The Castaways

Many of the estimated 11,000 people living with AIDS in the U.S. commonwealth of Puerto Rico have been abandoned and left for dead. The local and federal officials entrusted with protecting their health have been accused of mismanaging AIDS funding, which leaves positive Puerto Ricans in a lethal limbo between American and Puerto Rican aid—and feeling utterly lost on their own island.

September 1, 2008 By Nicole Joseph

At 2 a.m. on a warm night in April 2007, Anselmo Fonseca—a leading AIDS activist in San Juan, Puerto Rico—was awakened by a call from a crying woman. Her name was Yolanda, and two days earlier her brother Ariel, who was living with AIDS, had become terribly ill. Yolanda and her mother had checked him into a local clinic. But they learned that he'd been transferred, without their knowledge or approval, to a hospital. The reason? The clinic doctor who'd first seen Ariel had pronounced him "rotten" and refused to treat him. When Yolanda reached the hospital, she found that the situation there was no better. Ariel had been placed in a tiny, hot room with a broken ceiling fan and was left unattended by doctors and nurses—who, Fonseca believes, were afraid to touch Ariel for fear of contracting HIV.

When Fonseca got Yolanda's call, he immediately set to work on Ariel's behalf. Having advocated for people living with HIV in Puerto Rico for almost a decade, he lobbed calls to his network of activists, politicians and government officials. Within hours, he got Puerto Rico's secretary of health on the phone and explained Ariel's crisis, employing the trademark Fonseca mix of outrage and logic. The next day, the hospital finally ordered Ariel's meds, which he hadn't been receiving. But two days before they arrived, he passed away.

Ariel's story is but one example of the hundreds of Puerto Ricans who lose their lives each year to their homeland's AIDS health care crisis, which has devastated the island for more than 10 years. The AIDS prevalence rate there is almost twice that of the mainland, and positive people are going without services and medications. Yolanda and Fonseca typify the many family members, friends and activists who are forced to face the crisis each day—as they lose loved ones and watch a community crumble because of HIV stigma and a lack of infrastructure to care for and treat people in need.

That's why Ariel's death hardly surprised Fonseca. Mention the words "Puerto Rican AIDS crisis" and everyone— from the 11,000 Puerto Ricans estimated to be living with AIDS, to the doctors and nurses working in the island's hospitals and clinics, to Washington, DC, officials who direct funds for services to the island, to activists both in the States and in Puerto Rico—invariably sighs. It is a

sigh of disgust, an acknowledgement that the problem has no discernible solution—at least not anytime soon.

The crisis is complex: an ongoing problem with injection-drug use; a lack of services for positive people, especially in rural areas; crippling stigma around the behaviors that lead to HIV infection; a deep-seated debate about the island's status as a U.S. territory; and the disappearance of federally allocated HIV/AIDS funds.

Year after year, rallies have been held, letters have been written and pledges have been made. AIDS advocates have proposed and implemented a number of short- and long-term solutions. Yet blame is placed on one party and responsibility is then shifted to another, while HIV infection rates on the island, which is a U.S. territory with little say in Washington, DC, and no formal congressional representation, soar. Activists and people living with HIV feel abandoned both on a large scale—from the federal government—and on a very individual and personal scale, as in the case of Ariel, left alone in his hospital room. Sandy Torres, an activist who runs a community-based food program for HIV-positive people on the island, put it this way: "Who cares about Puerto Rico?

Hola, welcome to Puerto Rico," says Fonseca, leaning from the driver's seat to kiss me on the cheek. "Here in Puerto Rico, we kiss everyone hello." As we zip through the streets of Old San Juan, a man selling trinkets and water hobbles toward the car. "He's a PWA [person living with AIDS]," says Fonseca. "You know him?" I ask. "Yes, his name is Bill." Anselmo Fonseca knows everyone. He was diagnosed with HIV in 1995 but says he'd known he was positive a few years before that, when his partner died of AIDS-related complications in 1991. Born and reared in New York City, Fonseca traveled back and forth to Puerto Rico, but having fought a post-diagnosis depression, he decided in the mid-'90s to build his life on the island. Growing up in New York gave him a perspective on the relationship between Puerto Rico and the United States, which has informed his activist work.

