risk for the disease, believing in the interconnection of health promotion and the protection of human rights. He criticized the first Cuban sanitarium as "a pretty prison."[2]

Rumors about the sanatoriums spread and mutated. When Perez traveled in the early 1990s, at the invitation of Scheper-Hughes, to give a speech at the University of California at Berkeley, activists in the crowd jeered and accused him of running concentration camps. "I would have throttled people and jumped off the stage," Scheper-Hughes said. "[But] the second he got up to speak, he disarmed the crowd."

Scheper-Hughes was amazed at how well Perez kept his composure. He listened patiently to his critics, acknowledging their

concerns, and tried to explain why what he was doing was in the best interests of his patients and of Cuba. Although Perez defended Cuba's system abroad, at home he was quietly trying to change the system he had inherited in 1989, when he was asked to take charge of Cuba's single AIDS sanatorium. He set about trying to design an approach to HIV/AIDS that took into account individual patient differences. "He dispelled a lot of myths and fears people had about HIV/AIDS," said Dr Byron Barksdale, director of the Cuba AIDS Project, an American organization that has provided medical assistance to Cuba since 1995. "He destigmatized HIV/AIDS in Cuba."

Perez began by opening sanatoriums all over the country so that patients, whose family members were traveling to Havana to see them, could be closer to home. Then, along with a commission of psychiatrists, social workers, and public health specialists from the Cuban Ministry of Health, he performed pilot studies that allowed certain patients to return to school or work or to go home with their families on weekends. Contrary to the beliefs of Cubans, the studies showed that these patients were not spreading HIV to their colleagues and family members. Eventually, arguing that HIV is a chronic infection and that most patients, if given education, will not transmit it to others, Perez convinced governmental leaders that an ambulatory care system made sense.

Mandatory long-term confinement in sanatoriums ended in 1994. Now, most patients spend a minimum of 3 months in the sanatorium learning how to live with HIV, how to take their medications, and how to avoid spreading the illness to others. A commission in each Cuban province recommends, on the basis of factors such as past "behavior" and available support network, whether or not a patient needs further commitment or is "responsible" enough to be treated as an outpatient. Some choose to stay voluntarily in the sanatoriums, attracted by the strong sense of community and perks like air conditioning. Perez estimates that 52% of patients are currently in the ambulatory care system and 48% are in the sanatorium. Since the lifting of automatic indefinite commitment, he said, more people have come forward to be tested for HIV.

Arachu Castro of Harvard University, Daniel López-Acuña of the Division of Health Systems and Services, and Dr Perez at the PAHO offices in Havana, August 2001. Photo by the author.

> *"He dispelled a lot of myths and fears people had about HIV/AIDS. He destigmatized HIV/AIDS in Cuba."*

It wasn't only the system Perez changed; he transformed himself. Raised with the typical prejudices of macho Cuban society, getting to know many homosexuals with HIV has led him to promote acceptance of all kinds of love—"love without boundaries," he calls it. Although the first AIDS patients in Cuba were heterosexual international workers, an increase in homosexual and bisexual patients occurred in the 1990s. According to Ministry of Public Health statistics provided by Perez, as of July 2002, homosexual men made up 67% of the total HIV-positive population in Cuba. Early sanatorium residents became some of Cuba's first outspoken gay rights activists, living together openly as couples and experiencing a level of acceptance that exceeded that in the generally homophobic society.

At first, before the discovery of antiretroviral medications, all the sanatoriums could offer was supportive care. Survival rates of HIV-positive patients were comparable to those in developed countries. When medications became available, their price tag was too high for the poor country to purchase them for every patient. For years, the supply was tenuous and largely consisted of donated, "recycled" HIV medications from richer countries. Cuban pharmaceutical companies set about developing generic versions of antiretroviral medications and have now succeeded in producing five. Since the spring of 2001, every Cuban HIV patient has been put on 1 of 4 therapeutic schemes according to a national protocol.

