



## Lifelong Partners and Advocates



For life partners Jose and Anselmo, the current crisis in Puerto Rico's HIV/AIDS community has far too many similarities to the "Instituto del SIDA, San Juan" scandal that worried this fragile community from 1999 to 2001 and led to the conviction of fourteen government employees and private contractors.

Both scandals involved the rationing of desperately needed medication, dismantling of community-based organizations, reduction in vital services due to funding shortages and the dismissive response from government agencies at all levels. Jose and Anselmo, and many others involved in the previous healthcare debacle worry that there again will be extensive Federal investigation and subsequent House/Senate hearings.

Then, as now, both activists are deeply involved in denouncing governmental ineffectiveness and alleged corruption as "administrative terrorism"—implying that administration-sanctioned attempts to divert funds and conceal information regarding the true depth of the AIDS epidemic is a malicious attack on an ailing HIV/AIDS healthcare delivery system and the patients who rely on that system for vital treatment.

Their genuine zeal for HIV/AIDS advocacy is evident as they go about their daily work, mobilizing patients and community groups to respond to the growing crisis. But long days, increasingly tense confrontations with officials and direct personal threats have taken their toll on their lives and on their fifteen year relationship. And, as people living with AIDS (PLWAs), their work has impacted their already fragile health. Their suffering is increased by the fact that they bear not only the burden of their personal health, but also that of so many others who do not have the courage or strength to raise their voices.

As Anselmo pleaded for Federal intervention in Puerto Rico's crisis before Congressional legislators, national advocacy organizations and Latino community leaders, Jose was in the hospital, due to AIDS-related complications.

Though ill, Jose wanted to continue his advocacy work in any way possible, so he staged a hunger strike. The coverage of the hunger strike was so widespread that it provoked leaders from all political parties and community organizations to travel to his hotel room and pay their respects.

But Jose's chronic respiratory problems, uncontrolled diabetes, failing heart and gradually spreading thrush were weakening his determination to continue his hunger strike. Sleep was a rare luxury.

He also worried about the other AIDS patients, especially one young man that the ward orderlies had rolled into a solitary room two doors down. Nurses quietly informed Jose that his neighbor had spent nearly six days in the emergency room with no signs of progress, little practical treatment and infrequent family visits.

Sarah, the night nurse, who often sneaked Jose a treat when the ward doctors were not around, provided periodic updates on his neighbor's condition.

Sarah's suspicion was based on the family's testimony, as well as her professional experience dealing with HIV/AIDS patients. She told Jose that many families with relatives living with HIV/AIDS cannot afford medical care and are fearful of the stigma associated with it. Those that do seek help in their communities often find agencies that cannot provide even the most basic HIV/AIDS services, such as transportation to and from appointments. On more than one occasion, Sarah has seen families drop off loved ones dying of AIDS at a hospital emergency room, long after it is too late for them to respond to treatment.

Jose cried himself to sleep that night, knowing that this story repeats itself *ad infinitum* in Puerto Rico; but also hopeful that Anselmo, miles away in Washington, DC, was persuading the government to help.





# From Success to Significance: An Addict's Story of Recovery

Sandra is committed to stemming the decay of Puerto Rico's fragile HIV/AIDS system of care. She joined Bill's Kitchen, a community-based organization that provides food and nutritional services, as an outreach worker last year. Providing homeless and disenfranchised HIV/AIDS patients a modicum of hope is her passion.

## HIV/AIDS Service Delivery Crisis in Puerto Rico

Two agencies in Puerto Rico administer 75% (over \$54 million) of the Federal funds allocated for the treatment and care of HIV/AIDS. One of these is the Puerto Rico Department of Health (PR DOH), which administers all Ryan White Title II, AIDS Drug Assistance Program (ADAP), US Department of Housing and Urban Development (HUD), Housing Opportunity for People with AIDS (HOPWA), Substance Abuse and Mental Health Services Administration (SAMHSA) and Centers for Disease Control and Prevention (CDC) prevention funds. The other is the municipality of San Juan, grantee for the San Juan Eligible Metropolitan Area (EMA), which administers the Ryan White Title I funds (and some HOPWA funds) for over 30 municipalities – including, but not limited to, San Juan.

Historically, the deepening HIV/AIDS crisis in Puerto Rico stems from several challenges, including: administrative ineffectiveness; severe shortage of both qualified personnel and administrative resources (computers, telephones, fax machines, office equipment, etc); willful non-compliance by grantees of federal conditions of awards; unwillingness or weakness of local and national political leaders to step forward; and possible fraudulent practices and/or corruption.

