

**PUBLISHER ABSTRACT** AB The role of the family within the AIDS pandemic, a disease with a pernicious social stigma, cannot be underestimated. A central question of life with HIV concerns how one will die—alone or with a family? People follow several routes: some go home to die with their birth families or with members of an extended family; others depend on anonymous health-care workers in a hospital or hospice; and others die by themselves. An unfortunately huge number are rejected by their families because, for reasons of ignorance and prejudice, they have a disease that families perceive to be somehow different from cancer or leukemia. Women have twice the burden of depending on a family, because they have not only their own lives to worry about, but those of their offspring. Although Maria did not have children, the problems she, like many people with HIV disease, encountered within family relationships became extraordinarily complex. After her engagement, Maria was told by her future sister-in-law that she could not marry into the family because of her health status. As the years with the disease passed, Maria learned what sort of people would and could be family for her. Maria grew up in Independence, Missouri. Her family had fled from Yugoslavia, where she was born, because of pressure from Tito. That was in the fifties; U.S. Government officials kept a close eye on them to make sure they were not perpetrating any sort of un-American activities, anything subversive. After earning a degree in acting from Brandeis, Maria moved to San Francisco in 1979 to follow her calling. She has sandy blond hair, vivid blue eyes, and a body losing strength. In her Bernal Heights house with wall-to-wall bookshelves and a vibrant garden, Maria observed that research efforts must begin to take into account that women have entirely different immune systems, different bodies from men. Although she accredits her HIV status to a 1982 blood transfusion, Maria never branded herself an "innocent victim" as Kimberly Bergalis did in blaming her dentist for her infection. This is her oral history.

In August of '82 I went to a beach party out at Drake's Bay with some of the people from the Renaissance Faire where I was working. After the party, my boss was driving and we had an accident. He was barely hurt but my face was completely smashed in and my foot was destroyed. I had to be taken to the emergency room at Novato Community Hospital where I was given two units of packed red blood cells, which is probably where I was infected. Not only did I, at that time, have to overcome massive contusions of the face, but they had to literally pull the bones because I looked like one of those cartoon characters that had a frying pan hit them in the face.

When I tested positive, I couldn't help but think back to that accident and the blood transfusion as the source of my infection. I had gone with a friend and I turned out to be the one who got the positive result. I got tested on another occasion and I again turned out positive. The guy I was seeing turned out negative on three separate occasions. Although there was a really good likelihood that I could have infected him, he was not infected. In fact, the few boyfriends that I talked to were all negative as well. It was a shocker to me. I said to him, "I know that we have been seeing each other for a while, and I have no idea how much time I have with this. If you'd like to get married, I'd like to get married." And so he said, "Yeah, sure, let's get married." We went back to New York, where his family's from, and met his family. They all seemed very nice towards me and very friendly. Then his sister shows me a reception hall where we were going to have the reception, and I'd met with the reverend, and we didn't seem to have any problems with the marriage, no questions, no nothing. Afterwards we walked across the street to this park and that's where his sister told me that the wedding was off. He was sitting there but he didn't have the courage to tell me himself. He had his sister tell me. I was obviously devastated but I was also very angry, and I swore to them at that time that I would survive this, just to prove them wrong. I would survive this. When we came back out here, he just packed up all of his things and left for Los Angeles without really talking to me about it. I asked him to please just not contact me again because it would be much easier for me to just have him gone like he has died or something. So I was then alone out here.

His sister definitely had a problem with AIDS. I think that she was afraid that I was going to be too much trouble for him and that I was using her little brother. She also was very devout and wanted to make sure his first marriage would be his last. I think that that may have figured into the thing. Why marry this girl if she's just going to die? You know?

