Wonder Women

Women are uniquely vulnerable to HIV. Lack of self-esteem, few resources, gender power imbalances, legal and political limitations, societal misperceptions and even basic biology have contributed to the fact that HIV/AIDS is now the No. 1 cause of disease and death among women ages 15 to 44 worldwide. But many women are not taking the assault lying down. On the next pages we feature first-person accounts of seven amazing women who told POZ about how they not only overcome HIV every day, but also help their sisters along the way.

March 1, 2010 By Laura Whitehorn

Women and HIV. Once upon a time, those two words were seldom found in a sentence together. In the early 1990s, the AIDS activist group ACT UP made a T-shirt that read: “Say It: Women Get AIDS” because so few people beyond the HIV community knew that women could get HIV. Over time, things have changed dramatically, and in November 2009, the World Health Organization (WHO) announced that HIV/AIDS is now the leading cause of disease and death among women of childbearing age (15 to 44) worldwide. (That’s been true in the United States since 1995 for African-American women between the ages of 25 and 44.) Yet despite these staggering statistics, much of the world still misperceives HIV as a disease that only happens to men. And this misperception—along with a variety of other social, biological, psychological, political and economic factors—contributes to the raging spread of HIV among women and girls.

Women are especially vulnerable to contracting HIV for the many reasons you will hear about on the following pages, in the stories of seven remarkable women living with HIV around the United States. The particulars of women’s heightened risk include the specifics of female biology; high rates of sexual abuse and gender-based violence; battles for self-esteem and respect; women’s need to be accepted by sexual partners; a chronic lack of resources and income; and homophobia, which can drive lesbians to unsafe and unhealthy practices. The cycle is vicious: Without access to the same opportunities and rights as men, women may end up in situations where they need to be subordinate to men in order to provide for their own survival (or that of their children). This fundamental power imbalance too often puts even the strongest and most self-directed women in positions that lead them to compromise themselves. In such cases, women sometimes take risks or engage in practices they know will endanger their health, putting themselves in harm’s way because that is what is necessary for them and their families to survive. There is bitter irony in the notion that many women contract a deadly disease while they are struggling to stay alive.

What was most interesting to us when conducting these interviews, which we edited as first-person narratives, was how a woman’s self-sacrifice—an arguably admirable quality—can make her especially vulnerable to contracting HIV, and even keep her from caring for her health once

she tests positive. And what was equally compelling was the notion that, when women contract HIV and find the courage to face fighting the disease, they often fight not only for their own lives, but also for those of the people around them. Over the years, *POZ* has found that positive women don't move from a place of vulnerability to one of empowerment alone—they take other women with them. As we interviewed these seven women, one refrain resounded: "Now that I know what I know, I will share it with my sisters." As usual, when greeted with a mess, women get to work taking care of those they love—together. And their combined tales, recounted on the following pages, prove that nothing, not even HIV/AIDS, has the power to keep a good woman down when she sets her mind to survive—and to fight.

Vicki Derdivanis, 75 Retired Oakland, California HIV diagnosis: 1991
In 1991, my daughter had been married and my husband and I were ready to slow down and live the good life. But my husband kept getting the flu. Finally, after many months and many doctors, he was diagnosed with AIDS and I was absolutely knocked off my pins. So I got tested too.

My husband was very sick by this time, and when the doctor came into his hospital room and told me I had tested positive, I was stunned. I was perfectly healthy. I began right away taking care of my husband. I had my hands full. He was on oxygen and all kinds of medications, though HIV meds were not yet available. His will kept him going. Then, 26 months later, he died.

After the memorial service, after all the relatives left, I sat down and came apart. Then I became angry and finally let loose my emotions. Once, I stood in the kitchen with a plate in my hand and felt I wanted to throw it through the window. But then I thought, "It's a new dish, and a glazier to replace the window would be expensive." Where was I going? I had no idea. I withdrew and went into near seclusion. He died in September, and it wasn't until about mid-December that I realized I needed some consolation.

I began going to daily Mass. I had an epiphany, feeling God just pouring into my life. I felt that it had been such a dirty trick that I got HIV, now God was saying, "I'll do a little something extra for you."

In HIV support groups, I have often found that people say there is something greater in their lives now, something new [since getting HIV]. Sometimes it's God, other times it's just "something greater."

