A Woman of Substance

Michelle Lopez has seen the dark side; now she's spreading light

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As the Number 6 train rumbles from the bowels of a gritty subway tunnel through Manhattan and rises onto elevated tracks toward the open sky and tree-shaded Bronx neighborhood of Parkchester, Michelle Lopez breathes a sigh of relief. And accomplishment. The journey and its destination—her own home—are both solace and transcendence.

Her circuitous journey takes her a world away from the heady challenges and notoriety that AIDS activism has recently heaped upon her. As one of a few open lesbians with AIDS—and someone who is also black, Latina, a mother and an immigrant—she punches all the right buttons for those who seek to use her as a symbol of where this epidemic has gone. Yes, she is being used. At the same time, she relishes the attention and her renewed sense of purpose to help others even as she helps herself.

"I've been battered and abused, I've been on drugs, I've been in and out of the city's homeless shelter system. And through it all, I've learned that as a poor woman of color, I do have resources to help myself and others," Lopez says. "When my daughter was diagnosed with AIDS in 1991, I hit rock bottom. I decided right then that I had to fight for her survival as well as my own. Many poor women have been put down so much by men, by society and the medical establishment, they feel helpless."

Lopez belies the media's caricature of a person with AIDS. Her eyes sparkle with a zest for life and a readiness to laugh, not only at others' foibles but at her own. Her cheeks are round and full, and when she smiles, her eyes almost disappear beneath carefully drawn eyebrows. She believes in style: At a recent Gay Men's Health Crisis party for volunteers, Lopez and her lover, Diane Watts, wore matching pastel linen ensembles made by a local designer and friend. Lopez wore a long skirt and enormous glass star earrings; Watts wore long pants. They held hands all evening as they wove through the dance floor.

She's also extremely stubborn, a trait she possessed as far back as friends and relatives can remember. It's a trait that serves her well today.

"I remember when she was younger, our mother had planned a big Sweet 16 party for Michelle. But she spent the night before at a boyfriend's house. Mother was furious," says one of Lopez's big sisters, Erica Callender. "My mother told her when she came home that the party was canceled.

Michelle tried to commit suicide. She drank something like paint thinner and Mom was so upset that she allowed Michelle to have the party anyway."

Callender, a health coordinator at a local agency and a nurse's aide, says everyone in the family was shocked when they learned about Michelle's health status. "But being the activist that she's become, everyone respects her for being a strong fighter. If she wallowed in her woes, we would be more concerned. She's like a little Supergirl. She never stops: Wherever she wants to be, she gets herself there. She's not led around easily. She has very little fear."

As Lopez clearly understands, there is little time for fear or inaction. At a time when few black or Latino elected officials and even fewer members of the clergy have addressed AIDS within communities brimming with drug abuse, poverty, inadequate medical care and housing and other crises, Lopez stands as a beacon in a sea of ignorance, denial and despair.

But don't for one minute think it came easy.

Lopez's father is Latino; her mother is black. Lopez immigrated from Trinidad in 1979. When the Centers for Disease Control and Prevention (CDC) talks about the changing face of AIDS, it's talking about Michelle Lopez. "Some people still think of AIDS activists as gay white men," she says. "Gay men set the tone for advocacy, and they deserve credit for that. But a few of us are starting a peer initiative group called Pioneers so that poor women, especially women of color, can learn to speak for themselves. We want to say to them, 'You can hold onto my hand and we can do this together.'"

The CDC reports that blacks and Latinos accounted for 59 percent of all AIDS cases reported in 1995. Blacks and Latinos also accounted for 75 percent of women infected, 77 percent of heterosexuals infected and 81 percent of children suffering from AIDS or HIV complications.

Nationally, HIV is spreading almost six times as quickly among women as among men, recent CDC statistics show. Black women in the United States are nearly 15 times as likely as white women to have AIDS. New York City's Gay Men's Health Crisis (GMHC), the nation's largest and oldest AIDS service organization, reports that its female client caseload grew from 7.4 percent in 1990 to 18.2 percent in 1995. Equally as striking, GMHC's client breakdown for 1995 is 39.5 percent for all whites, 26.6 percent for blacks and 27.9 percent for Latinos. More than half of GMHC's clients are now people of color, and these statistics, which reflect the city at large, mirror the phenomenon around the nation.

