

## **Staying alive: among the rising numbers of black women in Chicago with HIV/AIDS, three stay strong by speaking out**

Lindsay Edmonds

Waver "Frankie" L. Franklin's heart jumped when she read the letter. It was from LifeSource, a blood donor center where she had received a blood transfusion about two months earlier.

She was instructed to call the center.

Frankie knew something was wrong. She waited a couple of weeks before she responded. "I was immobilized by fear and finally I decided I better call them and get treatment for whatever is wrong with me," said Frankie, 50.

When she finally called the center, she was directed to three different people. They kept insisting that she stay on the telephone. Finally, she was connected with the man who was going to deliver the news.

He asked her to come to the center. Frankie told him she couldn't because she worked during the hours the center was open. "He said, 'Ms. Franklin, I'll wait for you.' And then my heart jumped again," Frankie said. "Why would this man wait past his working hours to talk to me? Something is wrong."

Frankie didn't want to go alone, so she asked a co-worker to accompany her. After they arrived, Frankie felt numb as she sat across the desk from the man she had spoken with on the phone.

Frankie was HIV-positive.

The room was silent. There were no tears, screams or sobs. Frankie didn't accept it. While she sat staring at the man behind the desk, he drew on a piece of paper. "There were images of a virus and T-cells, and, when the T-cells are all gone, you die," Frankie said.

The man had emotion in his face while Frankie sat frozen with no response. Frankie said the man thought she was brave. She knew better. She was in denial. "I listened and I asked questions, but I didn't act like I was getting the news that I was HIV-positive," Frankie said. "I rejected the idea totally."

But eventually Frankie, like a rising number of black women in Chicago, had to face the frightening truth.

In 1992 and 1993, black women made up 17 percent of AIDS cases in Chicago. A decade later, they accounted for 31 percent, according to a 2004 report from the Chicago Department of Public Health.

By the end of 2002, AIDS was the leading cause of death nationwide among African American women between the ages of 25 and 44, according to the U.S. Centers for Disease Control and Prevention. National statistics also showed that black women were 23 times more likely than white women to have AIDS.

In Illinois, approximately 66 percent of all women living with HIV--the virus that causes AIDS--are African American, while black women make up just 15 percent of the state's female population.

HIV destroys blood cells crucial to the normal function of the human immune system. Studies have revealed that most people infected with HIV carry the virus for years before enough damage is done to the immune system for AIDS to develop, according to the CDC.

The Chicago Reporter spoke with Frankie and two other African American women, Ida W. Byther-Smith and Tamara L. Wilson, about their challenges with coping physically and emotionally with HIV/AIDS and their quests to inform others.

Though their stories differ and span more than a decade--Frankie learned she was infected in 1988, while Ida got the news in 1991 and Tamara in 1999--these three women share overlapping frustrations and difficult experiences with prejudice and ignorance.

Initially, their struggles propelled them into advocacy work to help those suffering from the disease and educate others. Now they each derive a therapeutic healing from it--easing the past years of hurt, anger and rejection.

At first, Frankie didn't want to believe she was HIV-positive. Her denial lasted two years. "I proceeded on with my life like nothing had happened except I was telling people I had HIV," Frankie said. "Never once in those two years did it hit me that I've got something that's going to kill me."

Soon after learning that she was HIV-positive, Frankie was hospitalized and placed in an isolation room away from other patients, she said. Doctors would enter the room dressed like "astronauts" because, at that time, they didn't know enough about the virus.

Frankie said a doctor once wiped his hands on his pants after shaking her hands. Some people backed away because they were afraid of breathing the same air.

When Frankie told her husband, she expected him to ask her how she felt or what she was going through. "The first thing that came out of his mouth was: 'I'm not using any rubbers.' And those were his exact words," said Frankie. She divorced him.

She also quit her job as a life insurance correspondent. "The job was fine until I got the diagnosis, and then nothing about anything was fine."

Eventually, the shock wore off. But Frankie was diagnosed with AIDS in 1996, and the realization that she lives with AIDS has hit her several times over the years: when she was sick, when she was upset, when she saw 13 close friends die as a result of the disease during February 2004.