"Being in the States…there was an abundance of opportunities; here [in Puerto Rico], it's just the opposite," he says.

In 1999, Fonseca and his current partner, José F. Colón—another well-known Puerto Rican AIDS activist—started Pacientes de Sida Pro Politica Sana (AIDS Patients for Sane Policies), an advocacy organization for people living with HIV. The group was founded in the late 1980s as a response to Puerto Rico's first brush with mismanaged HIV/AIDS funds. In 1999 and 2000, several former officials of the San Juan AIDS Institute were convicted of stealing more than $2 million of federal AIDS funds for personal and political gain while they were in office from 1988 to 1994. The case was shocking, but Fonseca says that the true outrage was the public's and media's misplaced focus on its political ramifications—such as whether the scandal would hurt then-governor Dr. Pedro Rosselló.

"The real victims were patients that died and their families," Fonseca says heatedly. He and Colón picketed outside the trials, holding demonstrations and shouting, "¡Mas que pillos—assasinios!"

(“more than thieves—assassins!”).

“Pacientes de Sida Pro Politica Sana was created out of a need to refocus [after the] San Juan AIDS Institute scandal,” says Fonseca. The group is client-focused, providing support and care referrals on the island and to Puerto Ricans living in the States. Though the group does not provide direct clinical services, many positive people rely on its immense networks for linkages to care. Fonseca says some members of the group have even worked together to create a surplus of unused medications, saved up to be used in emergencies.

Fonseca and Colón also pressure Puerto Rican political officials but say that winning commitments is tough. As Puerto Rico waits to elect its new governor this year, Fonseca says he’s received numerous promises about how politicians plan on solving the AIDS crisis—with little follow-through.

Yet another debilitating effect of politics on the Puerto Rican AIDS crisis is the silence of the island’s many activists and heads of community-based organizations (CBOs). They can be reluctant to speak out, fearing they’ll lose their hard-earned gains. “There’s a great deal of fear even among people that were most active,” says Dennis deLeon, president of the Latino Commission on AIDS, based in New York City. “People who haven’t been paid in eight to nine months are afraid of speaking out” for fear of losing even more funding.

Colón says Puerto Ricans are treated as second-class citizens. “We have been suffering [for] years,” he said. “We’re an after-, after-, afterthought for the Bush administration, especially people living with HIV/AIDS. With the economy in the U.S., who’s going to be thinking about AIDS patients? Everyone’s thinking about gas and food and foreclosures. I have no words to describe how frustrated I am.”

Sandy Torres and Jose Mulinelli sit on the edges of the flower-patterned chairs in my hotel room. Torres runs Bill’s Kitchen, an organization that provides support services and meals for people living with HIV. In the past few years, funding problems have forced her to cut her staff substantially. When I ask Torres to name her most difficult moment during the AIDS crisis, she pauses, close to tears. “The day I [had to] stand up in my distribution center and give out letters to people to be placed on waiting lists,” she says, with a hint of anger. “I will never forget that day in my life. I spent almost an hour with my clients, trying to explain why we were at that point. Deep inside, I feel like I’ve failed them.”

Perhaps the largest, most obvious problem facing the AIDS community in Puerto Rico today is that U.S. federal funds allocated to the island for HIV treatment and care often never reach people living with the virus. Whether due to incompetence or intentional misuse of funds, activists say, the funding problems have caused some clinics to cut staff and pull back on services in order to stay afloat. Others have had to shut down. While not as blatant as the San Juan AIDS Institute scandal, today’s mismanagement is just as costly; the closures and staff cuts have meant a reduction of services for thousands of people living with HIV.

Combined, the Puerto Rico Department of Health and the San Juan Municipality have received more than $47 million this year from the federal Ryan White CARE Act, which is administered through the U.S. Department of Health and Human Services' Health Resources and Services Administration (HRSA). Ryan White funds are separated into four principal parts: Part A goes to cities or eligible metropolitan areas (EMAs), such as the San Juan Municipality; part B goes to states and territories, such as Puerto Rico and Guam; and parts C and D—for early intervention services and care for women, children, infants and older youth—are doled directly to CBOs. An additional Ryan White Program provides funds for "special projects of national significance," innovative programs promoting care for positive people. Programs that get most of their money from the first two parts must submit invoices to the department of health and the San Juan Municipality for any reimbursement. The wait times for reimbursements have been as long as nine months—too long for poor clinics to survive.

