

STEP INTO MY PARLOUR



By Shaun Proulx

SHAUN PROULX TALKS TO LOUISE BINDER

Home for the Christmas holidays thirteen years ago, **Louise Binder** got a telephone call from her doctor with shocking news: she had tested positive for HIV. Binder was told she could expect to live another two to four years.



Needless to say, she defied those dire medical predictions, but that phone call changed her life. Today, the 5-foot Toronto resident is known as a firebrand in worldwide activist circles. One of the few women to speak *very* publicly about being HIV-positive, Binder travels the globe to do so, centering many of her energies on access to treatment and women's issues. She also doesn't cotton to mincing words when she voices for the cause, playing David against Goliath in criticizing the likes of federal governments and pharmaceutical giants, ceaseless in her demands and her outspokenness.

Stephen Lewis, the United Nations' special envoy for HIV / AIDS in Africa recently said Binder 'has emerged as the galvanizing symbol of activism against the AIDS epidemic in Canada and she stands almost alone in the passion, energy and leadership she has devoted to the fight.'

This fight, of course, is one we in the gay community know all too well, some more than others. But over two decades later, for many in our community there's now a fatigue, there's misinformation that the disease is under control, and there's an attitude that 'this problem isn't mine'. So this year, to mark World AIDS Day 2006, I sought to speak to Binder to get some sort of fresh perspective on the issue. Maybe it would be a female perspective, a straight perspective, an activist's perspective, but however it came, I just wanted to hear something different, something new, from someone who knows, as we head toward a third decade of a world with HIV / AIDS.



We're talking a week before World AIDS Day. Describe the face of AIDS.



Let's start globally: the face is 50% women, 50% men, which is probably a big surprise to a lot of North Americans. If I look at North America the face is still a preponderance of gay men, but creeping up are women, and people - both men and women - who are not infected through sex, so primarily through intravenous drug use. The face is not white - in the U.S., African-American and Hispanics are a big piece of the puzzle. In Canada we are also looking at aboriginals, south Asians and people from endemic countries. It's a much more heterogeneous population, too.



What do you think a city like Toronto needs to know and understand about HIV / AIDS right now?



One of the things I think we need to know is you can never let down your guard in terms of education and awareness. So for people who are not infected, they need to know they still can be, that there is no cure for this, and the meds we take are not very much fun. They come with a lot of side effects, some very severe. They need to know it is just not worth it to take risks.



I keep hearing that. But hasn't the education / awareness concept been hammered home by now? It's 2006 and yet I could go online to a sex hookup website right now and find twenty-year old kids looking to fuck raw. What do you say about that?



I say that I wouldn't be doing that if I were them! *(Laughs.)* I say we've let them down, partly. We have to understand that those gay men probably didn't get much education in the classroom. They didn't live through the period where some of us did, where we had no meds and people were dying horrible deaths. They don't have that 'benefit', so they don't understand how terrible this disease is. They see us managing and thinking we're pretty good. The truth is we suffer a lot. The toxicity and side effects of HIV meds are profound. And people are still dying. But we die of liver and organ and heart failure now, and so people say they we didn't die of AIDS, but in fact we did. The meds create weaknesses in our vital organs.



What do you make of the increase in HIV among gay men?



It's a tragedy. We can't let them down and we did in a sense. We shifted to treatments and research, but the reality is you have to sustain efforts in prevention; the next generation is one that did not live through the holocaust that we did, the massive, pandemic deaths that we did. So they don't understand what it is to see everyone around them dropping. We failed them.



You are one voice in the AIDS crisis, but obviously you stand out because you are a straight woman. Who has been better at getting their message out about HIV/AIDS - women, or gay men?



These days, women. That's very recent. Because women finally mobilized and worked very, very hard to have their voice heard. We wouldn't take 'no' for an answer.



Who takes better care of their own – women or gay men?



Women, although we're farther behind in terms of getting issues on the table.



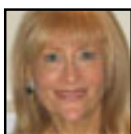
It's funny, because the original gay AIDS movement took cues from the women's lib movement. The gay men before me organized, got funding, supported AIDS service organizations. Is it now our turn once again to learn from a woman's movement, only this time the women's AIDS movement?



