

# FUSE

MAGAZINE

VOL. 15  
NO. 5  
SUMMER  
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between the lines  
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## EDITORIAL

INCREASINGLY, AS THE AIDS industry and the AIDS cause gathers steam, the actual space for those infected, rather than affected, becomes smaller and smaller. Only recently, in Canada, has there been an official recognition by the AIDS service industry of the needs and voices of HIV-positive individuals. The curse of liberal humanism is such that AIDS has become the cause of movie celebrities and rock stars. Witness the red ribbon campaign at so many high-profile events, a campaign that often leaves one wondering, "Where are the people living with the virus in all of this?" Isn't it ironic that Queer Nationals (problematic as they may be) were shut out of the Academy Awards while everybody inside was feeling empathetic by wearing a red ribbon? And what about the recent announcement of the mega rock concert to be held at Wembley Stadium in London, England in honour of Freddie Mercury who recently died of AIDS-related conditions? As stars like Elton John, U2, and Axl Rose (!?) rally around Mercury's death to raise money for AIDS charities, why doesn't anybody ask how it was that Mercury himself could not come out about his HIV status?

It's not easy to be critical of a phenomenon that pitches AIDS as a worthy cause deserving serious and immediate attention, but the processes through which charity and solidarity are expressed often seem to obscure evidence of the lives and deaths of the members of the communities which they are supposed to be helping. This issue of **FUSE** is, at one level, the result of having seen one too many pictures of celebrity AIDS galas and of having heard or read one too many stories about how AIDS had affected another HIV-negative person.

Originally, this issue was going to include only contributions by HIV positive people. Quickly, we ran into problems enforcing this editorial premise while trying to respect individual decisions about taking the test. Some contributors it that the test is meaningless because HIV alone does not cause AIDS and that the psychological impact of a positive test is of greater detriment in the long run. Whether we think it's right or not, it's a choice we need to respect. So, strictly speaking, not all contributors are known to be HIV-positive.

Interestingly, in reading through the numerous submissions we received, more often than not the author's status

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was made evident in the way in which they chose to speak about their experiences of AIDS. And so, without becoming overly concerned with proof-positive, we have been able to create a space for HIV-positive people to speak on their own terms about what concerns them, to engage in the process of self-definition, and to speak of the subjectivities that evolve in the course of living with AIDS.

Of course, what we are also trying to provide is a clearer picture of the diversity of those who are living with AIDS. For it is probably safe to say that we are all tired of the media representations of "AIDS sufferers as helpless victims" or sexual and moral deviants who threaten anarchy.

The kind of writing you will find in this issue is different from what we usually publish; most of it is much more personal and less analytical, encompassing a wide range of writing styles. From the "Personal Dispatches" to the essay by Michael Lynch, from the "Voices of Positive Women" selections to Stefan Collins' reflections on the intersection of the personal and the political, all the pieces resonate with a profoundness imparted by first-hand experience. The artist projects also represent a variety of responses ranging from the agitpop front cover by John Balatka and Mike Campeau to the memorials by Stephen Andrews.

As a special service to HIV-positive communities, we have, with the help of Levi-Strauss, been able to distribute this issue free of charge, through AIDS service organizations, to people living with AIDS. We would like to acknowledge their support in this project. If you have any comments or suggestions, please write us. Your feedback is important.

L. Wong and D. Taylor



# personal

REBECCA BLOOMSFIELD

Being an HIV-positive woman and caring for a husband who died of AIDS, has been an experience that has left me with an incredible hatred and fear of AIDS. You often hear about AIDS but you never think that you or your family could get it. But this happened to me and my family.

I got infected with HIV through my late husband, who died of AIDS two years ago. I tested HIV positive in 1987, a few months after my husband was diagnosed with PCP pneumonia. I am still asymptomatic and I'm on the AZT/ddI trial right now.

My daughter was born antibody-positive. After many tests at the Sick Kids' Hospital, it was discovered that she was just carrying my antibodies, and she was declared free of the virus when she reached two years of age.

My husband's condition was another story. It was as if there was no hope for him. I watched a man dwindle away to nothing. To see him like this scared the hell out of me. He suddenly dropped from 160 lbs. to 124. He had to quit his job and the only way that he could support us was through government assistance. Our whole life seemed to be run by doctors and Public Health. So, I had to work full-time to support the family. I guess you could say I was the breadwinner. This took my husband's dignity away.

During this time, I became a really strong person. I had to deal with not having a sexual relationship with my husband. We would never be able to have more children. He was in and out of the hospital. Sometimes he was there for weeks on end. It was like I was already a single mother, with all the responsibility of our daughter, the household expenses, etc.

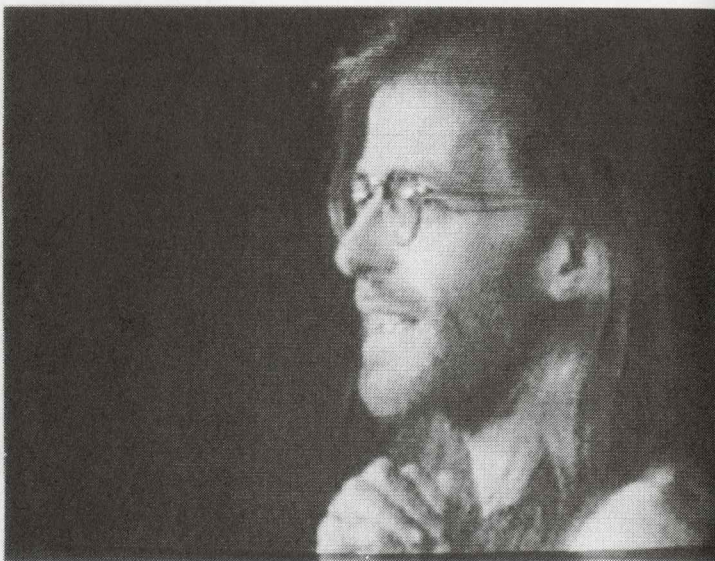
There was a lot of loneliness and stress, and no shoulder to cry on, no one for intimate conversations, no one to keep me warm in bed at night.

My husband came down with CMV retinitis and became blind. It was like the last straw. I had to become his guide. Our families were supportive, but we didn't have a lot of friends. They sort of drifted away when we really needed them. Through the AIDS Committee of Toronto, we were assigned two buddies to help us with the grocery shopping and hospital visits, and they became our friends.

I still have a buddy, Carole, and she's all I could ask for. When I think that the world is coming to an end, she's always able to show me the brighter side of things.

Going through the death of a partner from AIDS is not something that I would wish on anyone. I feel like I have been left with my husband's shadow inside of me. But I'm determined not to let this disease progress any further in me. I'm going back to school so that I can get a better job. I want to make a better future for my daughter, one without AIDS.

## PERSON LIVID WITH AIDS Last summer a bunch of us from AIDS Action Now! went to Ottawa to visit with Perrin Beatty, Minister of Health . . .



Sometimes I fantasize about chaining these bureaucrats to their desks and letting them really have it!

RODDIE MCFADZEAN

### Northern Ramblings

A close friend of mine recently commented that she found it so hard to accept the misery in my life. I quickly pointed out that that was how she saw things because my health is devastating to her. But she should remember that my life consists of many parts, most of which bring me joy. Too often our friends and family fall into the trap of only seeing our oncoming doom. I pamper that need in them—for awhile, but at some point it is necessary for my well-being that they also recognize my health and see me as a whole person with all the interests that I've always had and more.

With respect to the issue of whether or not to tell friends and family about your status, I have found that telling people has always lifted a weight off me. Reactions to the news, however, I would have to say, can be very different. Tell the people who you think will be supportive. I've been quite lucky because the people who I have chosen to tell (after lots of hard work in some cases) have come to the point of supportiveness. I have found that a period of time is usually necessary for them to assimilate their own grief and shock. When I informed people of my status, most hadn't been touched personally by AIDS and knew very little about it. I was fairly knowledgeable so it was "AIDS 101" for a little while. Sometimes I just wanted to scream, "Wait a minute, I'm trying to deal with all my own new thoughts and emotions. I can't handle your situation." They're just lucky I'm such a patient guy.

But if your friends and family truly love you, they'll be able to get beyond all the issues surrounding AIDS and focus on the two most important issues for you: your health and your need of support.

**Roddie McFadzean lives in rural Ontario. He advocates people living where they choose and resisting the pressure to move to a city for "better health facilities."**



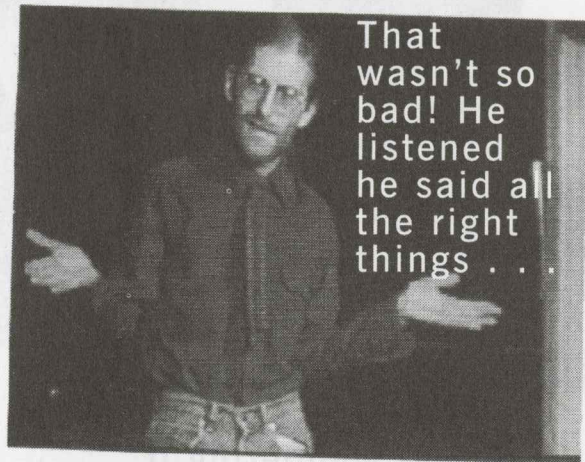
Ehrmm, minister, we were just wondering if you had any plans for the National Strategy on AIDS . . . ? Oh really? Soon?!