In this context, one understands why if Lopez didn't exist, someone would have to invent her. She's a living intersection of racial and ethnic identity politics, women's issues and the prickly politics of drug use. And she spreads around the wisdom percolating from this complicated cauldron.

She has served on the New York City HIV Planning Council and as an AIDS advocate with the Food and Drug Administration's Office of Women's Health. And since 1992 she has been on the Community Advisory Board of Bronx Lebanon Hospital's AIDS Clinical Trial Unit. She has organized

and participated in numerous AIDS and women's health conferences and carries a beeper to keep up with the demands for her help and counsel. The woman who once sold drugs without a beeper now uses one to keep in touch with activists, her lover and relatives.

But at age 30, Lopez is troubled by recurring cervical cancer, CMV infection and what her doctors fear may be the beginning of wasting syndrome. She is shaken by the thought that she may not live long enough to see her children become adults.

She says that desperation fuels her. She has become self-educated in the lingo of AIDS research and treatment protocols, and no one—no one—is going to tell her to defer to the wisdom of the establishment. Since 1991 she has been active in organizing demonstrations and negotiating with national governing boards of pharmaceutical companies to start programs and services for people with AIDS, especially for women and children.

"One of the things people don't realize is that AIDS doesn't just affect an individual but the families as well," Lopez says. "We have to acknowledge the families surrounding the person with AIDS and get them involved in the therapy.

"As soon as an HIV or AIDS diagnosis is made, you look at how the family responds or how it relates," she continues. "The first level of discrimination often is in the family. If my daughter falls and cuts her knee, one of my sisters has told her kids not to touch my daughter."

Lopez's aggressive advocacy can be intimidating at first, says Julia Ortega, a coordinator of the community constituency group of the AIDS Clinical Trials Group. "It takes a lot to gain the respect of researchers. Advocates have to prove themselves, and she's been able to do that. Once researchers value your opinion, they do listen." Especially to Michelle Lopez.

To see her in action—stylish, animated, disarmingly cheerful and optimistic—one easily forgets that for much of her life she lived in the shadow of drugs, low self-esteem and the predictably immobilizing horror of an AIDS diagnosis. She looks forward to a marriage later this year with her lover, Diane. Lopez describes herself as "futch," a term she says means she's a feminine butch who wears makeup and form-fitting women's clothes with a kick-ass attitude. In earlier years, some might have called her a feminist.

The flower of her advocacy grew from seeds of despair. At 13, she started using drugs to escape the pain of her parents' separation and to be accepted by a neighborhood group of toughs who used drugs. She started with cocaine and pills, and though she hung out in shooting galleries, Lopez never injected heroin -- the needles bothered her. Now she must endure constant needle pricks for blood tests and intravenous therapy.

"I came from a middle-class West Indian family," Lopez says. "I saw friends on drugs and I saw them get attention, so I figured that route would bring my parents back together. They did come together eventually, to see what they could do to help me get off drugs. But I started liking what I was doing."

Erica Callender says that Lopez's temerity was apparent even when she was a teenager. Callender used this analogy recently: "I would be afraid to get in the water, but Michelle takes a bath."

That lack of fear didn't always serve her well. "You have to earn your level in the gang," Lopez remembers. "The badder you are, the more you are respected as leaders. And I did whatever I needed to do to get the juice."

Although she has been a lesbian as long as she can remember, Lopez learned she could trade sex with dealers for drugs. Too often, people who aren't destitute don't understand how much pain-numbing comfort illegal drugs can bring, Lopez says. So the food money ends up going for drugs, then the rent money.

When she bore her first child, a son named Rondell—now nine years old and HIV negative—he grew up seeing her use drugs and being battered by men. Things got so bad, Lopez says, that her parents took Rondell from her when he was nine months old and kept him with them in Trinidad for nearly two years. Years later, still taking drugs, Lopez overdosed on cocaine and learned she was four months pregnant.