Torres and Mulinelli say that parts A and B of the CARE Act should be administered directly to the community-based groups. In 1989, the U.S. Centers for Disease Control and Prevention (CDC), which had funded Puerto Rico's CBOs through the island's department of health, switched to direct funding, handing the funds straight to the CBOs. Though the move was well received by activists on the island, the money is targeted almost exclusively at prevention efforts, not actual care and treatment for people already living with the HIV/AIDS. Now, says Torres, many of her clients are running out of time. "We tried to put the people who weren't too frail on the waiting lists," she says, so the sickest patients could access to the services first. However, cutting food services was too much for some of even the healthiest patients; once they got off the waiting list, many became ill and some progressed to AIDS.

Other clinics have been forced to ration medications. Ivette Gonzalez, 40, was diagnosed with HIV in August 1992. She says it's been hard to get meds from her clinic, San Juan Municipality's Mas Salud Sida Con Salud, because of constant rationing. "Sometimes I'd have to take four trips to the clinic to get my meds," she says.

In December 2006, the FBI, the IRS and the Human Services Office of the Inspector General raided several AIDS program offices in the municipality of San Juan to determine what was hampering the reimbursement process. Activists say that these investigations have proved more costly than helpful. The FBI reportedly demanded files and records from some community groups, which some say placed a heavy burden on them because of the cost of printing out hundreds of records.

Such was the case for Rosaura Lopez-Fontanez, who runs a community clinic called Puerto Rico CONCRA, an organization founded in 1990 for people living with HIV/AIDS. The organization has a full clinic with doctors, dental care and mental health care, as well as case management, youth programs and support groups. The organization has suffered many setbacks because of the wait times for reimbursements, and Lopez-Fontanez says that if it weren't for the parts C and D direct funding that CONCRA receives, it might have closed. "We've had to minimize doctors and staff and minimize services to our clientele," she says. Lopez-Fontanez says that other smaller organizations that don't get direct funding like CONCRA haven't been able to remain open.
Yadis, a 40-year-old homeless drug user in San Juan who asks that her last name be withheld, says

the community-based group Iniciativa Communitaria has been “a blessing” for her. She started using drugs when she was 14 and has suffered a variety of mental illnesses including depression. Iniciativa Communitaria offered her a warm bed, shower, detox for her cocaine habit and a supportive environment. “I have a lot of good motivation to [quit],” she says. “The drugs are worse now. They have more chemicals, more poison, and people are getting sicker. Every time it’s harder to get the money, and you want more. They make it that way.”

Injection-drug use is the leading cause of HIV infection in Puerto Rico. Recent studies have found that more than 20 percent of injection-drug users (IDUs) there are living with the virus, and approximately half of the new infections stem from injection-drug use. And for women like Yadis who aren’t injection-drug users, the combination of homelessness and addiction puts them at high risk for engaging in activities that make them vulnerable to HIV.

Created by renowned doctor Jose Vargas Vidot, Iniciativa Communitaria works to tackle the problem of drug use and other factors that play a role in HIV risk. The organization, founded in 1990, assists homeless individuals, sex workers, drug users, high school dropouts and other people at high risk for contracting HIV. In recent years, Dr. Vargas Vidot has been forced to shift his personnel after budget cuts, switching full-time workers to part-time and relying heavily on the hard work of volunteers. A program directed at sex workers took the hardest hit—in 2007, the Puerto Rican Health Department slashed funding, decreasing the number of women it served from about 1,775 to around 600.

Vargas Vidot says the stigma around sex work and injection-drug use fuels the city’s reluctance to fund CBOs like Iniciativa Communitaria. “Many doctors think drug users are low-compliance people [and don’t want to waste] medications on them if they will not use them,” he says. “But that’s not [our] experience.” He adds that it has been hard to reach drug users with needle-exchange and other services because users are often moved from abandoned buildings, where they gather in the city, to remote mountainous areas. José Colón agrees: “People in Puerto Rico are begging for money because they’re IDUs, and they’re treated like criminals when they’re sick and they need medications. They’re dropping homeless people off out of the municipality, far away. How do you get back home? How do you get back to your support group?”