Oh, that's very good to hear, minister . . . Thank you very much for the visit! I guess we'll see you next year and the year after and so on . . .

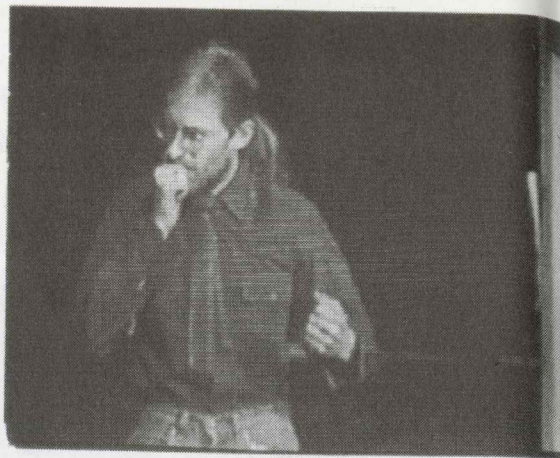
# dispatches





That wasn't so bad! He listened he said all the right things . . .

Wait a minute . . . that was last year! Where is that National plan? What's going on here?! This man's a scam! He's fucking us over!!



**RODDIE MCFADZEAN**

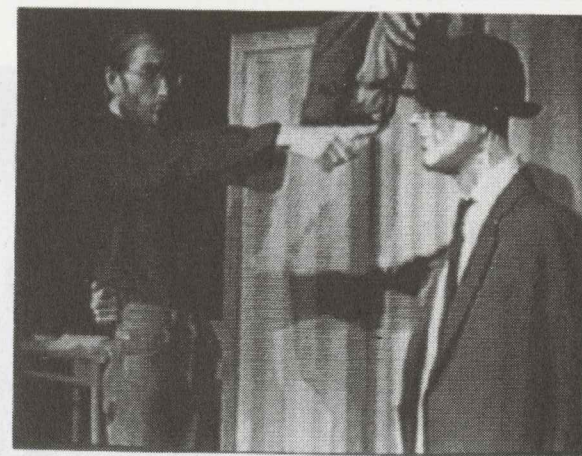
When I discovered that I was HIV-positive, my first concern was to find a doctor who could handle the day-to-day health problems which would undoubtedly arise. Before approaching a local doctor, I made a list of questions which I wanted answered. After all, this wasn't just the occasional cold or ache he was going to be dealing with. I wanted to be certain that my doctor would be able to deal with me on both a physical and an emotional level.

At our very first meeting I told him that I was gay, in a relationship, and still quite sexually active, because I wanted to be sure that he was comfortable with those aspects of my life. I also needed to know that he was okay with AIDS in general and if he had any knowledge in that area. He frankly admitted that he didn't but would be more than willing to learn. And he has. Perhaps I've just been extremely lucky, but I feel a large part of finding the right doctor is asking the proper questions and telling him or her the whole truth. It is your life.

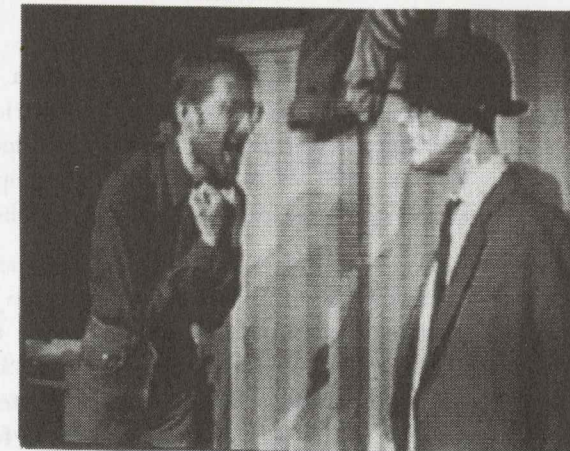
I have a few suggestions that may help those of you who haven't been tested for the virus or have concerns around the issue. First call PARN (Peterborough AIDS Resource Network) or any local AIDS committee and get the information which you need to make your choices. If you know already that you are HIV-positive and need a general practitioner, you should expect the doctor to be only somewhat informed. So once again, educate yourself enough to know what questions to ask. One way to take some control over this disease is to use information to better understand what it is doing to you and what you can do to fight its progression. Be very direct in asking your doctor if he or she is willing to keep abreast of the ever-changing information surrounding drug treatments and symptoms. Keep in mind that this person is someone who may go through the dying process with you. Thus, you have every right to ask as many questions as you need in order to feel comfortable with your choice.

There are sound reasons for using a family doctor. As someone with a compromised immune system, the colds and influenza that we used to allow run their course perhaps should now be more aggressively treated. A family doctor is someone you can talk to; specialists probably don't have much time, especially for listening. And I have certainly found that this disease has its fair share of "downs."

So, from an HIV-positive person trying to deal with life evenly, keep well and inform yourself about this disease. Information can be frightening stuff, but the fear of not knowing is truly worse.



OI! YOU, ASSHOLE!!! Who the fuck do you think you are in your fancy hat with your fat salary doing DICK ALL for people with AIDS!!!



Well I've had enough of this bullshit from you and your fucking bureaucrats!

**RONN WRIGHT**

I am a PDWA. Person *Dying* with AIDS.

I know that many people will think that I have a shitty attitude or that I'm going through a period of anger (Stage Two: Elisabeth Kubler-Ross) but I just don't believe that adding the word "*living*" to People with AIDS (PLWA) means that we are living.

Living was when I could paint for hours without getting tired. Living was when I could dance until 3 a.m. at a club and still make a 9 a.m. class. Living was when I had enough money to go to a film or play. Living was when I loved sex. Living was when I could still safely drive my car. Living was when I could still ride my beautiful horse. Living was when I could still run with my dog in the park or play a game of twenty-one at the neighbourhood basketball hoop. Living was when I planned and dreamed of what I would do with my life, of the greatness that I knew I was destined for.

I was nineteen years old in my first year at the Ontario College of Art, a farm boy in the big city for the first time, when I became infected with the virus. I didn't know shit! Now, eight years later, I puke almost every day. Two nights ago I had a bowel movement (read: diarrhea) while sleeping and didn't even wake up. I depend on the state. I jump through hoops and degrade myself to get help from PWA and other organizations. My whole life is focused on medical appointments and which medications are helping and which are harming me. Sometimes the highlight of my day is watching *Oprah*. I have to sleep fourteen hours a day. I need a pill for nearly every human function: to clarify my thoughts, to stop me from puking everything I eat, to help me to breathe, to stabilize my weight, to help me sleep, to make the pain go away, to stop diarrhea, etc.

That one great (no, euphoric!) night of sex wasn't worth sacrificing the next *sixty* years of my life. I now belong to a group of people who allowed their penises more power than their brains—the "I never thought it could happen to me" club.

Ever since the rural doctor tested my blood without my consent, who then called my *MOTHER* to say I had AIDS, until now, I have been in a dreadful nightmare. There is nothing romantic or heroic about dying from a sexually-transmitted disease. There is nothing funny about dying from a disease that a rational person could have easily prevented.

I am a PDWA. A Person Dying With AIDS. And I wouldn't recommend it.

**Ronn Wright is a bored house-husband.**



MIRINDA LA FAYE

My name is Mirinda La Faye. Mirinda is a Keltic name, a faerie name, which means warrior. Woman Warrior. La Faye is French for fate. Mirinda La Faye: Warrior Fate. My name just about sums up how I feel about my interaction with the AIDS establishment.

I have a few things to say about living as a healthy, asymptomatic HIV-positive woman in the sexist society into which I have had the misfortune to be born. I have a lot to say about my dealings with the medical establishment, which is more interested in seeing me as a "vector of transmission" (heaven forbid that I ever infect that holiest of sacred cows: the heterosexual white Canadian male!) than it is in studying HIV infection in women.

Since testing positive for HIV, I have yet to experience one kind or reassuring gesture from a nurse or doctor in any AIDS clinic I have attended. The cold, clinical, fluorescent corridors of hospitals have come to me to symbolize betrayal, oppression, and sexism. My response has been to change my name, arm myself with knowledge . . . and accept that AIDS is big business.

On my first visit to the Toronto General Hospital, I was handed a sheaf of papers and questionnaires. One form wanted to know about sexual practices. How often did I engage in anal sex? How often did my partner ejaculate into my anus? Did I have anal intercourse with more than one partner? Did I engage in fisting? How often? I struggled to keep my composure. Why was I being asked questions about things that were so foreign to my experience? The implication was that because I was HIV-positive, I no doubt got the virus from participating in these "non-heterosexually-sanctioned" practices. I'm sure gay sex is great but I'm a bi gal not a gay guy.

And so it came to pass that I was initiated into the nightmare world of AIDS bureaucracy. Going out the door after this first appointment, the doctor turned to me, as though in afterthought, and said, "And by the way, no kids." The arrogance! The callousness! I wanted to slap his face. I turned on my heels and got out of there as fast as I could. I was shattered.