For nine months, I was pretty much alone. I figured that I was just not going to meet anyone else; I was just going to live as best I could. Then, in the fall of '88, I started doing a show again. It was a Christmas show at Dickens Faire that was here at Pier 45 ½, in Fisherman's Wharf. Same folks, same producers, the Renaissance Faire folks. I was asked to do a comedy spoof of a Dickens story family. My son in the production was a very nice man named Mitch. For some reason he started to take an interest in me. At the time I thought, Well, that's all very well and good, but nothing's going to come of it, and that he's a very sweet man. He's a very good-looking man. As soon as he knows about my health, that's going to be the end of it. We would talk and go for coffee and things like that. Finally one night it got very, very romantic and I had to tell him. I said that I was HIV positive. That was the hardest thing in the world that I've ever had to do—the hardest. I literally could not bring myself to say it, in a lot of ways. Finally I got it out and he said, "Well, couldn't we use condoms?" (Laughs.) I realized, Yes, yes we could. And he moved in with me two months later. We married two years ago, on Valentine's Day. We married down at City Hall, because we couldn't afford, really, anything, but we knew we wanted to get married. It was very charming; it really was. He's been with me, supporting me and doing partners studies with me. He is why I am alive, in many ways, he and my family. I know that there are a lot of people out there who don't get that kind of support; they, generally speaking, in fact get abandoned by their family and friends.

At first my mother was so shocked, she said, "Yah, why did you ever go to San Francisco?" She's German, obviously. She was angry that I'd gone because maybe I wouldn't be infected if I'd stayed back in Missouri away from all the crazies in San Francisco. But once she began to realize exactly what was going on, that this was my health and I had to fight it, she has become the best coach a person can have. She has written to Germany; she has called numerous places; she has spoken to numerous people for information. She is always on the lookout for anything that might help me. And I can't think of very many people whose parents are doing that for them. Even if they love them, it's not this general who's taking charge like she is. But then, during WWII she and her family were forced out of their home by the Russians, and she had to care for her mother, her father, and her sister, all of whom died. She took care of her mother and sister, who both had different types of TB. She slept with them, and she cared for them, and she never got it because she is that strong willed, I think. She is just absolutely the strongest person I ever knew, so that helped.

Obviously, Mitch has helped. Mitch has been more than just a husband; he has been a great deal of strength for me. Even my brother and my sister, who are far away, have been very, very positive. In '87, when I knew about my HIV status, and there was a lot that was not understood about HIV and AIDS, my sister had just had her baby and she had no qualms at all about having me hold it. At that time, virtually anyone else might have. Virtually anyone else might have said, "I'm sorry, but that's too risky." That's what the times were like back then. I always admired my sister; she's always been very, very supportive and very, very scared for me. But I think she's beginning to realize just what a tough cuss I am. And my brother was very worried about me when he saw me at ninety-nine pounds. He was terrified because I did drop down to a very low weight. He was shocked by it. I think he's gone through a lot of relearning of what AIDS is like. And I think he understands a great deal more about it than he ever would have. He's in Dallas; he's very conservative; it's just amazing how much he's grown over it. Then I've got friends. And it's funny because I used to know all these actors, all these performers—I never hear

from them. I really never do. It's that rare occasion when one or two of them may call and say, "Hi." But all of my friends who are gay have all stuck around me, have all helped me get fed when I couldn't get out on my own. I just have a bunch of big brothers. They have all been so really good to me. And if I didn't have them I don't know, I don't know where I'd be.

#### **A WOMAN'S POINT OF VIEW**

The point of view of a woman? I guess the best way to organize it would be, let's talk about T-cells. Men and women have differing T-cells. I've been told many times that they don't differ by very much, but that is not true. They do differ, by significant numbers. In 1987, I had 294 T-cells. By, I think, 1989 or so, I was down to below 200. So technically, technically then, I had AIDS. But that definition did not exist yet. I had two T-cells last year, and I have seven right now. Obviously there is something more involved than just T-cells. A lot of people with sarcoma have T-cells of up to 700 yet they've got the lesions all over their face. With women, because you can have a lower T-cell count and that there is something else at play, the medical community doesn't recognize that.

If you're trying, as a woman, to get into social services, to get disability, to get anything, it's easier to get it now with the 200 T-cell definition; but it was not easy to get doctors to look at you and say that what you had might be related to HIV. For example, in '83 I had a case of genital warts. Because that happens to a lot of women, no one suspected that it might have been brought on by my being immunocompromised. Then I started to have pains and I was told I needed a cunal biopsy. I said, "Please, you've got to understand, I'm HIV, that this is going to be harder for me to heal from, and that needs to be taken into account." They did the cunal biopsy and I was in pain for three or four years because the skin layer had been basically scarred.