Both the PR DOH and the San Juan EMA suffer from some or all of the above symptoms of a healthcare system in administrative decay.

Sandra overcame a seventeen-year heroin addiction, only to return to the streets. This time, however, she was deterring drug trafficking and offering prevention, education and treatment for a small community of HIV/AIDS-infected addicts a few blocks from her house. As an outreach worker Sandra visits this area – known as *el punto* and *el chootin*, both of which translate from the Spanish as “shooting gallery” – every Wednesday afternoon to bring the residents clean needles and fresh food, as well as offer them a chance to join her on the path to recovery.

When she was using, Sandra had a \$500-a-day habit, and had moved away from her home village to make a living as a sex worker in San Juan. The work proved lucrative and Sandra was able to support her mother, who had suffered from depression after her husband's death several years earlier. Sandra's mother worried about how her daughter earned her money; but did not say anything for fear of pushing her away.

Sandra realized she needed help when she learned that she was pregnant. On the night Manuel was born, Sandra's mother and aunt drove to the hospital, entirely unaware that they would return three days later with two HIV patients. Sandra had kept many secrets from her mother, but this was the most devastating.

In her new career as an outreach worker, Sandra pursued patient referral opportunities as vigilantly as she had scoped jobs in her previous job. An addict's day with Sandra can be a head-spinning afternoon of driving to the emergency room for outpatient care, darting to the state electoral commission for a valid identification card and speeding back to the emergency room for the lab results. With documents in hand, Sandra and her prospect will sit, entrenched in her makeshift office, until she has all the service referrals for

HIV/AIDS treatment, temporary housing, public health assistance, food and emergency funds. This last item she generally retains on behalf of the prospect. Instead, she goes with recovering addicts to pay light and gas bills to ensure they don't spend their money on a quick fix.

Sandra continues to do her job even though Bill's Kitchen can no longer afford to pay her. As an organization receiving Ryan White Title II funding, Bill's Kitchen has not been reimbursed for more than nine months. When most of Bill's Kitchen employees were suspended and subsequently dismissed because the agency had maximized its line of credit and was forced to reduce its services, Sandra kept coming to work.

She cannot rely on the State Department of Health to fulfill its financial commitment to this and dozens of other agencies that eventually may be forced to close. But with the support of her mother and her new husband, Manuel's father, Sandra is building a new, if uncertain, life of purpose.



## State of the State Department of Health

The PR DOH has for many years had chronic infrastructure problems and persistent shortages of qualified personnel. The central offices of the PR DOH are unable to administer the funds necessary to ensure a quality healthcare delivery system. In 2005, an Office of the US Inspector General report detailed a series of incidents around the "misuse" of funds that made it necessary for Elizabeth Duke, Federal Administrator for HRSA, to require the PR DOH to return over \$1.5 million to the Federal government. Each year, the Central government returns to HRSA millions of dollars in unused funds, because it can not administer them effectively.

Similarly, a PR Office of the Controller report, in 2006, detailed significant financial losses by the PR DOH due to its inability to purchase, inventory and distribute HIV/AIDS medication to patients through the ADAP program.

Remote clinics in rural areas serving hard-to-reach communities have it even worse. A recent Office of Minority Health and the PR DOH report (September 2006) details the dilapidated conditions and severe personnel shortages in the eight HIV/STD clinics operated by the PR DOH. Many of these clinics do not have basic amenities such as running water, bathrooms and electricity, much less working computers, telephones and faxes.

These state-operated HIV/STD facilities, clinics that purports to provide service to over 9000 PLWAs, have only a handful of nurses and doctors, only one nutritionist, and no dedicated local administrator. In one clinic, patients share the waiting room with a storage closet filled with moldy boxes and cleaning supplies. These clinics do not have the current State Health Inspection, Occupational and Safety Health Administration and Fire Department Safety

certificates required to remain open. Most also do not have current HIV/AIDS treatment protocol or personnel training programs, according to the report.

Because of these shortfalls in the field and in the central offices, estimates of how many patients are without medications are sketchy at best; they range from a conservative 131 (via a patient advocacy group) to over 1300, as estimated by the state legislature in a December 2006 resolution. Given the rampant carelessness by the PR DOH, their own assessment of the number of patients on the ADAP waiting list should be regarded with considerable skepticism. The truth is that nobody knows for certain; the PR DOH has proven itself incapable of effectively administering these programs and less capable of gathering, evaluating, and disseminating reliable HIV/AIDS patient data.