If you were to meet me today, five years into my experience with HIV, you would see a tall woman with long-ish hair, hazel eyes, and the body of an athlete. You would see an attractive woman with an aura of vitality. I'd let you know that I'm an accomplished downhill skier, yoga instructor, dancer, and that I love to swim. You'd hear about the dog sled adventure that I had last week. You'd see a woman who is very turned on by life.

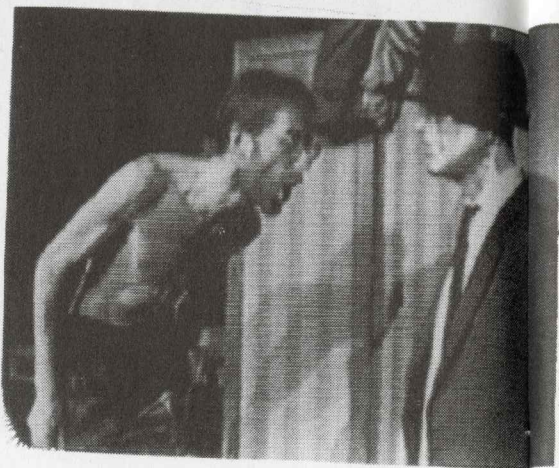
I am healthy today and refuse to downplay or downgrade this because I have HIV antibodies in my blood. There are things which I cannot do sexually and various moral obligations I must uphold. Beyond these, I am free. HIV has no hold on my mind and it doesn't appear to be doing much to my body, either. And anyone who says my defiance is a form of denial is denying what works for me.

This whole concept of denial is very interesting. Health professionals love to tell you you're in denial when you are well, want to live, and want to find a way of beating this virus. I have noticed that there is virtually no recognition or support of wellness in the AIDS bureaucracy. A recent visit to a techno-doctor illicit a response something like this: "You look well. It appears that the virus has not had a chance to start working in you yet." Where does this headspace come from? A more appropriate response might have been: "You are doing well. You are healthy. The virus doesn't seem to be active in your system yet and let's hope it stays that way."

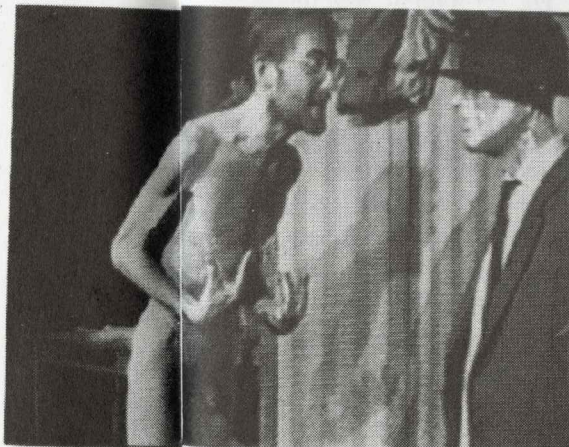
I have learned well that my life is my own. I have learned how to find alternative support and care that truly suits my needs. I have learned to "just say no" to the mindless bureaucracy of the medical establishment and to use it for what it is: a resource when I want certain scientific insights.

I encourage all HIV-positive women who have felt the sting of the techno-doctor to search out the support they need and to stay positive about their lives. The more self-empowerment you can take on, the better. Life can change. You can get back your joy.

And by the way, I never did hand in that questionnaire. I took it home and burned it.



. . . And I ain't dressing up for your kind of scum any more! I'm gonna show you the naked truth of what AIDS is about 'coz it's about time you quivered in front of it!



It's about time you knew the reality of someone living with AIDS and that's what THIS is!

STEFAN COLLINS

Speak If You Dare

"Are you a batty-boy, sir?"

It caught me off guard. Previously she was running her mouth off to someone else.

"Girl, what you doing—girl!"

"Yes," I said. "So what's your point?"

Now she wanted to get loud to impress her friends.

"I've seen you before—on TV. That was you, the faggot talking about AIDS. You got AIDS!" Stay cool, I told myself. By this time everybody was listening. Girlfriend had an audience—four Black dudes backing her up, while her girlfriend edged her on.

Again I asked, "What's your point? Why are you going out of your way to let me know that you know I'm a batty-boy and besides who cares?!"

She looked at me mockingly. "You a batty-boy with AIDS. What a waste." She spit on the ground.

I wanted to read Ms Thang into the middle of next week, but I chose to ignore her. Instead I asked one of the dudes—who I dealt with before—if he's happening. "I'd like a ———."

He sucked his teeth. "Shit man. I don't know what you're talking about. I don't deal shit man—especially to a batty-boy with AIDS. How I know your faggot money can't give me AIDS?"

"Yeah homeboy. Move your ass!"

Inside my body shakes. I want to lash out—physically—verbally, but I stay silent and angry and humiliated and embarrassed. I try to leave but I can't. Something has to be said. Do not stay silent, a voice within tells me. Don't accept the guilt . . . the shame . . . the pain. I look right into their eyes and say, "So what? You've figured me out. All my cards are on the table. But tell me who and what you are? If you as a man or you as a woman are to represent the alternative, then girlfriends, I'd rather be a batty-boy!" SNAP! SNAP! SNAP!!!

I walk away proudly letting them know that I wasn't shook or shamed by the comments. But inside, I feel pain. I feel as if they have taken my heart into the palm of their hands and squeezed it. I tell ya it hurt so bad. It's not their words that hurt but my silence. Yes. In reality, if I was to lash out it would have turned into physical violence. I would have preferred to endure their physical pain rather than the emotional because the physical pain slowly heals and disintegrates, whereas to heal from emotional pain one has to learn to forgive in order to forget. The silence is like a poison running through my veins. A poison that slowly destroys my sense of strength, realities and hope. A poison so deep that all my visualization and positive thinking can't reach.

Why didn't I tell Ms Thang all that I had to say or wanted to say? Why did I choose silence when I spend most of my time fighting silence when others choose silence as a means of safety or denial? So I try to rationalize my feelings by justifying their actions and fears. I look for reasons/excuses that would belittle them. There are no justifications or reasons; only my realities of being public about having to live with AIDS.

Stefan Collins is from Nova Scotia. He tested HIV positive in May 1982 and is currently an active board member of the Black Coalition for AIDS Prevention and various other AIDS organizations. His experiences are in buddying, AIDS outreach, AIDS education, AIDS prevention, and public speaking. He is 6'1" and weighs 220 lbs. He likes to frolic and seeks same for fun, romance and adventure.



And if you don't get your finger out, and organized real research, and get treatments for people, and support . . . then you can fucking get lost out of your office!



JOE LEWIS

**This is not fiction, I wish it was**

In the spring of 1989 for some reason that I still haven't figured out, I was asked by the local CBC evening news to participate in a "round table" discussion at City Hall. I was asked to come along and talk about "affordable live-work space for artists." Somewhere along the line I mentioned being HIV-positive and was introduced on air as "a person with AIDS living in

Toronto." I was asked, "Do you find this city compassionate?" I said, "No," and went on to talk about artists and housing. At this round table there were representatives of many issues: housing, pollution, traffic, race relations, and AIDS. At the end of this meeting, people stood around talking, exchanging cards and flyers promoting their different events. The two people that were there to talk about AIDS and myself found ourselves alone and not included in the exchange of cards or flyers or even a friendly hello. I commented on this, but being "ill" it was safer to assume that I was just being "sensitive" or "paranoid."

I was collecting Family Benefits and had applied for rent-g geared-to-income housing. In spite of a three-year waiting list, I received a subsidized apartment in less than four months. I can understand why people who had been lobbying for the homeless for years weren't talking to me after the round table—they could see that the little funds available were being served up in smaller portions and the AIDS community's needs were growing larger every day.

During this time I was in a support group, had a personal counsellor at ACT, was seeing a therapist, a homeopath, a G.P., and an immunologist, was regularly taking AZT, Acyclovir, Royal Jelly, and bee pollen. My T-cells bottomed out and then they slowly climbed towards the "normal range." I was very typical in some ways: trying to learn about alternative healing, keeping on top of the new language and drugs, not sleeping, and arguing with my friends. Then I stopped obsessing when my doctor said to do what I felt good about and could afford.

I have learned to negotiate the contradictions, the fear, the anger, the frustration, and the bureaucracy in order to focus on what I can do in a hands-on way in "the fight against AIDS." After being involved in the arts, both as a producer and an administrator, I felt that organizing events that were about information exchange and not raising capital were best suited to my skills. Fundraising, as most people know, is big business. And fundraising for AIDS organizations is hell. Many political and personal conflicts arise but three realities remain: raising money to keep going, getting information out, and distributing the condoms, dental dams, rubber gloves, clean needles, rent, food, handholding, or whatever else it takes to keep people alive. Forming alliances for the lobbying of funds is a very important part of fundraising and given that many AIDS organizations are relatively new, there is still a great deal of naivete on the part of AIDS communities. This is changing by hiring skilled people from different areas of social action, but the growth is not without pain.

During AIDS Awareness Week in 1990 in Toronto, a group of eight people (including myself) from three AIDS organizations managed to get 60 generous local performers on and off three stages over three nights without drawing any blood. The bars involved—the Horseshoe, the Cameron, and the Rivoli—were more than happy to assist, and liked the idea of an "awareness event" where raising money over and above "costs" was not the major concern. The artists who performed along with those who donated their artwork for the poster and auction, were very co-operative. Even the poster's designer and printer gave their time and work for free. A fundraiser's dream—but only to a point.

