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## **Latinos ACT UP: Transnational AIDS Activism in** the 1990s

M. Alfredo González June 29, 2008

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When the AIDS Coalition to Unleash Power (ACT UP) was founded in New York in 1987, it not only introduced a proactive stance into the United States' AIDS crisis, but also united people at opposite ends of the political spectrum. In the years following the Stonewall riots, the philosophy that fueled the lesbian and gay movement's social and cultural critique and linked it to the struggles of women, workers, and people of color, lost sway as many settled on the path to assimilation. By 1981, young, well-educated gay white men, poised to take their place among the elite, were ambushed by an unforeseen foe. Thus, when ACT UP was born, the political differences between lesbians and gay men had largely been rendered trivial by HIV.

The author (center), together with the late Luis Salazar (left) and Luis "Popo" Santiago, protests in front of the Argentine consulate in New York to demand legal recognition for Comunidad

For some, losing the promise of assimilation to the stigma of HIV infection was an affront. In anger, they dedicated their activism to establishing scientific protocols that would match the urgency of the Homosexual de Argentina, a Buenos Aires organization, in 1991. epidemic. Others, watching HIV thrive in (By Lee Snider / The Image Works) poverty, injustice, and oppression, dressed the wounds that the disease left on the social body. As the organization's membership grew, it became more diverse and so did its priorities,

with many people joining who could not help but see the global and historical dimensions of the pandemic. For them, the call to action went beyond the borders of the United States, and the tensions that despair had forced many to overlook emerged grotesquely. In a more heterogeneous ACT UP, committees that had previously been used to quick and certain support found their judgment questioned and funding support far from guaranteed. The rise of Bill Clinton to power, the advent of protease inhibitors, and the combination of several

antiretroviral medications in "cocktails" as a new therapeutic strategy spread a triumphalist sentiment vis-à-vis HIV/AIDS in the United States. Although ACT UP did not endorse political parties, its membership's loathing of Republican politicians and policies suggested a silent endorsement of the Democrats. The HIV/AIDS movement lost momentum and membership after 1992. Toward the end of the decade, as a smaller, more radical organization, ACT/NY resurged with a global agenda. Its association with the anti-corporate-globalization movement re-energized it with a new

goal of making HIV treatments available in the Global South. The coalition that still spearheads these efforts, the Health Global Access Project (Health GAP), has since its inception in 1999 targeted the World Trade Organization while focusing on Africa. Its Web site states: "At all times, we have sought to do this work in solidarity and in alliance with people living with HIV/AIDS and treatment activists in the Global South and throughout the world." A small group of Latinos working within ACT UP had begun this transnational work in the early 1990s. We faced an uphill battle, not only in fighting for the rights of HIV-positive people, but

framework for its analyses, new methodologies, new allies, and new horizons—driven in part by the

sometimes within our very own organization. I joined the Latino Caucus of ACT UP/NY in 1990 and remained active until 1994.<sup>2</sup> Initially, I only

part in general meetings. In our meetings, we shared impressions of the HIV/AIDS epidemic in the Latin American countries we knew best. A common theme emerged: Financial and informational gaps in the region limited the quality and length of life of people with HIV, many of whom did not know about and could not

pay for treatments. The contrast with North America's response to the social and individual toll of

HIV infection was bold: on the one hand, self-asserting and combative population; on the other,

attended the meetings of the caucus, and began to participate in ACT UP's general meetings after

a few months. Many Latinos/as entered ACT UP through the Latino Caucus, but some never took

desperate people with secrets, seeking help amid medical and state paternalism. In the North, HIV triggered community formation from preexisting lesbian and gay enclaves. From these platforms, people with HIV proactively and even defiantly advocated for their health care. Still, few Latinos/as were able to adopt this outlook and struggled with stigma, inadequate services, poverty, and other health and social conditions. The "take charge" response model gradually empowered people with HIV in their encounters with medical authorities, recast them as medical

If this attitude existed in Latin America during the first 15 years of the epidemic, it had been an

individual strategy. No social movement could compete with the biomedical establishment, even if

immunology was still a young specialization and its body of knowledge limited. People living with

and public health experts and shaped the HIV/AIDS movement.

HIV submitted to their doctors' authority if they had them, hoping they had their best interests at heart. By the 1980s, the politics of social class was at the core of Latin American social struggles, less so the politics of difference. The lexicon and methodologies that U.S. HIV/AIDS activists inherited from the civil rights, feminist, and gay rights movements were practically absent in Latin America.