One of the things that they now are starting to realize about HIV is that it dries out your body. Your skin gets dry; the mucosa in your throat get dry. That's one of the reasons I'm always having to drink something. You start to dehydrate. (Drinks.) At that time they didn't know that, so I was going without medication for this painful vaginal condition. It wasn't until I started taking some antibiotics that I got relief. Up to that point the doctors were saying, "Oh, just lubricate it and you'll be fine." There's been a lot of patronizing, especially if you're a woman, and not only from the men but from the women, from nurses. I'm a fairly intelligent woman and I have tried my best to speak in the language of the doctors, of the medical community, and to get on a one-on-one with them and have them take me seriously.

#### **ALWAYS CRISIS MANAGEMENT**

There was no special consideration given to women's problems like cervical cancer, like cervical problems. They could happen outside of HIV but nobody began to suspect that they could be triggered by it. For years, nobody suggested that. That's why women could get really bad cases of AIDS and then finally get treated. Even though the doctors knew they were HIV, even though the doctors were seeing these gynecological problems, they still were not treating these women. They were always waiting for what I call crisis management. One of the biggest problems of HIV and AIDS, particularly among women, is that doctors would not act on something until it was too far gone. The whole attitude of the medical community was, "You look okay. You're having normal things. You're asymptomatic." It wasn't until these women were coming down with TB or pneumonia, PCP or, in some cases, PID, which is Pelvic Inflammatory Disease, that they started looking at them and saying, "Hey, maybe we should be looking at these women sooner, and checking for these sorts of symptoms." In my case, it's gotten to the point of being bacterial infection. I was allowed to go for years. In one case, certainly with the afregilis that I have in my lungs, for a long enough time for it to show up as a cloud on my lungs. I have low cholesterol, for example, and because everyone thinks that low cholesterol is this wonderful situation no one bothers with it. Yet there is a reason why I've got low cholesterol no one is looking into it, no one. Again, because it's not a crisis. Only if I got into a crisis situation with it would anyone bother to look. Those are clues, those are very important clues.

The doctors just do not respond well to finding an answer and then treating it. They guess at the symptoms. One of the major problems that has happened with AIDS is that the symptoms have not been defined. They are not understood in the context where they might be treated. I would like to see more therapy that would help me to rebuild my bone marrow, that would help me bring my white platelets up, that would help me bring up my lowered cholesterol.

The other problem is that women are expected to get the same illnesses as men. Sarcoma, for example, which was such an obvious condition and which had been diagnosed and thoroughly talked about, rarely happened in women. A lot of the illnesses like wasting syndrome were happening in men, but they, just as now has been discovered, do not really happen all that much in women. They were so eager to find Hairy Lucal Placea (the cottage-cheese effect in the back of the throat) in me but I wasn't really having it. I wasn't having it, but because it is a male symptom and because I had herpes, they expect me to have it. So it's been rough.

#### **WE'VE GOT TO STOP GUESSING**

Everyone is stuck in the past. It's the way that they've always done it, the way that they feel is the only way it should be done. And it's just as barbaric, it's just as tortured, it's as unnecessary as any of the so-called cures of the past. We shouldn't be looking for a drug answer; we shouldn't be looking for a vaccine answer. We should be looking at the human body and seeing how individual it is, how every individual has a different genetic make-up, how every individual has a different way of staying alive. We recognize distinctions in terms of ages with children and elderly people; their age is taken into consideration. But for some reason we still treat women as half men, and expect them to have the same dosages as men, the same results as men, the same reactions as men. It's just not happening. If the doctors and if the researchers could finally just come together and say, "We were wrong. We were wrong; let's try this route, let's try helping the body help itself." A lot of the alternative therapists are saying that, but what they are offering is just herbal remedies. There's nothing wrong with a herbal remedy; it'll certainly not give you side effects like a drug will. But by the same token, it's a guess too. We've got to stop guessing about what's going wrong with the body. We've got cars. We put gas in the tank because we know that if we put sugar or something else in the tank it'll destroy the car. But we're willing to put sugar in the tank in people. We're willing to really screw up the whole human system because we don't understand it. The immune system can provide answers that people have never dreamed of, until the doctors give up this notion of being pharmacists. Until the pharmaceutical companies can start looking towards therapy, we're just going to see more of the same.