This was a new experience for me in many ways. In order to make it happen, I aligned myself with CIUT-FM (the University of Toronto campus community radio station). I still can't

remember what they did except send someone to the Rivoli on the last night of the event to take a "thank you for all your help" bow. By the end of the third night we had raised about \$1,800 (to be split three ways) and had entertained, if not educated, about 340 people. Not bad. People at Xtra, one of Toronto's gay publications (upon receiving the press kit) wanted to know which, if any, of the performers were gay. After all, the event wasn't happening in a "gay club" so why promote the event? People at the PWA Foundation thought it was odd that "straight clubs" were participating in an AIDS event. One performer when asked to participate said he wasn't gay. I reminded him that he had done a benefit for the homeless and yet lived in an apartment. The bars that did host the event wondered afterward why nobody asked them to participate in events like it more often.

I used to work at a campus community radio station in Peterborough. If the myth about campus radio hadn't been totally dislodged after that experience, it has been since. Last year when I was out west spending the holidays with my dead lover's family (we have adopted each other), I phoned campus radio stations from Winnipeg to Victoria to see if they were interested in holding a one-day, nation-wide AIDS Awareness event. When I got back to Ontario, I phoned the National Campus Radio Association and the Canadian AIDS Foundation, and bought a listing of AIDS organizations from ACT. A few friends lent me office space with access to a fax machine and I was able to get on line with radio station with modems.

Student newspapers at several campuses had just reprinted "A Gay Man's Guide to Safe Sex," an AIDS Committee of Toronto pamphlet. At Memorial University in St. John's, the Board of Directors threatened to resign because of its publication there. Campus radio stations, while following this story in an attempt to show solidarity with papers as they were threatened with takeover or shutdown, decided that creating a national AIDS Awareness event was an important challenge.

There are approximately 32 stations of various sizes and capabilities across Canada. Some like CKLN in Toronto, CKCU in Ottawa, and CJSW in Calgary have large listening audiences outside of the university population; others are community college broadcast training classrooms. Most lean to the left and all are hotbeds of intrigue. As I made phone calls to these stations trying to find solidarity for my proposal, many interesting things happened. Some program directors or station managers initially reacted with "Oh I will give this information to our GAY programmers" or "We don't have any GAY programmers." I

do not recall stating anything about "GAY"—I was trying to organize a nation-wide day of special programming or events focusing around the issue of AIDS. Some people simply listened and then said, "It sounds great, good luck, but we are busy with this project at that time and it would be impossible to attempt something." While these responses were awkwardly stated, they were perfectly acceptable, and so much easier to deal with than "We'll get back to you. What's your number?"

Unfortunately, I was not able to give the attention needed to publicize the national aspect of this 17-city, nation-wide event because I had to play nursemaid to CIUT. They never made the connection that they themselves were supposed to organize their component of the event. I felt pretty stupid about the possibility of there being no Toronto component so I organized a benefit. At one point I told CIUT that it would be best if their name was dropped from the publicity but they thought it would be embarrassing. In the end nobody from CIUT showed up for the event yet they received a thank-you letter from the Toronto PWA Foundation for the \$69 which they raised. One station which had initially declined when approached in January managed to pull together something in spite of the fact that the week before had been their annual big bucks local music awards night.

This January I was on the phone again to five different radio stations about doing it all again. The people who I talked to had no idea what I was talking about. "Well you know what it's like at a campus radio station."

This may all sound like sour grapes, and it is. It is 1992 and I am a 34-year-old HIV-positive gay white male who has been a cultural worker for the past 15 years. Like you, I have witnessed a generation be destroyed. I don't wonder about the fear that causes people to disassociate themselves from others, but I do worry about those of you who can't get over it. My health is my business, just like your health is your business. Sharing information is a great thing but running from it is another.

It is like this AIDS issue of FUSE. It will be easy to ignore it or pass it on to one of your gay friends. But no one person or specific group of people has AIDS. We all do.

**Joe Lewis is an artist/activist whose work over the years has explored the contradictions between marginal society and putting-your-pants-on-one-leg-at-a-time daily reality.**





FUCK  
YOU,  
ASSHOLE  
!!!

AAAAAAAAAAAA  
AGGHHH!



Excerpted from  
*Person Livid With AIDS*,  
a play written and performed  
by Michael Smith.  
Presented at the QueerCulture festival,  
April 1990.

Transcription and photos  
by Robert Kennedy

BY X.J.

SINCE TESTING HIV POSITIVE a few years ago, I have come face to face with AIDS in my personal life, as well as in helping others in the gay Asian community. I realize it is risky to make generalizations because this crisis is such a personal experience; nonetheless, I feel it is still worthwhile to give a critical view on the affairs of AIDS and the gay Asian community as I see it in 1992.

Except for a lag time of about three to five years, AIDS has impacted gay Asians in many ways that parallel the mainstream gay community. In the early days of the epidemic, before reported cases of AIDS in Asians, I was hearing brave assertions from my Asian friends that maybe we had super-genes to fight off the AIDS virus. Other times I was hearing from my white friends that Asians were less sexually-inclined and therefore not as likely to catch AIDS. These myths were passed around by word of mouth and perpetuated in the minds of many Asians as a way of dealing with an impending crisis.

Such denial of it won't happen to me was also prevalent in the gay community in the early days of the epidemic. It worked for a while until we found out one of our friends had fallen ill to AIDS. The shock sent waves of anxiety through us which were quickly hushed up by the veil of confidentiality. We all knew what was happening but pretended that we didn't. Some of us were courageous enough to mention it, the rest of us were too awkward to know how to respond. The dilemma was that if you responded too casually, you would look callous, but if you were too concerned, you would look alarmist. It certainly wasn't a topic for conversation in nice company. It still isn't in many places today.

When the first few of our friends fell ill to AIDS, there was little support available to them. Either they did not have families in Canada, or they were too afraid to disclose to them. The problem of language and culture, as well as the fear of beingouted, prevented many of those taken ill from going to

## A VIEW ON GAY ASIANS AND AIDS

services available in mainstream gay community. The reasons for the lack of support are complex and multifaceted, but the result was that they often remained isolated and alone until close to the end. The double oppression of HIV-positive Asians from racism in the gay community and homophobia in the Asian community, contribute much to the isolation and loneliness of these individuals. I would like to examine closer the impact of this double oppression on gay Asians with AIDS.

Although the oppression of overt racism in the gay community may not seem obvious in everyday life, it becomes much more apparent in the politics of the bedroom. In my early days when I was cruising, I often experienced the dichotomous attitudes of either I am not interested in going to bed with you because you are not white, or else I want to go to bed with you because you are Asian. There is also often surprise that I can speak perfect English or carry on an intelligent conversation. These kinds of past experiences with white guys in the gay community gave me little confidence to go to an AIDS service run by GWM. I do not

have reason to believe that these GWM at AIDS services can understand me or respond to my needs any better than the ones I have met in the mainstream gay community. I had a hard time being comfortable and fitting into these services.

In addition to overt racism, there are more subtle forms of oppression. This is exemplified by the lack of Asian images or perspectives in the gay press. The images seen are usually submissive or subservient stereotypes. The low and distorted profile that gay Asians are assigned mystifies us into exotic delicacies. We are, therefore, treated as objects of desire as one would go for dim sum, or chop suey, on a particularly adventurous night. We are not generally thought of as human beings with strengths and vulnerabilities. This more subtle form of oppression also makes AIDS services in the gay community less accessible to gay Asians.



The gay community, indeed, has had enough problems of its own in fighting the epidemic. It took a lot of work to unite and organize the community to its present state in establishing AIDS services. In the process, however, minority groups were left out. The gay community responded to the crisis instinctively, using the best available resources to get the community together. Unfortunately, gay Asians and other minority groups were not high on the priority list. This was not a conscious decision. This was, however, a reflection of the lack of awareness of the needs of minority groups in the gay community. This subconscious lack of awareness and concern can be just as offensive as overt racism. They both have the same effects.

Within our own ethnic communities, the discrimination and prejudice that gay Asians experience are not as subtle or subconscious. Being homosexual is not acceptable and homophobia is rampant. One example is the government of China: Government officials had insisted that homosexuals did not exist in their country, and therefore had no need for AIDS-related services, until this year. Such attitudes from home countries are, in effect, promoting and sanctioning overt homophobia in ethnic communities here. This means gay Asians have to be very closeted, which in turn makes any attempt to organize the gay Asian community a very underground affair.

Fortunately not all Asians are as homophobic as the Chinese government. Many Asians have had the experience of studying abroad in North America and have been exposed to more liberal ideas. These Asians are more tolerant of certain gay lifestyles. This courtesy, however, is only extended as long as gay people remain non-confrontational. Most gay Asians who are out to their families are accepted on the basis that we don't talk about it.