Southern activists knew about general strikes and popular revolts but not much about civil disobedience, creative nonviolence, or the "subordinate expertise" of laypeople who appropriate biomedical knowledge. The dearth of historical precedent begged questions of cultural fit and political feasibility. Pondering these topics with the Latino Caucus led to unavoidable conclusions. Even if many of us were HIV-positive or recovering drug users, struggled with English, or were undocumented and cleaned apartments to make ends meet, the disparities we witnessed between the United States

and Latin America demanded solidarity. The Latino Caucus conceived some initiatives to that end,

and in 1991, it created ACT UP-Americas, an open-membership committee dedicated to HIV/AIDS activism across the hemisphere. We invited the members of ACT UP/NY to join us and explore the possibilities of transnational activism. They praised our work and our political savvy, but we did not capture the imagination of our fellow activists. Nobody joined our efforts. Our first step was publishing the *Boletín de ACT UP Americas*, a Spanish-language newsletter offering HIV-related scientific, social, and political news. We hoped that disseminating this information would inspire new political strategies to confront the epidemic. ACT UP-Americas sent the Boletín to people and NGOs throughout Latin America, translating and rewriting medical articles to make them more accessible. Some articles addressed drugs and therapeutic strategies not

available in Latin America in the belief that awareness is the first and unavoidable step toward

as health care partners, and to portray people with HIV as agents of change.

change. We also reported on conferences and discussed HIV-related developments in the region's

social, cultural, and political spheres. Our aim was to suggest that medical doctors ought to serve

We also started a program to collect unused medications and medical equipment in the United States and delivered them to NGOs in Latin America. As people in the United States generated resistance to medications targeting HIV and opportunistic infections, their doctors switched them to newer drugs if they were available. Months' worth of drugs and equipment already paid for went unused and caregivers disposed of them. Eager to contribute against the disparities between the United States and the rest of the hemisphere, ACT UP-Americas collected unused medicines and paraphernalia and sent them where they were needed. The in-flow of medical goods was uneven and the opportunities

"Money for AIDS," reads a placard at a

War in October 1990. (By Tony Savino /

The Image Works)

needed to administer and replenish their supplies efficiently. Public health observers called our "recycling" effort dysfunctional. For many people with HIV in Latin America,

storage, and all of them had expiration dates. Recipients had to

to deliver them random. Some drugs needed refrigerated

however, medication recycling remains the only way to gain access to treatment in the face of the near total disinterest of the regional power elites toward the HIV epidemic. This small-scale strategy is the same one that medical doctor and anthropologist Paul Farmer used

understand that each delivery could be the last. Thus, the NGOs New York rally against the Persian Gulf

to this type of operation. A national AIDS program cannot depend on recycled unused medications, of course, but almost two decades after we first tested this strategy, it remains a viable—and unfortunately still necessary—bottom-up strategy in grassroots HIV activism.

member of ACT UP-Americas, founded Aid for AIDS, a nonprofit organization dedicated exclusively

in 1998 to provide HIV medications to his patients in Haiti. More recently, Jesús Aguais, former

Our third, more directly political effort, was a campaign in solidarity with Comunidad Homosexual Argentina (CHA), an Argentine group founded in 1984 that presses for gay rights and access to health care for HIV-positive people. At that time, CHA was struggling to operate as an NGO and to support itself financially and legally. As a community-based organization, CHA was in a privileged position to engage in HIV education and prevention, and legal recognition of the group would allow it to tap into available resources. In 1990, the Argentine national Court of Appeals rejected CHA's request to secure legal recognition because, it would amount to recognizing a "hybrid third gender" and a threat to what the court referred to as established "morals and good customs." CHA brought

an appeal to the Supreme Court, and as it waited the court's expected negative ruling, it began

parallel discussions with the executive branch to overrule the decision with a presidential decree. The Latino Caucus began exploring how to support the CHA in the late months of 1990 and decided to apply international pressure. We picked noon, February 5, 1991, to stage a demonstration in front of the Argentine consulate on West 56th Street in Manhattan. Three of us requested a morning meeting with the general consul but were granted one with just an adjunct consul. As we arrived to our meeting that morning, we found that the consulate's facade had been defaced with graffiti in favor of CHA. Once inside, an aide asked us to wait in a tiny room. The general consul, we were told, wanted to discuss the desecration of the consulate. Pinned to a wall of the room where we waited was a map of Iraq.