## The View from the Inside

Unlike most patients, Samuel never has problems with his appointments, treatments, referrals or medications. This weighs heavily on his conscience. He knows that as a government employee working within the HIV/AIDS healthcare delivery system in Puerto Rico, he can readily gain access to the best available treatment. To him, this is a mixed blessing.

On the one hand, he is well aware of the shortages that patients endure, because of the ineffectiveness of the leadership from within his own office. He is often uncomfortable and embarrassed by the misinformation he is obligated to prepare and present to other agencies regarding the operations, availability and preparedness of services within his organization. He sometimes sees how critical, but constructive internal reports, well-intentioned with meaningful insight, are whitewashed by his supervisors to project a more pleasant façade.

He cringes when he walks past the boxes of unpaid invoices to community-based organizations, suppliers, drug companies and contractors, knowing that every folder represents dozens of dedicated professionals that will go week after week without getting paid. He

files the warning notices from bill collectors, fully knowing that each one will suspend their services, leaving yet another part of this fragile system without the resources it needs to operate.

More than that, he worries that this misrepresentation on the part of his office may lead to misappropriations and corruption. He is concerned about his complicity in the matter and potential legal ramifications. Who will defend him when the investigators come? And they will come, he's sure of it. They must come; because this is getting out of hand.

He is even outraged that many of the clinics and offices operated by his agency do not have electricity, telephones or even running water. An employee at once of these agencies recently fell through the floor boards of his building's second floor; only then did management fix the problem.



### Activist concerned for women and AIDS

Samuel has lots to worry about. Most of all, however, he worries about the many, many patients that are silenced by a bureaucracy that undermines all forms of dissent. These are lives silenced by the inadequacy and malpractice of a healthcare system in collapse.

He is grateful, though, that the universe has given him the opportunity to be in a influential position for so many others. He is filled with a sense of accomplishment when he finds a loophole in the system permitting him to get help for someone. When opportunities come up, he hurries to find a patient that can benefit. When a health fair is in the early planning stages, he alerts the council members and gives them advance notice so that they can take care of their unmet needs. Not long ago, he learned of housing vouchers that were



available and unused, but would soon expire and be returned to the central government. He scurried to find the list of contacts that he maintains, and on his own time ensured that the vouchers were properly used.

When he closes out his government career in the coming five years, he knows that his final performance review will neither reflect the administrative agony that he has endured nor the overwhelming joy he has shared. He is less concerned about the continuity of his own treatment. He is more concerned that he will disappear from public service only to worry about who might fill his shoes.

## San Juan EMA: A Legacy of Corruption

The story of the San Juan EMA resembles that of the PR DOH, with one important exception: twice in less than ten years, this agency has been involved in alleged charges of corruption. Details of the current investigation are limited. According to the press, the primary issue involves the alleged misuse of funds by the AIDS Task Force, an administrative agent. The agency has been in administrative non-compliance with Health Resources and Services Administration (HRSA) and has been negligent in its payments to community-based organizations for years. In a November 2005 letter from HRSA, the San Juan EMA was placed in restrictive drawdown for continued non-compliance, for a variety of administrative reasons. One key factor was the mayor's disbanding of the community-based planning council, a volunteer committee required by law. HRSA's restrictive drawdown, an administrative procedure requiring direct federal funds supervision, has now been in effect for more than a year and is an indicator of the agency's inability or unwillingness to take corrective steps to become compliant.

For years, the tension between the AIDS Task Force and the planning council had been mounting. Persist complaints by community-based organizations that the agency could not or would not process proposals, contracts, issue notice of grant awards, or pay invoices on time impeded the delivery of healthcare services. Community-based organizations used to operating on a shoestring were asked to hold out longer and longer between payments. Often the AIDS Task Force blamed the community-based organizations, claiming that incomplete invoices hindered the process.

But a December 2004 Planning Council study conducted by an ad hoc committee of patients, community-based organization representatives, and AIDS Task Force staff, conclusively demonstrated that even when the community-based organizations' invoices were nearly flawless it took on average between

91 to 120 days to pay them. As a result, the AIDS Task Force, together with the Federal Affairs office of the municipality, changed the reimbursement policy and instituted new procedures, which included advance payments of up to three months projected expenses to allow the community-based organizations the necessary cash flow to operate.