Not only is homosexuality unacceptable, all sexual images in Asian cultures are usually subdued and oppressive. Sex is only discussed in joking ways. Sexual images are usually of women in seductive poses,

subconscious lack of awareness and concern can be just as offensive as overt racism. they both have the same effects.

presented from a male sexist point of view. Open display of sexual desires or affection is considered rude and disrespectful. It isn't that sex is forbidden in Asian cultures; I've learned from my parents that sex is acceptable as long as it is private and behind closed doors. The mystery of what happens behind closed doors, however, makes it very difficult for gay Asians to talk openly about safer sex practices.

This prudish attitude of not knowing what goes on behind closed doors makes HIV, a sexually transmitted disease, a distasteful topic for discussion in Asian cultures. This closed-mindedness also makes fertile grounds for homophobia. For example, in Toronto, the proposal to set up a house for HIV-positive people on the fringe of Chinatown raised a lot of opposition from local Chinese residents. It was not so much that these residents were ignorant about HIV; they were quite familiar with the mechanics of the transmission of the virus. Their fear, however, was that these gay people and drug users must be bad people. The local residents believed that these bad people were going to stalk their wives and rape them, leave contaminated needles around in the playground and endanger their children. Such a severe degree of homophobia, sex-phobia, and ignorance about PLWA do not give HIV-positive gay Asians any confidence in turning to their own ethnic communities, friends, or family members for assistance. As a result many gay Asians compensate by belonging to pseudo-families within the gay Asian community. These pseudo-families form an important support base for most HIV-positive gay Asians.

Because of the oppression of homophobia in the Asian community, many gay Asians have sought refuge in the gay community by idolizing the gay clones. Fitting in with the gay clones, however, means identifying with a predominantly white culture. This has led many gay Asians to internalize racist attitudes from the gay community, thus alienating themselves from their own cultural identities. I myself had ignored other gay Asians for many years when I

as minority groups become more organized, the mainstream gay community can no longer afford to ignore our needs, nor can they continue the elitist attitude of sharing bits and pieces in order to

keep minority groups quiet

first came out, and I see many gay Asians doing the same nowadays. This again results in a rather fragmented gay Asian community, which makes political organization difficult. Often it is the same few vocal individuals who purport to represent gay Asians trying to do too much with too few resources.

Part of the oppression that gay Asians experience, however, comes from their own inherent racist, sexist, and HIV-phobic attitudes. It is often too easy to externalize our problems rather than to take the responsibilities ourselves. In order to overcome what we have subconsciously internalized from clone and mainstream cultures, we have to be more aware and critical of our own passivity and self-hatred. The process of self-examination can be painful but can also lead to inner growth.

Confronted with losing an increasing number of our friends, this painful process of self-examination slowly began. This was one of the positive payoffs from the AIDS crisis. Within each pseudo-family, small inner sanctums of caretakers started to develop in response to the necessity of having to look after an ill member. As the epidemic developed, the inner sanctums also grew, and eventually intersected and merged with one another. The pain and hurt from loss and helplessness led to anger and frustration which later turned into the driving force behind the community. As a result, gay Asians have started to get organized in the last few of years like never before. There is now a common focus to unite us. We can see that if we don't help ourselves, no one will come to help us.

In fact, the concept of self-help seems central to the solution to the AIDS crisis. It comes from a sad realization that we have been alienated from our families, our governments, our health care system, and even society at large. In reaction to this recognition that we are on our own sprang self-help groups, community groups, and activist groups. The way we have organized to help ourselves has been an empowering process, but the reality of

we have been alienated from our families, our governments, our health care system, and even society at large.

self-help also means that we won't help others unless they are one of us.

As AIDS services are becoming firmly established in mainstream gay community and public funding is shrinking because of the recession, the question arises as to how much the mainstream gay community should be responsible for helping minority groups. My experience tells me that unless gay Asian initiatives fit into the mainstream gay community agenda, there is little help forthcoming. As minority groups become more organized, the mainstream gay community can no longer afford to ignore our needs, nor can they continue the elitist attitude of sharing bits and pieces in order to keep minority groups quiet.

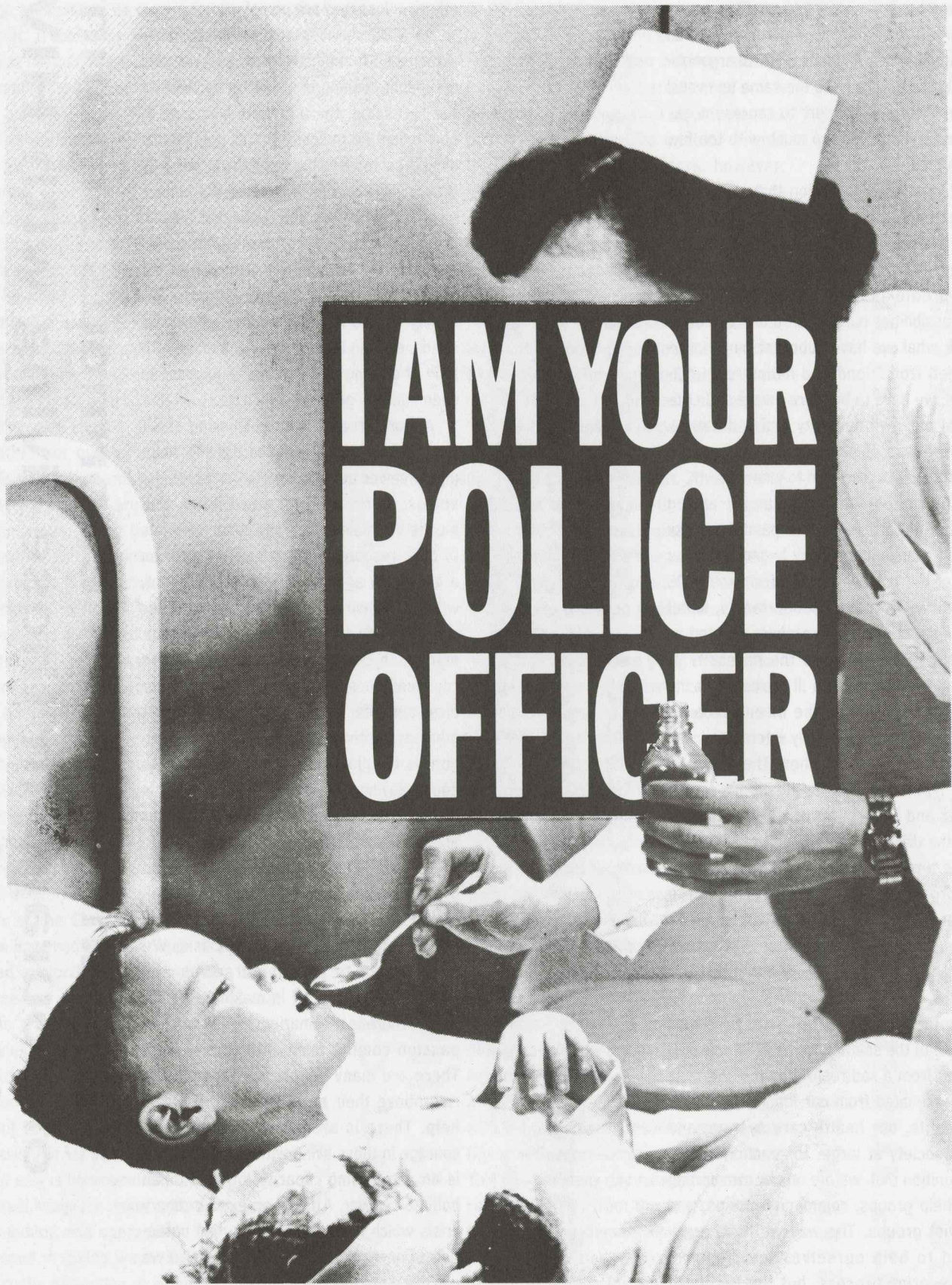
A more creative way of thinking about the self-help model includes not only helping ourselves but helping others help themselves. In the case of gay Asians, this means the mainstream gay community has to offer resources to gay Asians based on a gay Asian agenda. It makes sense that, without knowing the culture, an outsider cannot decide on what is best for that community. In the same vein, the gay Asian community has to overcome its own prejudices and offer to share its resources with other, less privileged groups. The ultimate goal is to allow the minority to achieve equal playing field with the majority. This equalization of power will make a stronger and more united community all around.

In 1992, there is still much hurt and grief around me in the gay Asian community. But amidst all this trauma, I see many positive aspects to the AIDS crisis. We have grown to accept ourselves and learned to participate in making a better world. There is an amazing amount of compassion coming from unlikely sources. There are many people who are able to rise above their prejudices and fears to help. There is an enormous amount of courage in those living with HIV. And there is an astonishing capacity for the human body to recover. AIDS is an extra-ordinary crisis which has challenged human potentials to new heights. Only time will tell if we can live up to this challenge.