One of her closest friends, Vera Rodriguez, was the last to die that month. Feeling distraught and helpless, Frankie decided to get a tattoo in Vera's honor. As she stood in the tattoo parlor, Frankie experienced a "spiritual moment," she said. As if prompted by Vera herself, Frankie realized that her tattoo would not just be for Vera, but also in memory of all those infected with HIV. The tattoo on her right arm features an AIDS ribbon and reads, "Til we meet again."

The tattoo gave Frankie some solace, but she continued to slide, reaching her lowest point in the middle of the night on May 20, 2004--when she tried to commit suicide by taking hundreds of tranquilizer pills with some tomato juice. "I was surrounded by nothing but death," said Frankie. "I knew what happened to them would happen to me, and I wanted to get it over with."

Frankie was living in an apartment at a Chicago House independent living facility in the Uptown neighborhood. Chicago House is a 20-year-old agency serving people with HIV and AIDS.

After taking the pills, she left her apartment to attend a meeting in the building. It was there that a therapist intern on duty that night noticed something was wrong and followed Frankie upstairs as she

returned to her apartment. "I told him it was too late," Frankie recalled. "There was nothing anybody could do about it."

The therapist intern managed to push the button on Frankie's emergency necklace to alert paramedics.

After she was released from the hospital, Frankie returned to her apartment in Uptown. She makes ends meet through social security disability and supplemental security income.

Living with AIDS is a constant struggle.

For nearly three months during the winter, Frankie endured strep throat, the flu and bronchial pneumonia--common infections for those living with AIDS.

Her treatment has included an extensive list of medications that often came with side effects like vomiting, intense gas pains, diarrhea and headaches.

Through the years, Frankie has spoken about the disease with others who have HIV or AIDS, as well as at church congregations and AIDS support agencies. She has also talked with those who do not have HIV or AIDS about the importance of getting tested.

"The very idea that you are helping, that you are contributing to the cause, ... makes you feel like you are serving a purpose for the cause ... even if you die doing it," Frankie said. "You take these women that are hiding and isolating and bring them into the fold. That's how I made myself stay alive--by helping others."

Ida W. Byther-Smith thought it was a mistake when she was first told she was HIV-positive. It would take three positive tests before she would believe it.

Ida had never worried about HIV. She was married and faithful to her husband. "It was like someone had slapped me," said Ida, 55. "I got a second opinion. After the third, that's when it came home. My knees were weak."

Ida thought you had to be a white, gay man or a drug user to get HIV. But she soon realized she was wrong. "You just have to live to be at risk," she said.

When Ida returned home after her third test in March 1992, she received a phone call that changed her perspective. At the time, Ida didn't feel like talking with anyone, but she answered the call anyway. To her surprise, the man on the other end of the line told her he knew why she was upset. He told her he knew that she was HIV-positive. "He said, 'I told your husband I had it, and he said it didn't matter,'" Ida said. "'It didn't matter.' ... 'Didn't matter.' ... 'Didn't matter' kept repeating itself in my head."

Ida realized her husband had slept with the man. And he was not just any man--he was her daughter's godfather.

Her life was shattered. Ida fell into a depression and was consumed by anger. "Before I found out, everyone said I was so lively. Once I found out, I would cry and cry until my eyes were swollen and I had to put ice packs on them," Ida said. "I had so much animosity and hatred because I felt like I was cheated."

Not knowing a lot about HIV, Ida was very careful with her 3-year-old daughter. She didn't want to touch her face. She wouldn't even kiss her. "I thought HIV would get on her," Ida said.

She also faced fear and confusion when she shared the news with others. Ida overheard a co-worker saying that all people with HIV should be put to death: "They should just put them all in a room and gas them like Hitler did." Parishioners at her church avoided her. Some didn't want to touch objects she had held. And they blamed her for her condition. "People told me that the choices I made got me here," Ida said. "What choices? All I did was get married."

Having HIV was a badge of shame. "You were less than human.... You were dirty," Ida said. "I felt like washing myself in bleach."

Ida even felt ostracized by others with HIV because she hadn't been infected with the virus through drug use as many others had. At a support group meeting, she was told she didn't fit in. Ida felt completely isolated. No matter where she turned, she faced rejection.

In 2000, Ida was diagnosed with AIDS. Meanwhile, she lost her mother, Josephine, and her brother, Ray Paul, to massive heart attacks.