AIDS has spread so rapidly through Africa because the wives have relations with their husbands, while the husbands have a little something on the side. We women are so vulnerable to HIV because we still have no equality. If a woman gave her husband HIV, there would be hell to pay. But the other way, it's "boys will be boys." I'm resentful of that—for myself and for all the other women who have become positive because of some guy, some jerk. Once when I was speaking, a girl told me, "Sometime in the future, I'm going to get married. How can I trust my husband?" I couldn't answer. The logical answer is you wouldn't marry someone who was untrustworthy. But in real life, it's a stinker.

The other problem is that we are the caregivers. We want to take care of the whole world. I spent the first two years of my life with HIV taking care of my husband. I was busy with his care day and night. I became his private nurse—and that is something I had never wanted to be. I once said to the priest, “I have chosen to take care of him,” and the priest said, “But of course you have!” It’s not “of course,” I thought. And now I have begun to take care of myself.

I had been in my husband’s shadow for 37 years of marriage. I did eventually gain my own power, though. When he became ill, I had to take over our business, then all the medical and legal details of our lives. So after he died, I was ready to go to work. Once I reemerged from my seclusion, Catholic Charities asked me to do some speaking to students and other groups. I was in my 60s, my hair had started to turn white. I would walk into a classroom, and no one knew exactly why I was there until I began telling my story. It was wonderful to see the expressions on the kids’ faces as it began to dawn on them that anyone can get this disease.

Linda Scruggs, 39 AIDS educator Baltimore HIV diagnosis: 1990
When I got my HIV diagnosis, I was surprised. I was 13 weeks pregnant. I have never used intravenous drugs. I didn’t realize the drug I did use, cocaine, put me at risk because I was trading sex for coke.

I had been a victim of incest at an early age. By the time I was 18, I had been raped twice and didn’t even tell anyone. I took on the blame as if I had put myself in the situation.

Life was ugly. I felt no value in myself. Instead, I turned to drugs to fill me up and got into relationships with abusive men. Then one morning I thought about my grandfather, who had really loved me. He had died when I was 10. But I felt him speaking to me, saying, “What are you doing? Get out of that bed,” and I did. I walked 14 miles to get home, and with my parents’ help I stopped using.

When I tested positive, I had been in recovery for two years. In my first post-recovery relationship, I got pregnant. At a prenatal appointment they told me I was HIV positive. They said I could terminate the pregnancy and probably live for five years, that if I had the baby I’d probably be dead in three.

I decided to have the baby. My son is 19 now, and he is negative.

Between him being born and me trying to figure out how to die, I figured out instead how to live. A friend’s sister was dying of an AIDS-related illness, and I watched her family being ashamed. What a legacy to leave your kids! And I decided that was not OK.

In my HIV clinic there was a beautiful 7-year-old who couldn’t go to school because her mom was afraid of what the school would say about her HIV. That didn’t make any sense, so I started working with kids, going with the clinic’s nurse practitioner to schools to talk about HIV.

Women are vulnerable to HIV because we compromise. We turn ourselves into Barbie dolls trying

to find that Ken. We search for that artificial something that will fulfill us.

When that friend's sister died, I thought, "If I have just three years to live, I want them to be my best." So I began to be honest with myself and others, telling people about my HIV. I lost some friends. But every time I tell somebody, I feel a key turning in the shackles. I had some pretty heavy secrets for a little girl, and HIV became one more. I have to be free.

HIV has brought on a new sisterhood. With HIV, it doesn't matter your height, race, education—none of it matters. What women want is to heal, be whole, find their path on life's journey. If it had to be HIV to get me to the place I am now, where I'm whole, then I'm grateful.

I tell young women, "If the word 'I' or 'me' isn't in the reasons why you do something, don't do it. You are valuable."

The government won't combat stigma for us. It's a battle we have to fight. And you can live rejoicefully and be healthy. In the midst of taking care of the rest of the world, we have to learn to take care of us.

Lisa Corso, 45 makeup consultant for Clinique New York City HIV diagnosis: 1988
I was diagnosed back in 1988, a few months after my son was born. I was having stomach problems. At the hospital they asked me if I wanted an HIV test, so I said why not. When the doctors phoned me to say that I was positive, I wasn't really angry. I have von Willebrand's disease, a type of hemophilia. I had to get blood transfusions my whole life in order to survive. But it did make me bitter sometimes knowing that over 10,000 people with hemophilia contracted HIV [before blood products were screened].

