Leading Ladies

Longtime HIV/AIDS advocates Dawn Averitt Bridge and Mary Fisher discuss why women are particularly vulnerable to the virus.

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Mary Fisher was a young mother of two children in 1991 when she found out she was HIV positive. With a stirring speech at the 1992 Republican National Convention, she launched a career in advocacy that continues through speeches, books and art (maryfisher.com). A member of the Presidential Advisory Council on HIV/AIDS (PACHA) in the first Bush administration, she founded the Mary Fisher CARE Fund, a nonprofit organization that supports HIV/AIDS clinical research and education. Now 62, Fisher recently completed a three-year term as a global ambassador of UNAIDS.

Today, Dawn Averitt Bridge is the mother of two young children. Since learning she was HIV positive in 1988 at age 19, she has become a prominent speaker, writer and advocate for women's health issues including HIV/AIDS. Averitt Bridge, 41, founded The Well Project (thewellproject.org), a nonprofit organization formed to improve the lives of women living with HIV/AIDS, and the Women's Research Initiative on HIV/AIDS (WRI), which aims to influence HIV/AIDS research to include more women and people of color.

For this *POZ* special issue focused on women, Fisher and Averitt Bridge discussed their experiences living with HIV for the past two decades, and implications for what may lie ahead. Their conversation began with a question posed by *POZ* editors: Why are women particularly vulnerable to HIV/AIDS?

Mary Fisher: "Why are women particularly vulnerable to HIV/AIDS?" Because there are men! [*Laughs*]

Dawn Averitt Bridge: I think one of the joys of being Mary, and me, at this stage of the game is candor! If we can't be candid about this, who can?

Fisher: Seriously, though: Women are vulnerable to HIV/AIDS because men don't understand the importance of being tested, because our partners don't listen to the health messages we are giving them or don't love us enough to use protection, because doctors don't press the message that patients are at risk for fear of offending them, and because women still don't know they're at risk.

Averitt Bridge: It seems like a question we've asked and answered so many times over the years. Women's vulnerability to HIV has to do with everything from what kinds of prevention modalities we have available and what kinds of treatment, to how people get tested and what kinds of awareness messages are working or not working. On some aspects of HIV/AIDS, we have made significant progress; on others, things have not changed at all or may even be worse.

Fisher: I'll tell you what I think has changed. We went through a period in the United States where we couldn't talk about HIV/AIDS. Then we began to talk about it more and began moving from "It's a gay disease" to "It's a disease of all of us." But the disease was taking such a toll—so many people died, so many activists were lost that there were no voices left. And women, who feel more vulnerable in the world anyway, have not replaced those voices; they have not spoken out for fear of losing their jobs, their insurance, their children.

Averitt Bridge: We are invisible in plain sight now. In 1988 when I was diagnosed, I didn't know another positive woman. At that point in time, it was like you dropped down this abandoned well shaft—but there you found an underground community, almost entirely a gay male community: buyers' clubs [to obtain HIV treatments], networks, support groups. None of them focused on women, and few really spoke to me in a way I needed to be spoken to, but they were there. And now when people are diagnosed, everybody is so desensitized to HIV/AIDS that people drop down that well shaft and they're down there by themselves.

Fisher: In 1991, my two preschoolers were playing near my phone when I learned I was HIV positive. At that point, everyone infected with AIDS was headed for the grave—we knew it, our families knew it. So I spent those early years preparing to die: I started journals for my sons to read when I was gone; I wrote and rewrote wills. The [new] antiretroviral drugs emerged around 1996, and for those of us lucky enough to have access to them, they brought the miracle of prolonged life. But that was also an extraordinarily difficult time: We had buried so many people we loved, we had come to grips with dying, but we were not prepared to live. So it took some time, but we came to grips with [our newfound] hope. And hope, to me, meant more work to be done. I realized that if I was going to live, I would need to seek purpose in my life and keep working to fulfill it. I think that's what you and I have done, and what so many women living positively continue to do. We keep raising the children, managing the home, pursuing the career, because we know we can't give in or give up until the work is done. But it can be terribly discouraging because while we've made progress in places like Asia, Eastern Europe and Africa, we have lost so much momentum in the United States. The number of people in America who are becoming infected, and the number of people who are dying for lack of treatment, continues to escalate, and too many people just look the other way. Too many people think AIDS has been cured. You tell them, "You could get HIV," and they laugh at you—or they just don't care.