HIV is transmitted, we turned to the second item on his agenda: the graffiti on the building. He was enraged. Nothing like this happened to him in his entire diplomatic life. To make matters worse, these were delicate times: Argentina had recently joined the Desert Storm coalition. If we were not the perpetrators of the crime, he said, we were its "intellectual authors." The phrase brought a whiff of the dictatorial 1970s into the democratic 1990s. As the demonstrators began to chant slogans outside, the general consul insisted that we were responsible for the vandalism and that HIV infection was irrelevant in Argentina.

We were taken to a conference room on the top floor, where the consul greeted us. As soon as we

had sat down the he said, "I hope you haven't come to infect us." After briefly educating him on how

González)

demanded legal recognition for CHA with an admonishing expression.

the organization's right to have legal recognition.

and legal association?

The Boletín de ACT UP Americas, a Spanish

distributed to people and NGOs throughout

Latin America. (Courtesy of M. Alfredo

language newsletter offering HIV-related scientific, social, and political news, was

It was a rare warm, sunny February day. About 60 demonstrators showed up, of whom no more than 20 were Latinas/os. Spanish-language TV networks covered the demonstration. As the activists arrived, they received a square of pink fabric to wrap around their heads as the Mothers of Plaza de Mayo do. Others covered their faces instead; in a practice left over from Argentina's dirty war, a consulate employee took photographs of the demonstrators from the door with a telephoto lens. Many of the slogans referred to Argentine culture and history: "If Evita [Perón] were alive, she'd be a dyke!" From cardboard signs, Mafalda, the world-famous Argentine cartoon character, Our actions for CHA played with time and transnational space. Weeks before our consulate action,

Chagas disease, he said, was a more urgent public health

Argentine child gets lessons on how to prevent Chagas.)

hundreds of letters addressed to then Argentine president

After this futile conversation ended, we handed over

Carlos Menem, and joined the demonstrators outside.

priority. (The consul had good memory—in fifth grade every

—who was touring the United States, promoting Argentina as an industrialized nation with all the features of a modern democracy—was to visit the School of International and Public Affairs at Columbia University in New York. ACT UP-Americas quickly tried to mobilize a picket line at the building entrance, while in the auditorium, four activists would try to participate in the question and answer session, disrupting it if not allowed to participate. Only five people showed up. Four went upstairs; at the "picket line," one activist remained with 15 signs. He was not even an ACT UP member.

When Menem entered the auditorium, we recognized a man we knew as Ricardo among his

security detail. We had met him four days earlier at ACT UP/NY's work space. He introduced

we sent CHA a packet of flyers announcing the date, which we hoped they would reproduce and

distribute widely. Three months after the action, ACT UP/NY paid a Buenos Aires newspaper for a

The following November, an urgent call came from an Argentine activist in San Francisco. Menem

half-page ad denouncing CHA's plight. These tactics compounded and extended the discussion on

himself as a nurse with an adolescent daughter in Argentina. He had talked to her recently, he said, and the conversation left him anxious about her and her peers' ignorance about HIV infection. He wanted to do something about it. As odd as his visit was, we pointed to the file cabinets and the photocopier. Help yourself to anything you find useful, we told him, and left to meet behind closed doors in the other room. When we came out, he was gone. When we saw Ricardo strolling behind Menem, we understood the purpose of his visit and silent departure. After Menem's presentation, several hands went up during the Q&A. In the back, one of us stood up with his hand raised and remained standing as the president gave his first reply. The second

question was his: How democratic is Argentina if a minority group does not enjoy the right of free

A wave of expressions of surprise and indignation swept through the well-dressed first rows. "Querido amigo," Menem began. Argentina is over the issue of establishing legal recognition for the CHA, he said. He had given already instructions to reverse the Supreme Court's denial. The Argentine press corps took frantic notes, talked into their tape recorders, and hurriedly made longdistance calls. They were as surprised as we were. The next day, Buenos Aires newspapers trumpeted the brief exchange in New York with front-page

headlines. Less than a week later, the Supreme Court handed down the expected negative

decision. In March 1992, Menem reversed the court's decision with a decree granting legal

to convince each other of our achievement. Our picket line still had but one demonstrator.

