

NYUPHYSICIAN

THE MAGAZINE OF NEW YORK UNIVERSITY SCHOOL OF MEDICINE

Growing Up with HIV/AIDS

By Aubin Tyler
Fall 2010



José Roman, who contracted HIV at birth, stays healthy by taking nine pills a day. (Photo by Sasha Nialla)

To look at José Roman—a short, muscular Puerto Rican-American with sleepy green eyes, a slow, sweet grin, pierced ears, a backward baseball cap covering black hair tied in a bun, and the nickname REX tattooed prominently along one arm—you might guess the 23-year-old has seen a bit of life. And you’d be right:

José contracted HIV at birth from his drug-addicted mother, who died of AIDS when he was three. Some years later he learned of his status from his father, who, along with an aunt and uncle, also succumbed to the disease.

Still, José says he’s heard stories “a lot worse” from other young people he’s met at Bellevue Hospital’s special clinic for children and young adults with HIV/AIDS, where he has received medical care since childhood. Today he works as a peer educator for the clinic’s summer program on healthy living. “These kids are going through a lot of pain,” he says. “Some were

born in places like Ghana and were sent here to stay with relatives and get treatment while their parents stayed behind dying of the disease.”

Of the 105,633 New Yorkers now living with HIV or AIDS, 2,449 of them, or 2.3 percent, contracted the virus from their mother at birth, according to the most recent data from the city health department. These young people, most of them poor blacks or Hispanics—the groups hardest hit by the AIDS epidemic—represent a bubble in time, their fate sealed by the accident of having

been born before the mid-1990s, when scientists discovered that powerful antiretroviral drugs—first Zidovudine (AZT) and later protease inhibitors— could block viral transmission from mother to baby. On the plus side, the new drugs turned a fatal disease into a chronic illness, so that most babies infected at birth are now surviving into adulthood.

From the beginning of the epidemic in 1981, Bellevue was one of only a few hospitals in the city caring for infected pregnant women and their newborns. Its clinic for children with HIV/AIDS was started two years later. “By 1983, we’d started seeing a number of infants we thought were infected, but it wasn’t easy to diagnose because the antibody test didn’t really come along until 1984,” says William Borkowsky, MD, professor of pediatrics and director of the Saul Krugman Division of Infectious Diseases and Immunology.

By 1986, NYU physicians at Bellevue had learned that infants of infected mothers had a one-in-four chance of acquiring the infection, usually during delivery. In those years, about half of infected children who survived infancy were dead by age two. As the new antiretroviral drugs rolled out, Bellevue became one of the first centers in the country to take part in national clinical trials involving HIV-infected mothers and infants. “We tried to treat everyone we could,” Dr. Borkowsky says. “After 1996 we saw a dramatic reduction in mortality. In the last five years we’ve had only four deaths, usually because patients weren’t taking their medication.”

The clinic currently has a caseload of about 100 children born with HIV, most of them now teenagers or young adults who have been seen by the same doctors and support staff every three or four months since birth. Others have grown up and moved elsewhere or graduated to the hospital’s adult clinic. Like many of these young people, José was raised by his grandmother, who kept a tight rein on him. “She sheltered me,” he says. “In seventh grade, I realized I had a place to go every night, a plate of food, and clean clothes to put on the next morning. A lot of kids I grew up with didn’t have that.” To stay healthy, he takes five pills in the morning and four at night,

more or less the same routine he’s had since childhood. He’s had to change medicines a few times because of side effects, such as a risk of kidney stones brought on by Indinavir, a protease inhibitor, and ingrown toenails. “I’ve had five surgeries on two toes,” he says.

These days, José lives in his own apartment with his girlfriend and her two-year-old son, and commutes two hours each way to work at the clinic. Besides working on his GED, he coaches the neighborhood kids in basketball and writes rap songs “about life’s struggles, life without a mother or a father.” Unlike most of his peers, he’s open about his disease. “All my friends know what I have and they still accept me. They say, ‘You better not die on me!’”

“The biggest lesson for me is that I can still have a normal life,” he adds.

TYRA*, 20, taps her purple and pink acrylic fingernails against the table. World-weary, she leans her head to one side. Sloe-eyed and full-lipped, with her dark hair slicked back against coffee-colored skin, she takes a deep breath before speaking slowly, carefully.

She never knew her father, she says, and doesn’t remember her mother, who died of AIDS when she was four. A brother also died of AIDS, at 19. “I didn’t understand when he was getting sick,” she remembers. “I was 11. That’s when they sent me to the clinic.”

At age two she had been taken in by her foster mom, who later told her that the medications she took were “vitamins.” She found out the truth in a Bellevue clinic support group, when a social worker asked her if she knew why she was there. “I was like ‘What?’ I was thinking it was like cancer or diabetes.”

Last fall, after taking herself off her medication, Tyra’s weight dropped from 160 to 126, and she was hospitalized with pneumonia. She says that until then, she didn’t have a clear understanding of her illness. “It wasn’t sticking to me because I didn’t want to be like that. I didn’t want to think about having this illness,” she says. “That woke me.”

The people close to Tyra know her status. This includes her boyfriend. “He was glad I told him. He’s a caring person. I was pretty comfortable telling him—but we knew each other for a few years, first.

“I used to think ‘Why me?’” she says. “But if I didn’t have HIV, I would have had a baby already. I’ve always used protection. I used sex as stress relief and didn’t take anyone seriously. Now, I’m happy. I thought no one could love me, and I was going to be old and lonely. It feels so good that someone really accepts you.”

ANTHONY*, 18, found out two years ago that he had been born with HIV. “I always had regular checkups where they took blood samples. I thought everybody went to the doctor every three months,” he says with a shy grin. When tests showed a decline in his immune function, his doctor decided he needed medication

“I couldn’t believe it had happened to me—I was in shock,” he recalls. “As I got to thinking about it, I started to get worried.” I was 16! But it took me a short time to get over it, just two weeks.” He also learned that the woman he’d called mom since age two was actually his father’s cousin, who had adopted him. His father is still alive, but Anthony has no desire to know him.

The first few months on medication made him dizzy and drowsy, but after that, the side effects subsided. “At first, it was an obstacle,” he says. “I made it my main goal to make sure the disease wasn’t going to keep me back, and that forces me to take my medicine every day.”

Outside of the monthly Bellevue support group he attends, he’s decided to keep his status to himself, choosing not to reveal it even to his closest friends. “My mother worries,” he admits. “She says I should try and get some feelings out.”

With an A-minus average, Anthony plans to go to college to study computers. “I’m always fiddling with electronics, taking things apart and putting them back together.” He’s also crazy for basketball. At 6’3” and 200 pounds, he is waiting to hear from his coach about a college scholarship. Learning his HIV status, he says, has made him a more careful player. Before a game, he’ll study the opposing team. “If they’re an aggressive team, I’m not going to drive to the basket. I’ll take more jump shots,” he explains. “I do play hard. I’m not playing aggressively, but I’m still playing effectively.”

A serious relationship would be a “distraction” right now, adds Anthony. “I do think that having the virus has prevented me from getting close to a girl,” he says. “But when the time comes, I’m going to tell.” •

—AUBIN TYLER

* Names have been changed.