There are several drug manufacturers who for years have been funding research into protease inhibitors. Now they're finding that these ideas about coming out with a drug, a magic bullet, are not working. So they're willing to give up on AIDS entirely and not do any more research because their idea of what the answer might be just didn't pan out. Rather than look at something else, and rather than promote other therapies, they're willing to just wash their hands of the whole thing. Recently I spoke to a research nurse who told me that they have had a protocol on their desks, for a year now, for using sibling blood, from either my brother or my sister, that matched my HLA count. HLA genes are where many many answers can be found for AIDS. Back in '89, they were first discovered as being the difference in why certain people lived and why certain people died from AIDS. Five years later, nothing has been done about that, nothing. Now they're starting to

propose these therapies suggesting that if we replenish the HLA gene from a sister or a brother into an AIDS patient that the patient might be able to benefit. And because it is a type of transfusion, there is no profit to be made from it. But there is no funding even to do this research project because there is no profit motive. There are situations like that where a simple answer can be tried, an answer that makes sense. But unless it makes money, it's not gonna be tried.

But to get from here to there it's gonna take a lot more people screaming at them, basically saying, "We don't care about these drug answers because these drugs are not answers. We want to see something that will actually help our bodies." Antibiotics do not help the body. For a while they'll destroy bacteria, but in no time at all the body becomes resistant to them. The combination therapies have killed so many people. All of these drugs have been given in combination that were never tested in combination that have side effects that were always blamed on HIV. I was taking at one point ten drugs--ten different drugs! But as long as I've stayed off drugs, I feel better. The problem is that doctors give drugs on an indefinite basis. They do not believe that you can survive AIDS if you go off the drugs. I believe--knock on wood--I'm proving them wrong. The dilemma arises: If I take the drugs and something happens to me and I die, then they will not see it as the problem of the drugs. They'll see it as my HIV status. If I don't take the drugs, they will say it's my HIV status that killed me. So, you're damned if you do, damned if you don't, in their eyes. They will never ever see the harm that those drugs have done. Never. That is really distressing.

I don't know if you're familiar with the bronchoscopy. In this procedure a tube is forced down your throat, into your lungs. The tube is about the size of a quarter. I almost gagged on it, and I could have suffocated on my own vomit from that. It's a procedure they do all the time; it was the worst procedure of my life. I would rather have anything else done to me than another bronchoscopy. Then there are things like needle syphoning, where they'll put a needle inside your ribs to syphon out bacteria. And they will give some lidocaine in the area. But still, did it have to get that far? Couldn't they have done other tests much earlier to determine if it was present? Then there are CT scans, where they have to scan your body; it's sort of like a glorified X-ray. Sometimes you have to lie still for a good hour or so. When you have AIDS, you obviously don't have the same mobility you had before. You're like an elderly lady or an elderly man, and that is a painful position. But because you're thirty-six or thirty-seven or whatever they assume this is okay and you're just complaining. Just recently I had my teeth cleaned and just the act of cleaning my teeth left my whole mouth full of ulcers. So for a week I couldn't really eat, and then I saw an ophthalmologist, and he completely dilated my eyes and then held them open and put this bright, bright light into them. And for a week after that I had strained eyes; I had to wear sunglasses for days. And I had to really keep cooling my eyes because it was so painful. The doctors have no idea of their effect on you or the effect of any of their treatments. They're just as barbaric as bleedings.

And the drugs they give you! To me it's such a joke that marijuana, which is one of the mildest herbal drugs there is, is being touted as some sort of addictive hallucinogen, when if I take something like sulfasalazine, I have complete retching. There's another antibiotic that left me entirely in a painful body rash. I couldn't go into the bathtub because the water would be too hot, but if I stood out of the heat I would be so cold because there was nothing holding the heat in my body. So I was at turns freezing and feeling burnt, you know, just like a bad burn. And then there's Septra: they give you the drug; if you have a nasty side effect they take you off it. And they usually give you a very high dosage so you get a very bad reaction. Did you ever see the movie *Death Becomes Her*? She's given this potion so that she'll be beautiful forever. And they tell her the side effects after she's drunk it. And she goes, "Now you tell me? Now?" (Laughs.)