I had my children tested—my newborn son and my daughter who was already 2 years old. Luckily both were negative. It helped that I didn't breast-feed and I had them both by caesarian section.

I told my husband right away, of course, and he tested negative, which was great. But I left him a year later. Now, having relationships is difficult, I've learned. I mean, what am I suppose to do, put a sign on my head that says, "I have AIDS"? It's horrible—they can love everything about you, but when you mention HIV/AIDS, they're like, "Oh this girl has got the cooties." I try to move on from that because I can't think every man is going to be that way. As a single parent, there is no way to go but forward, leaping over every obstacle you hit.

I've been a single parent for 20 years. All I wanted to do is provide for my children and be able to afford a roof over our heads and survive—that's really the frustrating part, sometimes not being able to get the help I need. I work, so sometimes I'm told I make too much money to get help. That makes me more angry than having HIV itself. But I have children who are so supportive, and my sisters. My kids' friends are an enormous support too. They don't "Eek!" me, but the men I get involved with sometimes do.

There was a time when I was afraid of death. I thought I wouldn't live to see my children graduate

from high school. But it's all in the head. Living with HIV/AIDS, your mind is the biggest tool—being able to focus and say to yourself, "I'm going to live." Growing up, I had a mom who was physically abusive and an alcoholic. If I could live through that, I knew I could survive anything.

I have played Russian roulette—not taking my meds because everything else was more important: getting the kids to where they had to be. My doctor said, "You don't have to come in here if you're not taking care of yourself." I just cringed. Now I line up my meds and gladly take them, because I love life.

It's scary to know HIV/AIDS is the leading cause of death for so many women around the world. Women are at high risk because of the choices they make. I know women who still have sex without protection to please a guy because they fear they'll be rejected.

I would love positive women to come out more, no matter how they got HIV. I want to open my arms and give them a hug, let them know it's going to be OK because we're all going through the same things in different ways. For women who don't know, I say, "Get tested. Start now, because you are the future."

I want to be an example for people to put a face on this disease—so they can say, "Look at this girl! She's out there."

Aracelis Quinones, 45 HIV educator New York City HIV diagnosis: 1987
I found out I had HIV when I was nine months pregnant, but not because anyone offered me prenatal testing. I had come to the U.S. in 1986, already pregnant with my younger son. One night I called my mother in Puerto Rico, and she said some people we knew were dying of "that thing." Because I was pregnant she said I should get tested, so I did. We didn't even really know yet how you get HIV. But now when people ask how I contracted HIV, I say it's not important. By now, everybody knows how you get HIV. The real question is why positive people are afraid to say they have it. How can we women living with HIV empower others to come out?

Testing positive was a bad experience. They told me I had a year to live, and they didn't give me any information. I was really depressed, and it took me a couple of years of crying before I started looking out for places to help me connect with support. I told my mother and the rest of my family in Puerto Rico right away, and then my son was born negative—thank God!

I never stopped going to the doctor, and at the clinic I read magazines on HIV. That told me there were a lot of women like me and I wasn't alone. So I decided I needed a network, a purpose. I started going to support groups, meeting other people in my same situation. And I went back to school and started working in the HIV field. I became a group coordinator for support for other people with HIV. I became an advocate because I saw there were too many women getting infected with HIV.

I think Latina women are at high risk for HIV because of our culture. We never tell men to use protection. Then there's machismo. The men ask, "Why do you want me to use a condom?" and

they think you are being unfaithful. I know women who have gotten beaten because they asked a man to use a condom. And if a woman carries a condom in her purse, then she's a prostitute!

Latinas also have some barriers—not only language barriers. Some programs don't offer things we need, like babysitting. And people think that because we all speak Spanish we are all the same. But we have different cultures. For example, in a group I run, the Mexican women are more shy, they don't open up. Puerto Ricans are more talkative, more active. And Colombians make a group among themselves, they don't want to talk to others. We are all called Latinas, but we are from different cultures.

One thing we women all do, though, is take care of everybody first and ourselves last. My mother, my father, my dog—everybody before myself. We forget to love ourselves, and we take care of too many things. And a lot of women think we can't survive if we don't have somebody by our side. That leads some women into bad relationships, because it's difficult to deal with loneliness.