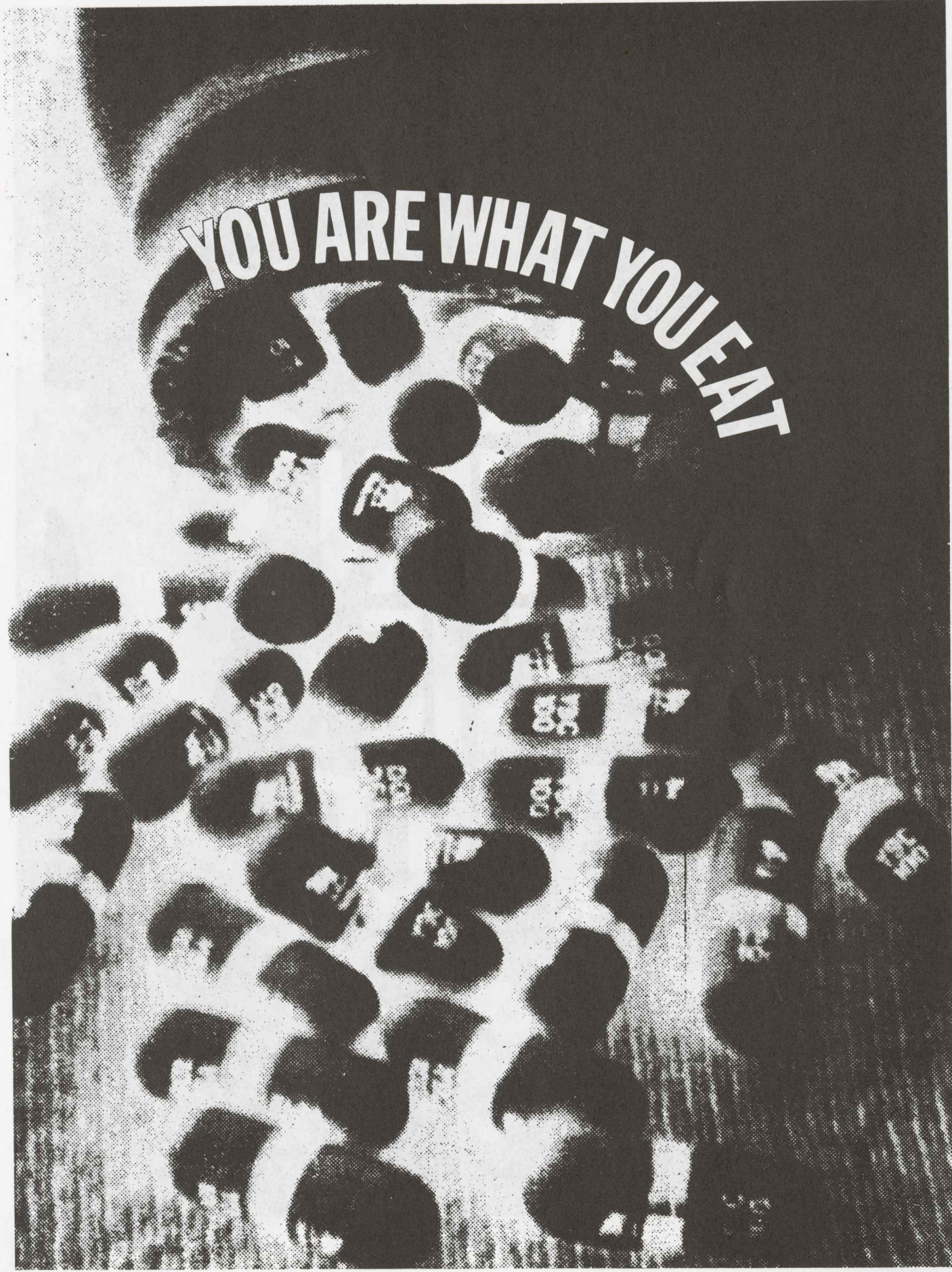
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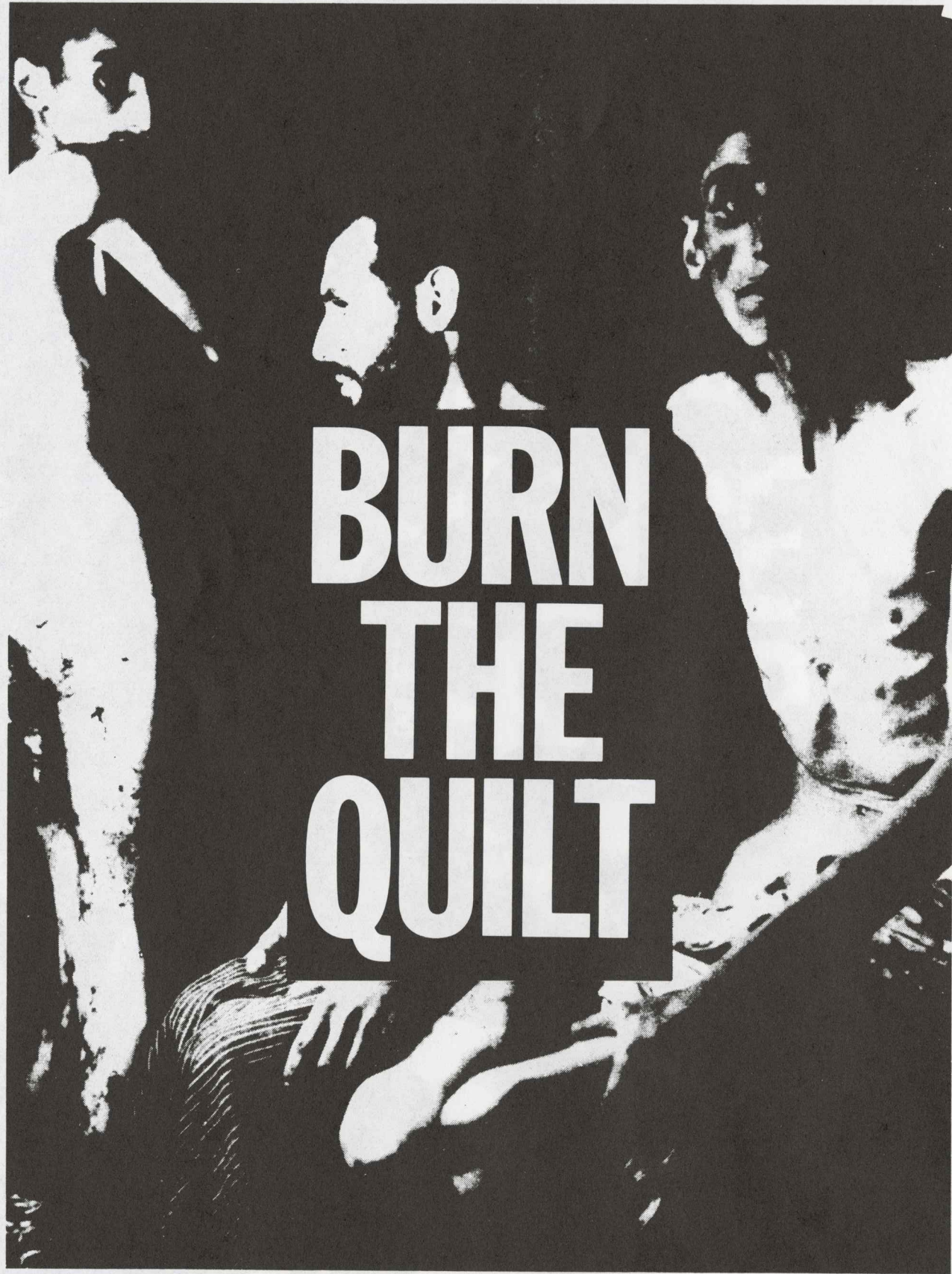
I AM YOUR  
POLICE  
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YOU ARE WHAT YOU EAT