And it's like that. They don't tell you the side effects before you take the drug. They don't tell you what to look for before you take the drug. And if you have side effects other than those that they expect from that drug, these side effects are not from that drug. They're not happening.

It's like this: If you take an antibiotic, the antibiotic will attack an illness. But your body gains a resistance to the antibiotic. There are also other side effects to the antibiotic. That's another great oxymoron, side effects. Like any effect of a drug is a side effect. (Laughs.) Just because a drug has a good effect doesn't mean that we should disregard a bad one. Treatment in my point of view is something that does not give you side effects; it should be something that nourishes your immune system. Treatment is something that does not make you sick. (Laughs.) I mean, really, it's something that makes you well. It shouldn't be my doctor managing the illness, it shouldn't be a pharmaceutical company managing my illness, it should be my body doing it. So to me, a treatment is exactly that, something that helps my body help itself. And that is just not being presented out there. More companies are still pursuing things like NAC and UCAP and various different odd drugs that are more harmful to the patient. I mean it's like the old adage, "the operation was a success but the patient died." That's really what's going on with a lot of the AIDS treatment.

#### **BEYOND WHY ME?**

A lot of women are still stuck in the "Why me?" stage. The women I've talked to are either depressed about their health and not ready to do anything about it, either medically or politically, or are so involved in the political side that they don't see that the answers are in immunology. They think that if we just push this senator enough or if we push the FDA enough, they'll come up with an answer. But nobody, nobody, has really sat down and said, "We need gene therapy. We need to make these bodies healthy again." I feel very much alone around a lot of the women with HIV. I think a lot of them are so damned sure they're going to die, and I'm not, I'm not so sure. Most of the letters to *WORLD* are all about poor pitiful me. I know that needs to be said by women who do feel alone, and I know that an important step towards counseling is getting a grasp of the situation. But after seven years of reading nothing but poor pitiful me from a lot of the women, I just really want to say, "Well, wake up honey, smell the coffee; let's get together and let's do these clinical trials and let's force our opinion on these doctors; let's force our opinions on these nurses; let's push them and then they'll push other agencies," and so it goes. It's just not happening. I mean the AIDS Coalition established by gay men is so much stronger. But then again, men generally have larger salaries; men generally have a lot more support; they don't have children. They also have been brought up to fight back and women have not. In fact, most women have been brought up to be obedient.

There was a time when I was driving a car, probably back still in '87, and for no particular reason, I started to cry. It really was like an unexpected thundershower, just buckets and buckets of tears. I was thinking to myself, "Why am I crying? Why am I?" I knew that I had this illness and this illness was depression. I'd always thought that depression was something that is not physical, but I found it is very physical. I also realized that my body needed that depression, but at the same time, it shouldn't go on and on and on. That made me aware of the fact that there is going to be an awful lot that I've got to deal with with my health, not just physical illness--to me it's mental, emotional, spiritual, and physical. Actually, physical is like one of the last things that you have to treat. Mental stability is very important, because you cannot live without mental stability. Emotional stability, you can't live without that. And the spiritual, determining for yourself who God is, or what God is.

I have a theory that you are a composite of all your ancestors, that they are still within you. When I was in the hospital in '90, my fevers were 104, going up to 105 sometimes, a little higher, and then I'd go through these racking body chills where you could put a million blankets on me and I'd still be freezing. I just got so tired of it that one night I called on all my ancestors and I said, "Please, come to me now." I called on my family; I called on everyone. I said, "If you can hear me, please help me now." I went back as many generations as I possibly could, to ask them to please help me now. Next day, I was just fine. I was relaxed. I was calm. I was healthy. I was ready to get the hell out of there. The doctor was taken aback; he thought, Maybe she'll have a relapse or something. And I didn't. I learned that that is there, that is the strength that is available to me.