The other day, I was telling one of my girls, "If you don't want to disclose you have HIV, then you keep the stigma going because you make it seem it's something to be ashamed of." More women have to be open about being positive. Tell the world, "I'm HIV positive, and I'm alive and well." I need to let other people know. I am full of life and can do anything.

Pam Goodrich, 56 LGBT education and training coordinator Staten Island, NY HIV diagnosis: 1989

When I got my HIV diagnosis, I wasn't surprised. I kind of expected it. I had been using drugs since I was about 12 or 13—smoking weed, drinking and then taking acid and using heroin. Everybody I was using IV drugs with was falling to AIDS. But that didn't stop me from sharing needles with them. I was caught in the grips of drug addiction so it didn't matter. I was running amok in Harlem where they had $2 bags of dope. I was in shooting galleries where you shared syringes out of a dirty jar of blood mixed with water.

I had been going to jail since I was 16, and it might sound crazy, but when I was incarcerated, I felt like I had arrived. My substance abuse had been a coping mechanism, reacting to a dysfunctional family—not wanting to be home, having two parents who were alcoholics, coping with all the volatile behavior. My mother is 76. She has stopped drinking for 25 years, and all my siblings had substance abuse problems.

In 1989 I finally decided to take a look at what was going on with me, and I got tested and realized I had contracted HIV. I decided to get tested because I was just tired—really, really tired of my life. I had 58 arrests and 28 convictions. I was just sick of me, and I wanted a better life. I was tired of where I was going.

But after I tested positive, I still continued to get high. I realized I had a problem, but I continued to rationalize the most insane thinking—telling myself, "It's not that bad." And I kept going to prison. It wasn't until the last time I got out of prison, in 1996, that I stopped using drugs and found organizations that would help me. I got out of my way and gave myself a chance and sat still. I

made sure to be around people like myself, with substance abuse histories, incarceration histories—people who guided me and mentored me. They could call me on my stuff. Then I started mentoring others too.

The first time I disclosed my HIV status was when I was a peer educator. As a peer educator, it's not a requirement that you disclose your status, but one day I met a very young individual who had contracted HIV. I was trying to comfort him, to give him hope and inspiration. I was trying to let him know how vulnerable everybody is.

Until eight years ago, I was very against HIV meds. I wouldn't take them, and I progressed to AIDS. And I talked bad about the meds. I had friends who were taking the meds, and I'd say, "Why are you doing that?" I ran on about the drama of AZT—how in the old days people were given too high doses and the side effects were awful. And every time my doctor would talk to me about taking HIV meds, I wasn't open to it. So she stopped talking to me about it until I had no other alternative. When my CD4 count was 20 and my viral load was really high, she said, "Pam, I can't help you if you don't want the help." And I realized I wanted to live. I know HIV is very toxic. The medication is toxic too, but it has to be a checkmate. Self-preservation came up, and I clung to it. So now my viral load is undetectable, and my CD4 count is 757.

Women are vulnerable to HIV because they've always taken care of everybody but themselves. They are unable at times to see that they're very important too. We put ourselves at risk because we need to feel wanted, needed and loved. And some single mothers are running two households—their own and another one for a loved one who is incarcerated. I'm not saying your children are not important. I'm not saying your parents, your family, your community are not important. But none of that is going to make a difference if you don't have you.

Tracey Dannemiller, 49 AIDS educator Lakeland, FL HIV diagnosis: 1985
When I tested positive I went into denial. I thought, "If I get sick, I'll know why. But if not, they must have made a mistake." I didn't want to believe it. I thought my life was over. I knew my husband had been diagnosed, but I was shocked and surprised, thinking, "Why me?"

Before I tested positive, I thought the stats were that one in a million people test positive. I envisioned a room to put 1 million people in, and I thought, "I'm going to be this person?" I stayed in denial for about eight years, until I finally came to grips with the fact that the children had to be tested. I had a second test performed in 1993 when my fourth child was born, and he is negative. But while I was pregnant with him, a doctor told me I needed to have an abortion because I was HIV positive. I have six children, and only one—she was born in 1989—has HIV.

Women are more vulnerable to HIV because we give our partners a chance to woo us, saying, "Oh, it's going to be OK, and I'm faithful." And women sometimes put ourselves at risk because we tend to be caretakers. We're caught up in taking care of children or partners, and we tend to let ourselves go. Honestly, at times that has been true for me. I have put myself on the back burner, even with being such an advocate. There have been times when, for whatever reason—taking care of the family—I'll say, "Okay, I'll let myself go and tend to a different need now." But the truth is

that if I'm not around, I'm not going to be able to care for my kids.