I spent one day as a tourist, walking around the streets of Old San Juan, visiting San Jose Church, one of the oldest churches in the Western Hemisphere, and La Fortaleza, the governor’s mansion. I passed a family of four, arms full of shopping bags, and I heard the mother ask her daughter for the time. “It’s 7 o’clock,” the girl responded. “But that’s U.S. time.”

The comment reflects the cultural and national dislocation that many Puerto Ricans experience, feeling not quite American, yet not quite foreign, either. Some activists feel that a desire to uphold Puerto Rico’s image as an exotic getaway from the States—lush beaches, luxury hotels—keeps local and federal officials from acknowledging that the Puerto Rican AIDS crisis is also a U.S. AIDS crisis. Many activists, moreover, feel that the separatist nature of the territory affects not only HIV/AIDS, but also numerous factors that lead to infection. “One of our major problems in Puerto Rico is that we are not a territory, we’re a colony,” says Lopez-Fontanez. “So if things go bad in

the U.S., the impact in Puerto Rico will be tripled. We have to import almost everything [here]. The school system is also in shambles. [And] when you talk about the way the U.S. economy is right now...it's bad over there, but triple that [for] us here."

The most widely proposed solution for tackling the problem of delayed reimbursements and unused federal AIDS funding in Puerto Rico is a third party that would take the funds from HRSA and deliver them directly to the CBOs. Such a plan would mean acknowledging a problem within the San Juan Department of Health and Puerto Rico Department of Health, an idea neither office is quick to embrace.

The Puerto Rico Department of Health maintains that it has strived to improve care in recent years for people living with HIV/AIDS. "The government has aggressively improved responsiveness to patients, pharmaceutical providers and organizations that support treatment and prevention efforts in Puerto Rico," Jorge Delgado-Rivas, of the department's HIV/AIDS program, told POZ. Delgado-Rivas adds that a majority of the department's "community partners" are reimbursed for services within 30 days and that new department initiatives—such as a pharmacy benefits manager, who will monitor and ensure treatment for ADAP-eligible patients—show the health department's devotion to battling the island's epidemic. "The government's commitment to proactively addressing HIV/AIDS in Puerto Rico has never been stronger," he says, citing added staffing to the department's HIV/AIDS team.

Delgado-Rivas does agree that the island's territorial status affects its HIV/AIDS treatment. "Puerto Rico would qualify for substantial federal investment if Medicaid funding rules were applied in equitable fashion to Puerto Rico," he says. (It has a tighter Medicaid funding cap than that of the States.) "While Puerto Rico's HIV/AIDS prevalence and infection rates are low compared to its Caribbean neighbors, they are still too high in comparison to the States."

Third-party plans have been launched in places like the U.S. Virgin Islands and New York. The head of HIV/AIDS at HRSA, Doug Morgan, says the U.S. government will start a third-party plan only if Puerto Rico's local governments accept it. "Essentially they would have to agree: The grantee would enter into a contract," he says, adding that HRSA is "trying to do the best we can to work [with them], and we hope some of them have begun to make some changes."

Through all the discouragement, there has been one source of hope—the indomitable spirit of those fighting for Puerto Ricans living with HIV. This summer, members of New York City–based advocacy group Housing Works visited the island to support an activist in the eastern city of Fajardo. Gloria Gonzalez, a former drug user, is working there to start a community-based clinic for people at high risk for HIV, including homeless injection-drug users. But Housing Works president and CEO Charles King says his organization's role is not one of stepping in and "saving the day." Adds King, "I think [it is] dangerous for people to think they're going to go in and help like they know it all; [that would] do a terrible disservice to the people that are working very hard there and the people living with HIV/AIDS. [But] I think we have an absolute obligation to be working and demanding that the federal government take appropriate action."

Still, as we come to the conclusion of yet another article about the crisis, one in which activists have again spoken out and government officials have again pledged to work to end the problem, the questions remain: Who does need to step in and save the day? Who, ultimately, is responsible for saving lives in Puerto Rico? And, when will they start?

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