"The doctors screened my blood but never told me I was HIV positive," Lopez says. "No one counseled me about HIV. They told me to breast-feed my baby."

Before her seventh month of pregnancy, she sought drug rehabilitation for her daughter's father. The counselors in the drug rehab center asked her about her own drug status. That's when she agreed to take an HIV test. The results stunned her. Her daughter, Raven, now five and a cute bundle of energy and braids, was born HIV positive.

"A nurse started telling me about early treatment and I cried, 'You all got to help me,'" Lopez says. "One of the counselors told me I had no green card, that I was on drugs, like I was hopeless. I asked to see the executive director of the agency and I asked, 'What are you going to do to help me? I have a bunch of issues and I need to know.'" The executive director gave Lopez the number of her direct line and told Lopez to call if she didn't get the answers she required.

The HIV-induced epiphany started a chain of events that lead to Lopez's present course. Months of living in shelters for battered women and in New York City's Emergency Assistance Units for homeless families steeled her will. She saw some of the security guards having sex with women for favors. When she spoke out about this and other injustices, she was labeled a troublemaker.

"One of the counselors taunted me, saying, 'You have this disease and you're not even a citizen,'" Lopez remembers. A friend in the Powers Avenue Shelter in the Bronx told her that the Partnership for the Homeless, an advocacy group for homeless people, might be able to help her get an apartment. But the counselor who taunted her refused to help or even give Lopez information about the Partnership, she says.

So to get that information, Lopez promised a security guard that he could have sex with her if he let her into the counselor's office. The scene developed into a *Mission: Impossible* plot. Lopez

waited for the office to close, then scouted around to make sure there were no witnesses. The guard then picked the lock. When she got the contact names and numbers, covered her tracks and locked the door, Lopez told the guard she wouldn't deliver the sex and that he could lose his job if he protested.

"I then called the Partnership myself, pretending I was a social worker, and referred myself to them," Lopez says with a characteristic deep-throated chuckle. "In two weeks, they did the paperwork and drove me out to areas of the city to look for apartments. That's when I saw Parkchester and thought it would be so nice to raise my kids there."

The stubbornness and determination that has enabled Lopez to cope continues in her activism. "I have to put on psychological armor to go into these meetings in Washington, City Hall or the 'Boys Clubs' like TAG [Treatment Action Group] or GMHC," Lopez says. "They try to shut me down and say, 'This is not the arena to bring up women's issues, this is not what the meeting is about,' or they say they don't understand what I'm talking about."

"All we ask is that they get us women in the door and we'll do the work that needs to be done to address women's issues," Lopez says. "We're going to come with an agenda. The men always do."

She takes this mission very seriously. Tracie Gardner-Wright, a senior policy analyst on AIDS for the Federation of Protestant Welfare Agencies, first met Lopez about four years ago at a meeting in the Bronx to organize women to form their own HIV advocacy group. She remembers that Lopez, one of few women of color in the group, was the only one who was open about her AIDS status. The group never really coalesced, but Gardner-Wright recalls that Lopez's education about AIDS skyrocketed from the effort.

"At GMHC, we worked in the area of newborn care, HIV testing and women's issues," Gardner-Wright says. "Michelle met with legislators in Albany, she met with other women, she spoke at press conferences, she did it all. And when she says at a meeting that she's a proud lesbian, she has HIV and a child with HIV— and now let's get down to business—people listen. She tries very hard to make people understand that when you talk about children's health and welfare, you're talking about mothers, too, and you cannot separate the two.

"When you sit down with her at a meeting, she's all there," Gardner-Wright adds. "She has run herself ragged into the hospital. She has to be threatened with violence not to talk. You have to say to her, 'Michelle, don't take your beeper to the hospital.'"

But such advice is for naught: Lopez is driven and time is precious. To be out of touch with her children, her lover or the advocacy community is unimaginable. Every morning, Lopez gets on her knees and thanks what she calls "the higher powers" for one more day. Another days' passing in the tumult of disease may not be as easy as one might believe. As she dresses for the day, Lopez girds herself in the faith that with one more day, she can make a difference, if not for herself and her children, then for others with HIV and AIDS.