Working Mom

Whirlwind Marlene Diaz tests the limits

December 1, 1998 By Evette Porter

“I feel like I’m living in dog years,” says Marlene Diaz, 35. “I just make believe each year is like a year in a dog’s life -- every one equals seven,” she says, sitting amid stacks of papers in her small two-bedroom apartment. The clutter, she says apologetically, is the result of her work as an activist with the HIV Law Project, Just Kids and ICW (International Community of Women Living with HIV/AIDS), among others. Pert but pleasant, she has a certain wariness that surfaces when she coolly talks about her HIV status and its origins.

“I tested positive in 1992 when I was eight months’ pregnant,” says Diaz, who lives with her 5-year-old daughter, Margaretha, in New York City’s Chelsea neighborhood (“HIV Mecca,” says Diaz, who has lived in the same building since 1967). “I was planning on breast-feeding, so I wanted to know if I was positive, because I had been raped when I was two months’ pregnant,” she says matter-of-factly. “I definitely had my share of intimacies, mostly with women. There were maybe a handful of men, so I couldn’t rule that out. But my daughter’s father was negative, and other people that I hunted down were negative as well. So I think it’s safe to say that I probably got infected being raped for five hours. It’s high-risk sex,’’ says Diaz, with a laugh. ”Nobody’s thinking safe sex and you don’t have much say in the matter.“ She pauses. ”Unfortunately, you don’t have any say at all."

Our conversation is interrupted momentarily by Margaretha, looking for her Beanie Babies. “I don’t know where they are,” Diaz says to her daughter. “Look in the pockets of the blanket you made for them.” Without skipping a beat, she picks up where she left off.

Her mood shifts as she begins talking about her daughter. “They tested her antibody positive at birth, but they also gave her a p24 antigen test two months later. Remember, this was five years ago,’’ she says with the casual familiarity that comes from years of poring over AIDS research. ”No one counseled me about the test. If someone had said to me, ’We’re going to test Margaretha, and if that test is positive, that means your kid is going to be positive forever,’ I would have said, ’I can’t deal with that now.’

“It was rough.” she continues. “My life went from finishing college to being focused on my T-cell count. And the more I stressed, the lower it got.” Diaz leans forward. “I remember watching TV and seeing an ad for cemetery plots -- pay-as-you-go. I’m still paying off that stupid mausoleum.” After about a year, Diaz managed to channel her anger and depression into advocacy. Not

surprisingly, she became involved in programs for women and children with HIV, and in outreach to the Latino community. She has testified at congressional hearings on legislation that would mandate HIV testing of newborns without the mother's consent -- something to which Diaz is vehemently opposed, especially without the proper prior counseling. "Imagine someone being tested without their consent, by testing their child," she explains. "Without any counseling, I would probably very briefly consider jumping out a window -- with my kid."

Perhaps one can better understand Marlene Diaz's transition from first-generation American daughter of a Puerto Rican father and a very Catholic -- and "very critical" -- Peruvian mother by hearing her describe her daily routine: "On a typical day, I'm up at 5:30 to give Margaretha ddI so she has an appetite two hours later. She just started kindergarten, so I have to pack her meds -- Viracept for the afternoon, bottled water, whatever lunch is going to be. Sometimes, if I know I'm going to be exhausted when I get home, I'll put on a pot of rice, so I easily make something when we get home. Usually I don't have time." By 7:45 she's out of the house.

After dropping her daughter off at school, Diaz heads to her job at Beth Israel Hospital, where she does counseling for the Families in Transition Project. She puts in about 20 hours a week there, Mondays through Thursdays. "Fridays I need to keep open for medical appointments," she says.

Once a month she must also help Margaretha through an IVIG (intravenous immunoglobulin), an injection of sterile solution of concentrated antibodies to prevent bacterial infections in children who are immunocompromised.

Although Diaz trusts her doctor, "we don't see eye-to-eye on a lot of things. Doctors seem to be very territorial, and I refuse to be bullied," she says with characteristic resolve. "I think the reason why my daughter's doing well is that I really believe in her doctor, although we didn't agree on the IVIG. I didn't want to have an IV pump in my apartment. There will be a time when we will need one, but now is not the time. So every month I put on my boxing gloves to go another round with the doctors.

"I've made it six years already, and that's a pretty old dog," Diaz says with a hearty laugh. "Maybe I can go back to human years now."

To find out more about Marlene and Margaretha's health today and in the coming months, check in on "What This Means."

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