Averitt Bridge: Mary, when you say people don't care, that's a really important challenge women have to face. I want to believe that people do care and want to help, they just don't know how. It sounds utopian, but believing that is how I keep going. I can't seem to make [some women] care when I'm talking about them. But I see them start caring when I start talking about anybody else they care about, especially their children. You'll see a woman who can't or won't make a peep for

herself when she's getting mistreated in any setting, whether it's the grocery story or the doctor's office or wherever—but watch her stand up for her kids. So when I'm on the road and people say, "I love what you're doing, but I'm not an activist like you," I always distill it down. I say, "If you go to the grocery checkout with a jar of pickles that's on sale for $1.39 and they try to charge you $2.50, do you just let them ring that up? No, you tell them it's on sale—because you're an advocate. You've been advocating for yourself and your family in ways you've never even realized. So you just need to take that and use it when you're asking for information and services around HIV/AIDS."

Fisher: That's a perfect thing to say to people—but if a woman had some other disease, would she really even have a problem standing up for herself about it? In this country, if you have heart disease or breast cancer, you have marathons and crusades launched to challenge your illness, and you are seen as worthy of support and care. But if you announce you have HIV or AIDS, you are seen as unworthy—you're a drain on public resources, you're a leper in society, you had it coming. And since women are more susceptible than men [to others' opinions] and [because they are] usually less powerful, women are hit especially hard by the stigma [of HIV/AIDS].

Averitt Bridge: I think it's critical to help people understand what the deal is with stigma. People will say to me, "It's 2010, everybody is willing to talk about HIV/AIDS, there's no stigma"—and I have to refrain from jumping across the table.

Fisher: There absolutely is stigma, [based on a] built-in judgment about you as a person for having gotten this disease. People still ask me how I got it! Some may be trying to say something about me, and some may just be curious. But I think many of them are trying to take themselves out of whatever risk group I was in, trying to make themselves feel like they don't have to worry.

Averitt Bridge: Fear fuels denial. When anyone asks you, "How did this happen to you?" that's a judgment-laced question. With a stigmatized disease, the vast majority of discussions you have about your disease are laced with judgment. And people don't even realize on a conscious level they're doing that or asking questions that way. But what they're really saying is, "Tell me how you're different from me; tell me why this isn't going to happen to me" so they can separate from you.

Fisher: [When] they can separate from you, [they feel they don't have to fear] the disease. In the last quarter century, we've built up this whole world of HIV/AIDS businesses, networks, media, organizations—but are they really reaching the people that need to be reached, for service and awareness? Maybe in New York City, but I can tell you, not in many other parts of the country. I've even had a hard time living in Sedona, [Arizona,] in terms of access to care. And I've felt a little ostracized myself. I've gotten denied visas when I've attempted to travel to China and to India.

Averitt Bridge: At some level, because of our advocacy work, you and I have a greater degree of access to doctors and decision makers, and may also have some influence. But at another level, we're just people who have to decide if we're going to lie about our status on a visa application and figure out how and where we will get our meds. I was going to Nepal to do important work and

didn't need a visa for transit through China if the stopover was less than 24 hours, but when it became clear it would be 36 hours, I called several lawyers and said, "What the hell do I do? I have a bagful of AIDS meds, and I'm about as public about my status as I can be." And one after another, the lawyers said to me, "Lie." And I really resented being put in that place. Those are the moments when you end up feeling incredibly small and dirty and frustrated. So when somebody says, "You've never experienced stigma, right?" I tell them about that. Or I tell them about what it's like to sprain your ankle hiking and go to a rural ER where the triage nurse sits 15 feet away from you and calls out across the room, "What medications are you on?"

Fisher: The difference is, in many cases when we are faced with stigma or discriminatory treatment, you and I will get up and walk out, or we'll object and refuse to take it, because we know what's happening. The truth, though, is that 99.9 percent of people who have this disease do not do that [because they] do not know they can do that. You want [people] to be strong, so they can fight wherever they have to fight. But so often [people] feel they do not have the strength or the options. It's not about being strident or militant. It's truly about saying that, if we have to have this disease, we still want to be like everyone else anyway. We want to be able to get our medications and raise our children, and we don't want to be treated like crap.

Averitt Bridge: And we don't want people to say, "I'm sorry, I didn't know you were sick." That sends me through the roof so fast.

Fisher: I have an even better one: "But you look so good!"

Averitt Bridge: Or, "I'd never know, you look really healthy!" [*Laughs*]

Fisher: Really, the stigma and the insensitivity are all a part of this larger ignorance about HIV/AIDS and this sense it's no longer an urgent, broad concern. If we assembled all the people living with HIV/AIDS in America, we would have a good-sized city, but still you will hear people say, "We have medications, so it's no longer a problem," or, "It's not something that could happen to me."