Ida hit bottom. She felt like she had no other choice but to fight back. "My choice was to speak out," she said.

Fighting the stigma associated with HIV has absorbed her time, her emotions and her savings. Ida has been honored for her advocacy work and coauthored the book "A Woman's Story Overcoming the Shame of HIV and AIDS." This year, she opened Jo-Ray House Inc., a transitional home at 23 W. 115th St. in Roseland, to help men with HIV/AIDS. She dedicated the home to the memory of her mother and brother. The home has eight beds, with one already occupied.

Ida spends most of her days on the phone trying to convince others to provide financial support for the home. It's been a constant struggle--and a constant weight on her mind. "I don't have anything because it's all in this," she said

But Ida's greatest fear is that some day she might not qualify for help with her AIDS medications--which cost nearly \$1,000 every month. Right now those costs are covered by AIDS Drug Assistance Programs, a nationwide coalition of organizations and health care programs providing HIV-related prescription drugs to the underinsured and uninsured. Ida fears that one day someone else might be sicker and need the help more.

Her dream with the Jo-Ray House is to provide a haven so that others with HIV won't have to worry. "I don't want this to be an AIDS house," said Ida. "I want this to be a place where people can be comfortable."

Tamara L. Wilson was raped in June 1999. While hospitalized, Tamara tested negative for HIV. But she took a second test and, was told to return in a few weeks for the results. She never did. "I didn't think that I would be positive," said Tamara, 36.

The Chicago Department of Public Health sent a woman to Tamara's home. After showing her identification, the woman asked Tamara to sit down. She told Tamara that her HIV test was positive. "I punched her in the face," Tamara said. "I just thought it was a cruel joke, but it was the truth."

Tamara struggled to come to terms with her diagnosis. For two months, she didn't comb her hair or take a bath. She only left home to get food or money from her grandmother, who lived down the street. "Oh, God, my days were ... so depressing," said Tamara. "There was so much darkness."

She turned to crack cocaine and got high everyday. It helped her forget, but the comfort never lasted for long. "It was like a one-minute escape," Tamara said. "When it was over, reality was still there. It was always there.... I'm still HIV-positive."

Feeling ashamed, Tamara waited weeks before she told her grandmother about her disease. Tamara said her grandmother had raised her because her mother suffered from drug addiction and mental illness. "I was scared about being sick and being alone," Tamara said. "But I thought she would consider me being dirty and nasty."

But things began to change when Tamara learned that her mother was also HIV-positive. Relatives had never told her.

The day she found out, Tamara stared at her mother as she lay in bed. "That actually changed me. That made me realize that I'm not gonna be a victim of HIV," Tamara said. "I'm gonna get through my drug addiction. I am gonna go to the doctor. I'm gonna do what I have to do to live."

For the next three years, Tamara fought to rid herself of her drug addiction. By 2002, she was clean. Her sobriety lasted for nearly two years until the day she walked in on her boyfriend in bed with another man. "When I walked in, I walked out," said Tamara. "I got sick and threw up. I was physically and mentally sick. But, because I liked him, I accepted it, and drugs helped me accept it."

Tamara had long suspected that it was her boyfriend who had infected her. She said he wasn't shocked by her diagnosis and wanted to have sex the same day she found out. "I had unprotected sex with him the same day because of denial," Tamara said. "I was numb. I think that was his way of showing me everything was gonna be okay."

Months would go by before Tamara again realized that she could not escape by using drugs. She ended the relationship with her boyfriend and did stints in drug recovery and a residential home for people with HIV. She has now been clean for nearly a year.

She has also started to build a relationship with her mother, with whom she had never really been close. The two of them now talk everyday and meet once a month, along with other women in the family, for a "women's day," Tamara said. "We get together and go out ... basically to keep the family together."

Tamara now wants to help others, especially children, cope with the stress of living with HIV. She's training to be a case manager for the Ryan White program, a federal program providing health care and counseling services for those with HIV and AIDS.

"We are here to show them that they can live and that they don't have to give up because they are HIV-positive," said Tamara, who lives in Rogers Park and earns a living through speaking engagements. "Just being able to help at least one person gives me peace."

Lindsay Edmonds is an Evanston-based freelance writer and former intern of the AIDS Foundation of Chicago. Contributing: Miriam Cintron.