Despite the changes, the problems continued. The advance payment for program year 2005-06 came three months late. That is, the advance payment, which did not involve processing any invoices and whose principal focus was to provide the community-based organizations a cash advance, was three months late. The tension between the planning council and the AIDS Task Force mounted.

It was clear to the planning council that the problem lay within the AIDS Task Force, and perhaps had to do with the six to nine staff vacancies. With this many vacancies, it was evident that the AIDS Task Force could not function effectively in processing contracts, issuing grant awards and dispensing payment orders. The planning council then renewed its focus on evaluating the inner functions of the AIDS Task Force. This is part of the planning council's job, and in truth the administrative functions of the agency had not been evaluated in several years as required by law.

For nearly every planning council meeting throughout 2005, the executive committee made a formal request via a motion to the AIDS Task Force, requesting a detailed breakdown of the agencies' budget. This was not an extraordinary request given that the agency prepares an operational budget for the Title I grant for both the municipal and central governments. Review of the overall grant allocation is within the role of the planning council and in good faith it was expected that the AIDS Task Force would comply.

In the October 2005 planning council meeting it became evident why the information had

been withheld. An internal AIDS Task Force budget submitted by the staff accountant to the planning council revealed that despite 7-9 vacancies through the program year, the AIDS Task force had spent 100% of the funds allocated for salaries and benefits.

More alarming yet was the presence of a peculiar line item in the budget. That line item, identified as "gastos indirectos" or indirect costs, accounted for 40% of the total Task Force budget. More than \$250,000 of HIV/AIDS funds were allocated to indirect cost - an amount clearly outside of the federal limits for indirect cost. The staff account clarified that this amount had been reduced from previous years, wherein it reached more than \$340,000. As they explained it, the funds were placed in the general accounts of the municipality for payment of operational costs.

Needless to say, the planning council meeting erupted and the audiotaped session tells the story of an angry, worried and disappointed HIV/AIDS community. The memories of the Instituto del SIDA/San Juan scandal were far too vivid for many people to forget about the potential for disaster. The council vowed to take effective action and prepared to formally request an investigation.

On November 19, 2005, while most council members were on their way to the next planning council meeting, having done their homework, ready to request a formal investigation, and armed with a well developed plan to work together with the AIDS Task Force to resolve these discrepancies, a storm of cell phone conversations erupted. Notice was given by the municipal offices that the regularly scheduled meeting for that night was canceled, because the mayor had dissolved the planning council.

Life in the HIV/AIDS community has not been the same since.

# The View from Above

**M**arcelo arrives at his Washington, DC office by 7:00 a.m. to avoid traffic and get an early jump on the day's work. And although he grumbles about staying late and argues that the traffic back to the suburbs is horrendous, Marcelo loves his job. He never imagined that a career with the Federal government could be so fulfilling. By contrast, his government career in Puerto Rico made him feel hurried and ineffective; everything about public service on the island has a political hue, making everything a chore. In Washington, DC, at least things seem to get done.

At least that's what Marcelo thought.

While it is true that Marcelo's family thought the move would be an adventure, adjusting to life in Washington, DC proved to be more difficult than they had imagined. Winter is particularly challenging. Marcelo's children regularly sleep much later than they did on the island; the darker, gloomy mornings making it nearly impossible to rise early for school.

For Marcelo, no winter storm could keep him from reaching his desk shortly after dawn, especially when he knows that many of his friends back in Puerto Rico will be calling with yet another tragic update about the island's HIV/AIDS crisis.

Often Marcelo takes the first call while taking off his coat and scarf. He always listens very intently, jotting down the weblink of the most recent news article and sadly offering condolences. He'll do what he can, he says. He'll bring it up to his director via email and blind copy them. He always asks that his colleagues not share the messages with anyone. He fears someone will someday slip and let on that he knows that nothing is being done. Not by the Director or by those above him or next to him or close to him. Nothing is being done by anyone. Nothing.



Marcelo once dreamt a dreadful dream. He sat on a wooden pew in corner of a well-lit church crying inconsolably – ironic enough, since he is not a religious man. Deep within the tears of his inconsolable dream he sees the faces of the many, many AIDS patients that he tended to, fought for and treated, only to later see them die. Not even the small voice in his dreadful dream could comfort his tears of despair.

Like coming to work early, Marcelo takes those sunrise calls because he loves his job. He may not be able to do much, but what little he can do is all that they ask of him. And although he is sometimes angry and always frustrated – he would never express it to them, they are not the the source of his ire – he often just prays. Prays for them, prays for strength, and prays that the anger in him will somehow produce meaningful change.