Averitt Bridge: We've done an enormous disservice in this country by portraying HIV as only happening to certain kinds of people: prostitutes, gay men, IV drug users or some category people can consider "the other." By fostering the perception that only certain kinds of people get HIV, we have created the problem we have on our hands right now. So much of the thinking about prevention and awareness is driven by this epidemiological model, looking at the patterns of disease, identifying the most affected communities and thinking that targeting them will get this under control. But to me that's half the job and a little shortsighted. We really don't know much about the AIDS epidemic in women in this country. There are plenty of women who will never be reached or identified through the targeted approach. First, we have to address the problems with the way CDC categorizes cases and identifies risk. The ways things are now, women fall through the cracks in a very big way. In addition, we must continue our efforts to change the way people think about HIV—the way everyone thinks about HIV. This is about doctors, care providers, policymakers and everyone else!

Fisher: Sometimes it upsets me. We really are the guinea pigs. No one truly knows the long-term effects of these medications on anyone, or the particular effects on women. "Just go on these drugs, and you'll be fine," they say—but we know that's not true. If bodies age more quickly because you have HIV and the medications don't really change that, then people like me may be 60-year-olds walking around in 80-year-old bodies—and nobody knows. We are the guinea pigs. We don't mind that on one level because we're still here. Somebody has to test these regimens and learn from the results. But let's pay attention, people. We don't want everybody to be in this guinea-pig mode forever.

Averitt Bridge: In these government panels where HIV/AIDS policy and guidelines are discussed, we need to be thinking proactively about what we will wish five years from now we had asked (or looked for) today. We are at an interesting point in the epidemic. In essence, in the beginning we didn't know much, then we made great advances and really learned a lot, and now we don't know what to expect because we've changed the natural progression of the disease so significantly with the treatments. It's a bit like being on the far side of the bell curve. This is a really important time for [women with HIV] to be involved in research and to push for the answers we want and need. This is one reason we created the Women's Research Initiative on HIV/AIDS. New advances are going to come from creative thinking and exploring outside the tracks NIH and WHO have formalized. There are interesting things on the horizon for women—but they won't happen without us making them happen.

Fisher: When I think about this, it feels like it did in the late 1980s—like a huge challenge I can't do a whole lot about. Sometimes it overwhelms me.

Averitt Bridge: Yes, I know, and so many people feel that. In 2008, Naina Khanna at WORLD (Women Organized to Respond to Life-Threatening Disease) spearheaded a new coalition of women living with HIV and our allies called the Positive Women's Network (womenhiv.org/positivewomen). In a little more than a year, more than 1,300 positive women and our allies have joined! PWN is making it possible for women who say, "I don't want to be on the national news, I don't want to be standing at podiums, but I do want to make things better on my block" really lend their voice to this work. I think it's an important step forward to start to bring together positive women.

Fisher: It's brilliant. This is what the gay community had, early on, that women have not had. You know, as you and I have been out there advocating in a more public way, we've never said to women, "Do what I'm doing." We've urged them to do what they can do best right in their own communities: Talk to your butcher, to your son's teacher and principal, to your faith congregation. In the past, positive women never have gotten a very good grassroots thing going. Perhaps this is it!

Averitt Bridge: For years I've been talking about starting an organization called the National HIV-Positive Soccer Moms Association. A reporter I mentioned it to was stunned: "Are there really enough of you out there?" Well, in 2004, at least 7,000 HIV-positive women gave birth to children, and if you figure that's been happening for perhaps 15 years, there would be more than 100,000

of us out there next to you on the soccer field. People are flabbergasted at the idea, but there is something to it. It takes this out of the realm of “who are you, and what have you done wrong?” And it says instead that HIV is part of the fabric and families of this country.

Fisher: It’s a different way of looking at it, which is exactly what we need because the issues for women surrounding HIV/AIDS are different, on prevention, on testing, on treatment. We need research [to develop] effective, female-controlled prevention, because most of the prevention methods now in use were created for men and adapted for women. We need opt-out testing promoted through ob/gyns and all doctors, because [the way] testing for women is [done is] horrible; it’s done mostly when they’re in the ER or when they’re pregnant. And we need to insist the government and medical establishments collect better data on HIV/AIDS in women, because the statistics are what will drive the research and the resources.

Averitt Bridge: I agree. I think we’re at an interesting point where things could shift dramatically for women living with HIV. There’s reason to hope for implementation of a national HIV/AIDS strategy. And through PWN, we’re hearing the stories of women living with HIV who once were homeless and now have their first home, women who are getting their lives together, women who are feeling like, “I do have something to say, and I can make a difference for somebody else as well as for myself.” For years I’ve used the word normalize—we needed to normalize HIV/AIDS and make it something with which every person is familiar and realizes the risk. Maybe we’re at that point where we change the way people think.

Fisher: You mean the way the mothers’ grassroots campaign succeeded in reducing drunken driving? Or the public awareness efforts on seat belts were so successful that every little kid in America learned to say, “Mommy, put on your seat belt”?

Averitt Bridge: Exactly, Mary. So I guess [in some way] we [really] are the HIV crash test dummies, aren’t we? [*Laughs*]

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