Recently I had had a catheter put in. I had asked them, Were they going to put in a catheter? and they said No, that it's just like an IV line. Well it was a catheter, and I was sitting there and I was angry and I was crying because they'd lied to me, they'd patronized me, they'd lied to me. Yet I knew that I needed to have this procedure done. I was lying there and they were starting the procedure, starting to put the catheter in. I had my head tipped away and could feel that the room was filling up with people. It was not even on my mind but I could feel these throngs of people there in the room and all of a sudden I had the strength to bear through this. I think that's a very important part of it. I think that Native Americans knew this, that the strength of your ancestors is in you. And I think that a lot of that has been lost in modern medicine, has been thrown out as too primitive. An important part of healing is where you find your strength, where you find that. I don't really see God as God. I see nature as a strong force in my life; I see History as a very strong force in my life; I'll talk to whatever I think God is, but I really find more that I feel like I'm talking to my ancestors.

#### **ADVICE...**

Well, usually my advice to all women is to keep on fighting. The men do understand it--not the doctors, but the gay men I know who have HIV; they know. They know what they have to do. And they are aware. I talk to them all the time and we're basically in accord; we're in agreement. But for women I would say, "Don't give up." The biggest problem is that the women are just obediently dying. And they shouldn't be so damn obedient. Not only women with HIV. I ran into a woman who's having several disk operations. She was in a great deal of pain. We were both in the waiting room at an X-ray lab, and we started talking. I told her that she must keep fighting because there are answers coming down the way, very important answers. She mustn't think that everyone has given up on her, and she must remember to support herself on her family--make them support her. Even if they don't feel like supporting her, make them. Use them.

A lot of women will not use their families; they will not be in contact with them. They don't want to trouble their family with HIV or AIDS. And the family is helpless, they don't know what to do. Those women who have families, who have that support base and are not using it should be spanked. Get together with them, show them you love them, that's the most important thing, and they will show you they need you. And you need that support for your health. And she just brightened up like nobody's business, just hearing some stranger say, "It's okay. Your family comes first." I think that's very important to remember.

#### **THE WOMEN'S HIV COMMUNITY**

It's hidden. And for many very, very good reasons. You won't find very many women who will break with confidentiality, but I have, because I know it's very important to research, to getting these women out of their cubicles, basically. It's important that they know that they're alone and that they're not helpless. Unfortunately, this world tends to tell women that they are. I think also they have to understand that they have to argue with their doctor about the dosages of their drugs. They have to really get in there and question everything. It's like the old Question Authority bumper sticker. That's exactly what it's going to be. The men did it in the '70s, but the women didn't. And that's part of what they have to realize now, and really awaken to, that it's their turn to question authority. And they won't get the support. The activism is more steady and more open now, but there are still a great many problems. Like most women still won't ask their partners to use condoms. You know? Something as simple as that, and something that might protect their lives. They just won't do it, because then all of a sudden the guy thinks that maybe she has it, and then it's this sort of game going: Well, if you don't have it and I don't have it then-- It's really a sad situation with women; and I think they do need to question authority, authority from men, authority from doctors, authority from everybody. And really speak out about it.

Well, right now, I really didn't realize this, but I am one of the few women who will talk about AIDS and talk about it in great detail. And not as... one of the TV-talk-show type of people. This is not something where I'm sitting here crying about my poor fate. I'm not. I'm also not sitting here saying "Government is really wrong," and, you know, "this is really wrong." I know what's wrong about this situation. There's a great deal of greed here; there is a great deal of resistance. I guess what I need to see is more changes. If I could change the minds of doctors--if I could change their minds, and get them to change the minds of pharmaceutical companies on what is the right way to treat a patient and what isn't. Right now, it's really a puppet-master situation. And if I could get out there and not only let women know that they can challenge the situation, but let everyone know, everyone with even any kind of illness know that they can challenge the situation, that is what I'd like to do. I'd like them to know that I don't intend to just sit here and die. And I think a lot of the artists, some well-meaning artists and producers, still think that people will just sit down and die. I'm just not going to be one of them. (Laughs.)

Added material

Postscript: After the interview, I asked Maria if she would be willing to have her picture taken for the book. She said that would be fine. So, a month later I called and left a couple of messages about setting up a time for the photo shoot and didn't hear back from her. One night at work, I picked up my messages and there was one from Mitch, Maria's husband: "Ben, I am sorry I didn't get back to you earlier. I don't know how to say this, and I hate to say this on the machine, but Maria died. She went home to visit her mother, got sick, and never came out of it."

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