By 1996, the Latino Caucus and the ACT UP-Americas committee did not exist as such. Members of both groups had grown disenchanted with HIV activism under the aegis of ACT UP/NY, were very sick, or had died from AIDS. A handful of activists remained active as an ad hoc group working

around international issues. One of these activists, Jairo Pedraza, had become the North American

representative to the Global Network of People Living with HIV/AIDS (GNP+). This informal

recognition to CHA. We had prepared for a more difficult exchange. We boarded the elevator trying

gathering of activists organized "Access to Treatment in Developing Countries," a satellite symposium at the International AIDS Conference in Vancouver, Canada. The group obtained the support and participation of GNP+, UNAIDS, UNDP, the World Health Organization, the White House's Office of National AIDS Policy, USAID, Glaxo Welcome, the International Association of Physicians in AIDS Care, Latino Commission on AIDS, and the networks of people with HIV in Africa (NAP+), Latin America (AP+), and Asia and the Pacific Islands.

Virtually every sponsoring organization contributed speakers to the symposium. Its goals were to raise awareness of the challenges of access to HIV treatment in developing countries; define and analyze the nature of access to treatment; and develop recommendations for collective action. A striking feature of the symposium was the diversity of the voices it brought together. The underlying premise was that the complexity of the task demanded the will and the concerted effort of a diverse collective of stakeholders. Their presentations reflected the breadth of the call for

contributions providing numerous directions to make a dent to the HIV pandemic and outlined multiple goals for change. A request of support to the conference's General Assembly accompanied each of the goals. We needed the expertise of our fellow activists as well as their labor to achieve our goals. Only when we worked on local issues did we receive the support we requested, and even that ended after a point; but that is another article. ACT UP welcomed and lauded our hemispheric projects, but its refusal to join in our work conveyed that Latin American issues belonged to us and us only. Perhaps the innovative features of

transnational activism were not apparent yet. It could be that during the early 1990s, ACT UP was still growing and had a wealth of local and national issues on which to spend its activist fire. Maybe it was that Latin America was too foggy a spot in the HIV activist imagination or that it is hard to empathize with people who are more familiar by their economic, sexual, and legal objectifications. Africa did not meet such indifference among U.S.-based HIV activists, although it wasn't until the late 1990s when the African HIV crisis received the attention it deserved. I am sure that in the Euro-American liberal imaginary, Africa elicits more guilt and fear than Latin America ever will.

Contemporary social movements draw a great deal of their strength from the combination of multiple voices. As they move forward, they skid in that diversity and reproduce at home the patterns they are committed to change in society. Yet in spite of the acrimony, transformation is possible.

AIDS activist, he has worked in New York, where he lives, and throughout Latin America. This article is dedicated to the memory of Luis Salazar. 1. There are more reasons underlying the waning of the energy of ACT UP/NY. As the group actualized its inclusive goals and its membership grew more diverse, so did the issues considered

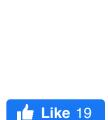
M. Alfredo González is an anthropologist specializing in health, poverty, cities, and Latinos. As an

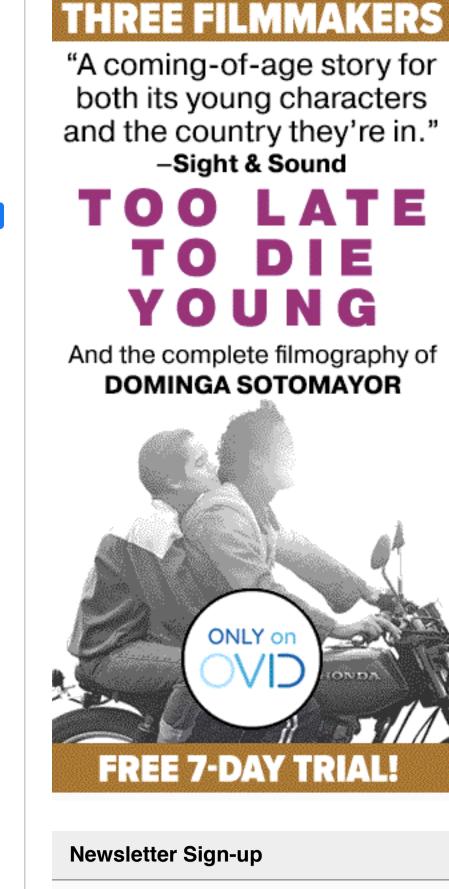
address these dynamics, as important as they were. 2. During my time as an ACT UP member, the urgency of HIV/AIDS politics in the United States, and its relevance for me, often took priority over such tasks as ethnographic note taking. Memory

urgent, and tension between groups with different aims grew. This article does not attempt to

and what sporadic notes I did take inform this account. Tags: HIV/AIDS, transnational activism, US latinos, ACT UP, solidarity









A discussion in Nicaragua in partnership

Crisis (WGNC).



(i)

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