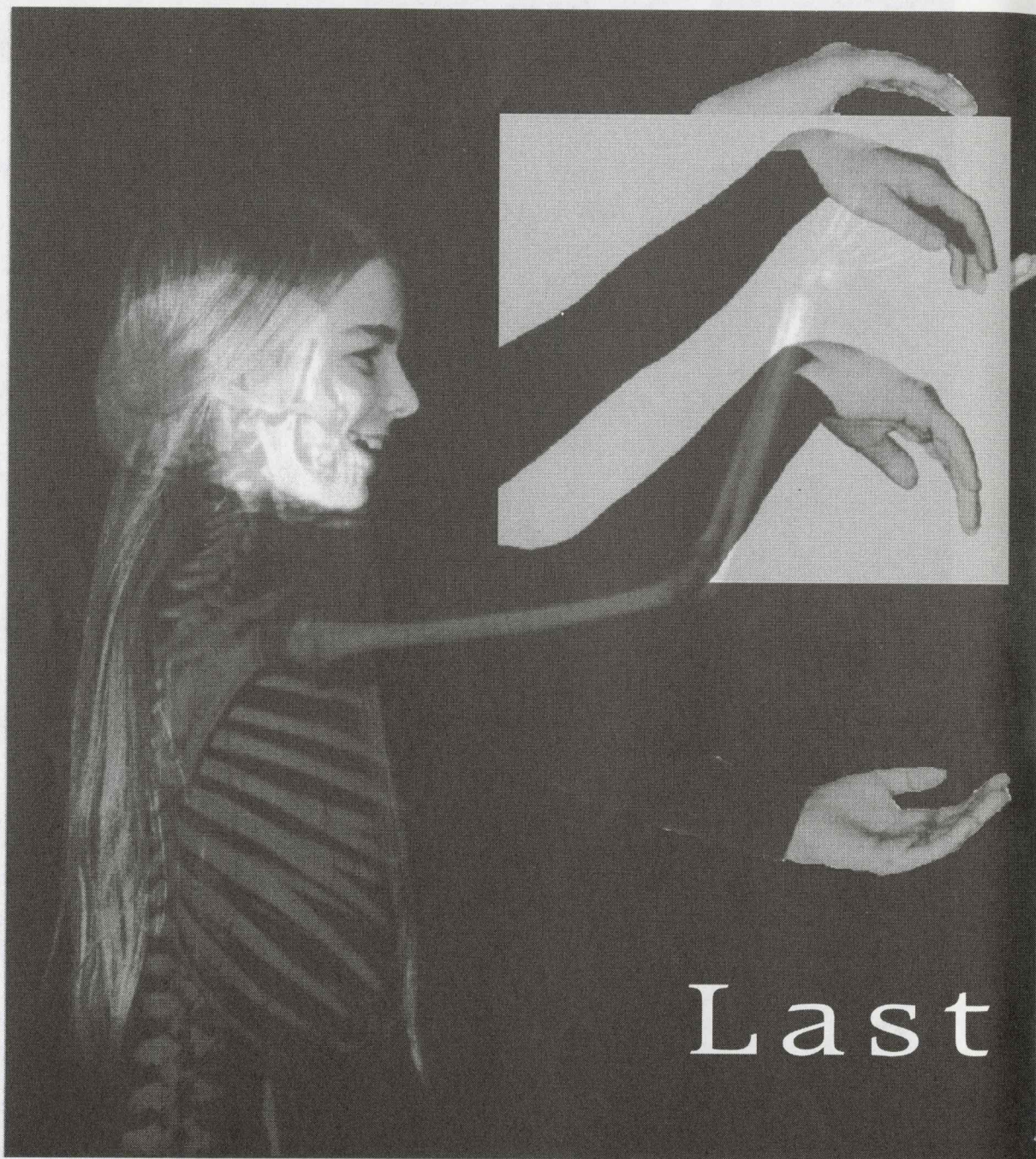
**BURN  
THE  
QUILT**



**BATTLE**

**GROUND**





Last

# Onsets

## Teaching with AIDS

by Michael Lynch January 1990

Setting: an ordinary university classroom, seats regimented in

tiers. During the lecture, a pixel-board displays the-section titles.

The lecturer, white male, hair newly shorn to a brushcut, opts

not to use a lectern but to stand in front of the desk, resting his

### I. Famous Last Words

weight against it at the backside.

You will, of course, remember Emmeline Grangerford, the young poetess who so fascinates Huckleberry Finn. "Buck said she could rattle off poetry like nothing. She didn't ever have to stop to think. He said she would slap down a line, and if she couldn't find anything to rhyme with it she would just scratch it out and slap down another one, and go ahead. She warn't particular, she could write about anything you choose to give her to write about, just so it was sadful. Every time a man died, or a woman died, or a child died, she would be on hand with her "tribute" before he was cold. She called them tributes. The neighbors said it was the doctor first, then Emmeline, then the undertaker—the undertaker never got in ahead of Emmeline but once, and then she hung fire on a rhyme for the dead person's name, which was Whistler. She warn't ever the same, after that; she never complained, but she kind of pined away and did not live long."

Emmeline, who died before she was fourteen, was also an artist of, to Huck, impressive achievement. How lovingly he describes her drawings, their titles ranging widely from "Shall I Never See Thee More Alas" to "I Shall Never Hear Thy Sweet Chirrup More Alas" to "And Art Thou Gone Yes Thou Art Gone Alas." Huck laments her early demise. "A body could see by what she had done what they had lost," and if you missed Twain's ventriloquized amissness in that line, Huck gives you another chance with the next one: "But I reckoned, that with her disposition, she was having a better time in the graveyard." Of all Emmeline's "crayons," her survivors most treasure one begun when she took sick and incomplete at her death. Huck has conned it with care. "It was a picture of a young woman in a long white gown, standing on the rail of a bridge all ready to jump off, with the tears running down her face, and she had two arms folded across her breast, and two arms stretched out in front, and two more reaching towards the moon—and the idea was, to see which pair would look best and then scratch out all the other arms; but, as I was saying, she died before she got her mind made up." This graphic irresolution unsettles him. "The young woman in the picture had a kind of a nice, sweet face, but there was so many arms it made her look too spidery, seemed to me."

Evoked indiscriminately by deathbeds, any deathbed, every deathbed, Emmeline's tributes come to an end only because of an unrhymeable name. (I fantasize introducing her to my friend Bob Schisler, but perhaps rhyming two proper names, like rhyming homophones, is cheating.) If "Whistler" ends her writing career, the onset of illness spurs her career in drawing. Alas.

I don't know when Euro-American cultures began investing so much in undertakings incomplete at death. Was Bach's *Art of the Fugue* always held in the awe that it is now? or Mozart's *Requiem*? or Michelangelo's *Rondanini Pieta*? When did the biographers fall in love with sentences such as this: "and here, Bach laid down his pen."



Whenever this investment became culturally mandated, I am pretty sure that it was big in the bourgeois nineteenth and early twentieth centuries. A staple of sentimental art, such as Emmeline Grangerford's, and antisentimental art, such as Mark Twain's, the deathbed scene held sway over many a body; Richard Howard, in fact, has called it "an age of Interesting Deathbeds."<sup>1</sup> In slavery narratives, however, Afro-American writers tended not to cathect the deathbed, even when the moment—the death of a beloved grandmother, for instance—might have evoked it in white writing.<sup>2</sup> How gamy, then, when Zora Neale Hurston's *Their Eyes Were Watching God* drew from the Twain heritage to narrate the death of a—well, of an ornery mule. "Lum found him under the big tree on his rawbony back with all four feet up in the air. That wasn't natural, and it didn't look right, but Sam said it would have been more unnatural for him to have laid down on his side and died like any other beast. He had seen Death coming and had stood his ground and fought it like a natural man. He had fought it to the last breath. Naturally he didn't have time to straighten himself out. Death had to take him like it found him."

The sentimental or antisentimental bourgeois deathbed scene is likely to have these markers:

1. The mortal man is white.
2. The mortal person is male.
3. He is an adult. (Emmeline is a precocious parodic exception, Twain's astrigent correction to the death of, say, Little Eva, as Wilde corrected the death of Little Nell.)
4. His last creative efforts are broken off before completion.
5. Whatever the broken-off project, it seems, by virtue of its moment in the course of dying, to have a greatness denied to projects that were part, merely, of the course of living.
6. His productivity increases in volume and in clarity. (Schubert.)
7. He claims to be just beginning to learn his art. (Michelangelo, for example: "I am dying just as I am beginning to learn the alphabet of my profession." Or as Huck might have said about St. Peter's, if he could make a church like that before he was ninety, there ain't no telling what he could a done by-and-by.)
8. He utters Famous Last Words to be recorded and remembered through the ages. (The greatest of the enlightenment poets, for example, calls for "*mahr licht*"; Bonaparte cries out "*iête d'armée*.")

9. His words are oracular, granting awesome expectations to those gathered 'round his bed.

This business of Famous Last Words makes an interesting study. Ever tried to find out just when Oscar Wilde said, "My wallpaper and I are fighting a duel to the death. One or the other of us has to go." Or when Gertrude Stein said, "In that case, what is the question?" The almost dead have the best editors, rearranging and polishing *post mortem*. And if the actual Last Words fail to speak an ultimate truth the culture desires, amnesia comes in. Walt Whitman had the longest deathbed of any iconic writer of the Euro-American nineteenth century. Horace Traubel jotted down his words every day for years but who recalls Whitman's last recorded words?<sup>3</sup> Who, besides me, repeats the last words of my own father? "Bring me the bedpan, Dorothy," he said to my mother, "I've got to shit."

Why the valorization, the authorization, the editorialization to achieve Famous Last Words? As one who has been at more deathbeds during the past eight years than I care to inventory, I'll testify to other scenes. Deathbeds tend to be rather ordinary. Bodies *in extremis* may suffer, they may not. They may articulate, they may not. If words are uttered, they may in themselves be as ordinary as any other utterance of the mortal person. Few great truths get said on the deathbed, and fewer yet get said better than they would be said under less terminal circumstances. Modern bourgeois terminal illness surrounds the body with such technology, indeed turns the body itself into such technology, that beeping i.v. monitors supplant words and visions, respirators outgas the patient, tubes and drugs paralyze the vocal apparatus.

The great art: the Famous Last Words. Perhaps both are progeny of a specific Christian tradition, not uncurrent among the bourgeois. Perhaps the most eloquent prose account of that tradition and its commodification comes from Willa Cather in *Death Comes to the Archbishop*:

In those days, even in European countries, death had a solemn social importance. It was not regarded as a moment when certain bodily organs ceased to function, but as a dramatic climax, a moment when the soul made its entrance into the next world, passing in full consciousness through a lowly door to an imaginable scene. Among the watchers there was always the hope that the dying man might reveal something of what he alone could see; that his countenance, if not his lips, would speak, and on his features would fall some light or shadow from beyond. The "Last Words" of great men, Napoleon, Lord Byron, were still printed in gift-books, and the dying murmurs of every common man and woman were listened for and treasured by their neighbours and kinsfolk. These sayings, no matter how unimportant, were given oracular significance and pondered by those who must one day go the same road.<sup>4</sup>



"Whatever the broken-off project, it seems, by virtue of its moment in the course of dying, to have a greatness denied to projects that were part, merely, of the course of living."