One thing that spurred me [from denial to activism] was seeing and feeling death all around us. It seemed like there were people dying, dying, dying. Then in 1999, I first disclosed publicly that I have HIV, at a university here in Florida. One of my doctors asked me if I'd speak at a World AIDS Day event. At first I was a little hesitant, and then I felt in my heart it was the right thing for me. I am driven by the fact that there is so much animosity out there, so much misinformation, so many myths circulating, so much stigma, fear and ignorance. When my daughter was younger, a soccer team forfeited a game because they didn't want their kids playing against her. So the voices of those of us who choose to be advocates need to be heard.

Another example of stigma: A family moved into our subdivision, our quote-unquote "typical" neighborhood. Anyone who moves into our neighborhood knows about "the AIDS family," which is OK with us. But two of our children were playing outside, and this gentleman came out with a gun and shooed them away from his house. So we talked to him. [To educate people,] we meet the people where they are, try to explain so they can understand. Fast forward: Today, we are friends. Another time, in 1996, we were kicked out of our church. They made me resign from teaching Sunday school and working with the children's choir.

I'm helping people along by speaking out through my nonprofit, Straight From the Heart of Florida. This is my purpose in life, aside from being a mother and wife. Speaking and sharing for me is very therapeutic. I have to do something to try to make a positive difference.

Ingrid Kloet, 61 Case manager Rio Rancho, NM HIV diagnosis: 1989
I was living in the Netherlands, where I was born. I was becoming tired and sick. I went to a doctor who said, "We need to do an HIV test." Some days later I got a message to call the doctor. An assistant told me that I had HIV, and I was shocked. I had been divorced, I was in a new five-year relationship. I never blamed him. My body was my responsibility, and I didn't use protection. When I told him, he said, "I can help you through the bad times." But I never saw him after that. He said, "I need to do some things," then he disappeared.

The first people I told were my kids, then my sister-in-law. Then I called my ex-husband. I felt horrible. I closed my curtains and was on my own. I didn't want anybody else around except my children.

During those months in the house, my eldest son came in and asked why I was crying. "I'm dying," I said. He said, "Mom, you're still alive. Keep your chin up. You're always tough and positive." So I thought he was right. I turned to the HIV Foundation in Amsterdam and met all newly diagnosed people. Gay and straight.

The first time I went to the foundation, I was scared. This was an unknown area for me. But coming into the building, what I experienced was that everyone was friendly—they took care of me because they had seen [other] people coming through that same door, scared. Right away we did a body project, doing some exercises, a warm-up. I felt so good. I remember there was just one

other woman there at that time. The rest were men.

I changed my life in a heartbeat. I had been an architect and interior designer. What I had liked best was doing upholstery. And then everything went away. I couldn’t handle it; it was too heavy for me. I changed from that to a volunteer. Now I am a case manager and an AIDS educator.

Then I went to the United States, and it was a different story. You couldn’t fill in paperwork if you had a communicable disease. Going back and forth to the Netherlands, I couldn’t carry HIV medications. A wonderful doctor in Santa Fe, Trevor Hawkins, helped me survive and supplied me with medication. Now I’ve lived in New Mexico for 10 years, and I’m married—to a man who is also positive.

When I was diagnosed I had AIDS. In Europe, if you begin with AIDS, then take medication and your viral load becomes undetectable, you no longer have AIDS, you’re HIV positive. But here in the U.S., once you have AIDS, you always have AIDS. I hear that here—“I have AIDS.” I ask, “How many CD4 cells do you have?” They say, “Oh, 700 or 800,” and I say, “You’re HIV positive!”

It’s very easy for women to contract HIV. I don’t think most women understand they are at risk. Especially older women, having a divorce or a deceased partner, then starting to date again. They are not thinking about HIV risk. And another thing: I often put other people’s health care needs above my own. We have to protect ourselves. If someone else isn’t doing it, you have to do it yourself. Everyone is responsible for their own body. Don’t be afraid and shut your eyes. The percentage of cases of women living with HIV has more than tripled in the past 20 years, and women of color are most affected. My advice to those who have never been tested is very simple: Know your status.

© 2026 Smart + Strong All Rights Reserved.
http://beta.docker.poz.com/article/wonder-women-hiv-18002-5953