But Perez is quick to point out that Cuba hasn't won its fight against AIDS. When he arrived at his job in 1989, fewer than 600 patients had been diagnosed with HIV; now there are 4214. Tourism is the biggest threat. "AIDS is increasing here like everywhere else," Perez admitted. "For many reasons or no reason at all people don't use condoms every time. They see AIDS from a distance. 'The other person will get it. This lady looks sweet and nice, like an apple.' They don't realize that apple could be poison."

Perez says the US embargo on Cuba has made his job both easier and harder. Easier, because Cuba's initial isolation helped shield it from the spread of AIDS. Harder, because obtaining medications and diagnostic machines—such as a flow cytometer and viral load and CD4 detector—has been difficult and subject to delays.

Late in a busy August morning, Perez sat down in his office, took off his glasses, and confided his greatest concerns. Cuba's economic crisis was making it difficult to continue providing free medical service and a good quality of care to AIDS patients, he

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said. But what really saddened him was to think of how AIDS was devastating other countries where people had no access to HIV education, treatment, or physicians. He lamented that pharmaceutical companies were "making fortunes on people's lives."

"I know they have to make money," he said. "[But] it's one thing to live and another to be rich off a problem like this."

LESSONS

In the afternoon, Perez took the Minnesota students on a tour of the infectious diseases institute. A 30-year-old patient stopped him in the hallway, her wasted, jaundiced face breaking into a huge, childlike smile. They had met 13 years ago, when she was only 17 and recently diagnosed with HIV. Now she was ill again, but he cheered her up, telling her she was a "war tank" that would get through this too.

"If I'm a war tank, it must be a Russian one," she teased back.

"I'm always on your side," he told her.

"You like to talk a lot," she said, rolling her eyes.

Watching Perez interact with patients evoked images of Norman Rockwell paintings. "I like them to joke a little bit, to have confidence," he said. "That's important, especially with young patients."

His kinship with his patients and his ability to help save their lives brings him great happiness. But that closeness causes him sadness too. "Patients for many years, they're your friends," he said, "It's like losing family."

Perez has deep creases beneath his eyes. The chest scar that extends above the button of his blue shirt is a reminder of his recent heart problems. Others have suggested to him that he retire or at least slow down. Although he's recently turned over some of his myriad responsibilities to colleagues—including the directorship of Cuba's largest HIV sanatorium, Santiago de las Vegas—there's no sign of Perez retiring any time soon. If he ever does, though, his legacy is sure to live on, not only in the system he has spent years crafting and the institute he designed but in the example he's set for those following his footsteps into medicine and public health at home and abroad.

"I think Jorge is one of those very rare physicians who knows that there need be no divorce between high-quality attention to every patient and also a public-health approach that seeks to protect and promote the health of populations," wrote Harvard's Paul Farmer. "I've been amazed at how often there are false conflicts between 'clinical' and 'public health' approaches to a health problem (whether HIV or TB or diabetes or whatever). Jorge embodies the best of both worlds and is, indeed, a sort of living synthesis of these approaches. I try to emulate him."

Farmer hopes that Perez's legacy will be a willingness of all to "move beyond partisan politics towards sensible and humane responses to the biggest infectious disease threats of our times."

Scheper-Hughes concurred. "He embodies for me the notions of a true healer," she said. "He has embodied a unity in his practice—the best aspects of a caring, healing medical professional combined with a social, political conception of medicine, of going beyond the individual to think about the well-being of the social body, of trying to create a society where it's less easy for people to get sick, where people understand their responsibilities to both care for and protect others."

The fact that AIDS was immediately seen as a human rights issue in the United States, she said, may have prevented the identification of risk groups and risk areas and thus blocked the chance to target people living in those areas for education. "A more aggressive public health response at the very start of the epidemic might have saved countless lives,"[3] Scheper-Hughes wrote in a 1993 article for the medical journal *Lancet*. "A strong and humane public health system has just as often protected the lives of socially vulnerable groups as it has violated their personal liberties." ■

About the Author

Sheri Fink has been an international consultant for the International Medical Corps and Physicians for Human Rights. Her book War Hospital: A True Story of Surgery and Survival, *about doctors working in Bosnia, will be published by PublicAffairs in August 2003.*

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