I think so. And it's also time not to see this disease as 'it's my property; it's your property'. Believe me, there's enough of AIDS to go around. We need to make it clear to everybody that this problem isn't solved until this problem is over. Some of us certainly were right there with gay men, fighting for treatment and prevention and not to be marginalizing any groups in this epidemic, but I don't think we got the same back.



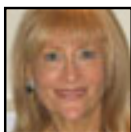
From the gay community.



Some of the AIDS activists were marvelous in working with women, but not on women's issues.



If women are one of the new faces of AIDS, how can women and gay men work together better?



I think one of the things we need to do is literally come together. Recently at a meeting I put it out that we should be dealing with women's issues. Some of the gay men in the room said we should be dealing with *their* issues. The person moderating this discussion said, 'Listen, we'll deal where people are passionate and take the lead.' I stayed in the room - *and the gay guy left in a huff*. We've got to *all* stay in the room and listen and find a common ground. Stigma and discrimination need to be faced. All the issues. It's really naïve and short sighted to see the issues as separate; they really aren't.



You were an integral part of AIDS 2006. What kind of impact did the conference have?



AIDS 2006 was very interesting. It was the women's conference - some would like to say - where finally women's issues got on the agenda. I do have gay friends and colleagues who felt their issues didn't get on the table.



Why not?



Why not is the question. The only way to do that in these difficult times is by fighting hard to get there and articulate and get your faces out there. Nothing happens to you, it happens by you, for you. Maybe it's out of fatigue; gay men have not been really putting out their issues in the same way they used to. It's as if there's an expectation some things will be automatic. Nothing is, unfortunately. It's going take an amount of passion and work to be heard. Particularly these days – AIDS is much less interesting, much less dramatic, and people are tired of hearing about it. You guys have to make your voice heard louder.



Where are the funding announcements from Prime Minister Stephen Harper that were pulled from AIDS 2006? I was in the front row when his lackie promised we'd hear announcements soon.



(Laughs.) He didn't make them and he still hasn't and I don't think he's going to. I'm pretty good at guessing him. I think there will be some drips and drabs on World AIDS Day, but other than that I have no expectation.



So should we be more demanding?



If I were doing anything right now, I'd be working on getting rid of this government. They don't listen, really. And no amount of discussion with this government is going to change their mind about 'us.' Women, HIV-positive people, and anyone who isn't Mr. and Mrs. Front Porch don't matter. So when we tell them anything, they don't listen. We could get through to them, if we told our stories to Mr. and Mrs. Front Porch, put our attention to their constituents so they knew that this is to their benefit, too



This summer you called this experience of HIV 'a ride'.



(Laughs.) I did?



You said, 'It's been a fun ride. I have no regrets at all and I wouldn't change anything. I think this is what I was destined to do and it feels good.'



I do think I was destined to be a social activist. I think it could have been the feminist movement; I was a big civil rights movement in high school. I was destined to be involved in social justice issues.



If someone really wants to help the cause, what can they do?



Everybody's abilities and skills are different. You have to find the place you fit in this puzzle and there are lots of different places. Whether it's working in this business or being an activist. Whatever you decide to do, it's got to be sustained. We need people to get involved in all aspects and stay involved.



What do you say to someone reading this who has just been diagnosed HIV?



Don't panic.



Isn't that what your doctor said? No, wait, she said, 'Don't cry.'



That's right, she did. No, they ought to cry, but don't think it's a death sentence. Don't do anything in a big rush. Don't feel the need to start immediately on treatments. If you're just diagnosed HIV-positive and have some kind of reasonable immune system, hold off, and do a lot of research. There are so many choices and treatments that you really need to find out before you leap in. Crying is okay; panicking isn't.



This will be published on December 1st. What thoughts go through your mind on World AIDS Day?



It's never another day. Every day is World AIDS Day in a sense. I keep wondering ... *(pauses)* ... It's always a sadness for me because of all the people I've lost because they didn't have treatment. So much talent; so many wonderful people. I certainly know I have to continue to fight so I lose fewer and fewer of my friends, and that's really a role that's important for me to play. For myself and the benefits of others. Every year I keep hoping it will be the last .



I admire you a great deal. Thank you for all you do.