Soul on the threshold: in the moment of passage, the soul of the Euro-American male is expected to gain access to the unimaginable scene; thus the oracular significance of lips or countenance.

Another account of the valorization of this moment would be the one where, in extremis, some deity would drop by to receive the passing soul. A black folksong such as "Swing Low, Sweet Chariot" evokes this script, but it's the white deathbed pulls watchers to it in hopes that they might get a glimpse of that deity. Waiting for the sweet chariot's band of angels is not a spectator sport, as it is within the white family. Emily Dickinson, who wrote more moment-of-death poems than Emmeline Grangerford wrote tributes, had many names for the visitant—names such as Death, He, the King. But if sentimental conventions would have the visitant appear, the Finn of Amherst finds his non-appearance the occasion for poetry; in this poem, the I is carefully non-gendered:

I heard a Fly buzz – when  
I died –  
The Stillness in the Room  
Was like the Stillness in the Air  
Between the Heaves of Storm –

The Eyes Around – had wrung them  
Dry –  
And Breaths were gathering firm  
For the last Onset – when the King  
Be witnessed – in the Room –

I willed my keepsakes – signed away  
What portion of me be  
Assignable – and then it was  
there interposed a Fly –

With Blue – Uncertain – stumbling Buzz –  
Between the light – and me –  
And then the Windows failed – and then  
I could not see to see –

*Mehr licht?* Less light. The King be witnessed? Rather, a dazed buzzy fly. Bad entomology, but good poetry to see it as akin to Emmeline's arachnid "crayon."

We don't know if Dickinson's watchers asked for their money back. All those tears, and still no King? It's even worse than sitting through a bad warmup band, and then Springsteen doesn't show.

## II. Who's Talking Here?

The mule does not speak Hurston's book. Emmeline does not speak her own narrative. The deathbed convention positions the reader as vigilant, recorder, rememberer: not the mortal subject. Cather's Padre Lucero is not writing his autobiography. Huck, for all his transvestite proclivities, is not Emmeline; he tells us what Buck told him people who knew Emmeline said about her greatest poem. Dickinson, on the other hand, astonishes by positioning her speaker and her reader as the mortal person, in this case the post-mortem person. This stance strains against the sentimental, devalorizes the importance of the uncompleted achievement ("what portion



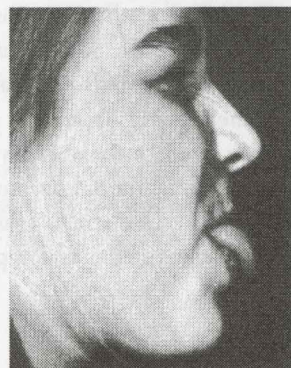
of me be assignable"), and by claiming speech which no vigilant could hear, throws any anecdotal frame of Last Words utterly askew. Its appropriation and repositioning of sentimental expectations is not unlike the appropriation and repositioning in the death of the mule, at least when we recall Nanny's words to Janie: "Honey, . . . De nigger woman is de mule of de world se fur as I can see."

### III. Oracular Expectations

I said just now that in my recent experience deathbeds aren't all they're made out, or made up, to be. What is bigger than I ever expected are the effects of saying, with the upright personal pronoun, "I have AIDS."<sup>5</sup> When one perceives oneself as one who has AIDS, or is perceived by others as having AIDS, a good deal of the sentimental deathbed apparatus activates itself.

First, let me say what the sentence means in my case. It means that a number of years ago—never mind how long precisely—I became infected by the human immunodeficiency virus, alias HIV. In 1987 a blood test registered positive, and may have explained some chronic but non-lifethreatening symptoms such as extreme fatigue. In 1988, a first bout of pneumocystis pneumonia shifted me, by some official categories, across the page, from HIV-positive to "full-blown AIDS." By a wide range of watchers, from friends to diagnostic personnel, I am perceived as someone for whom the odds of death-from-illness within the next one to three years are high, "I am dead, Horatio," says Hamlet, not yet dead; "I have AIDS" carries a ready translation into "I'm on the marge of deadduckdom."<sup>6</sup>

People (among whom is myself) watch this soon-to-be-dead-duck ever so closely. We overdetermine everything about me: he's wearing a black shirt today, it's because he's going to die soon. Or: he's walking more slowly than he used to, he's going to die soon. Or: this allopacia at the tip of my nose,



it's because I'm going to die soon. Every detail can become a marker not so much of mortality as of imminent mortality. Besides overdetermination, there's an awe, a drawing back from morbidity, an urge to say Important Things to me (as if I'll relay them to that band of angels about swing low), tongue-clucking pity. Most striking are the varieties of Oracular Expectations. We expect me to be more visionary, more productive of great works and wisdom, vulnerable to the max.

Many of these bits are indeed related to having HIV disease. Many are not. Many are, and are not. When I withhold the avowal "I have AIDS," it's sometimes an attempt to escape the overdetermined readings of my body. When I say upfront "I have AIDS," it too is sometimes attempt to resist overdetermination. Yet both the withholding and the giving may operate to further the overdetermination. Whether I sat it, or I don't, Oracular Expectations escalate. Willy-nilly, my life becomes a sentimental, or antisentimental, deathbed.

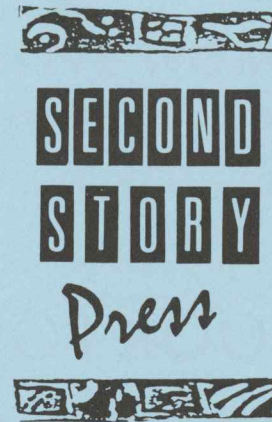
### IV. Caveat Emptor

Before I proceed, let me disentangle the equation that having HIV disease marks imminent morbidity. Even in the absence of a cure, treatments have begun to make a big difference post-diagnosis, in both the length and quality of life. Since September 1988 when I was sure that a bed in Women's College Hospital was, that weekend, to be my deathbed, I've lived and travelled and worked and diddled around. I've learned a lot about monitoring for illnesses and how certain early interventions up the odds for living another two or three years. Today's diagnosis is not tomorrow's guillotine.

### V. The Classroom as Deathbed

How clearly these cross-forces show up when I'm doing that part of my profession that brings me into a classroom. By definition, a teacher is watched. Closely. By necessity, teaching—often thought of as simply giving information—is just as much withholding of information. Some professional codes exclude the out-of-class life of the teacher from the classroom—a strategy I find not only impossible (where, after all, did even the most impersonal of lecturers learn his material?) but undesirable (whether in the microbiology lab or the violin studio, we teach who we are).

My reluctance to say to my classes over the last few years "I have AIDS" comes from no professional code. That body named "Michael Lynch" is already one of the most self-revealing on this campus, and I find the revealing itself animating, life-giving. But if I say "I have AIDS," and the oracular expectations kick in, everyone seems to keep one eye on me look-



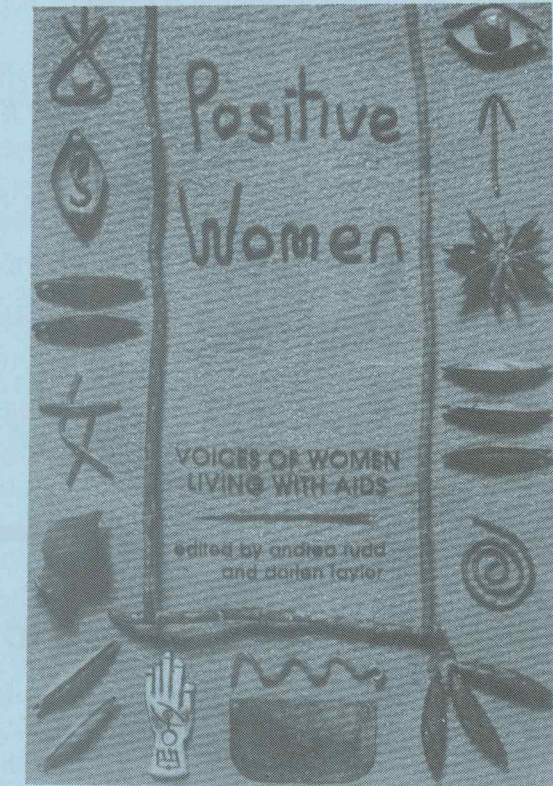
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Later, his sons and some women from his household are brought in briefly and then sent away. At the great sunset moment, when his students/watchers break into "noisy tears," Socrates upbraids them: "I sent the women away, to avoid such unseemliness . . . so keep quiet and control yourselves."

Fourth, Socrates' legs hurt while in chains, but when the chains are removed he feels pleasure from stroking them. To



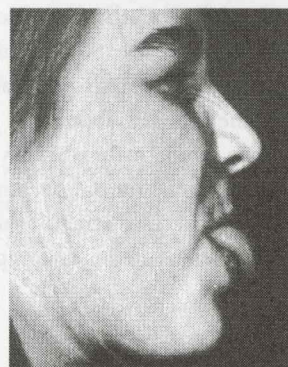
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edited by Andrea Rudd and Darien Taylor

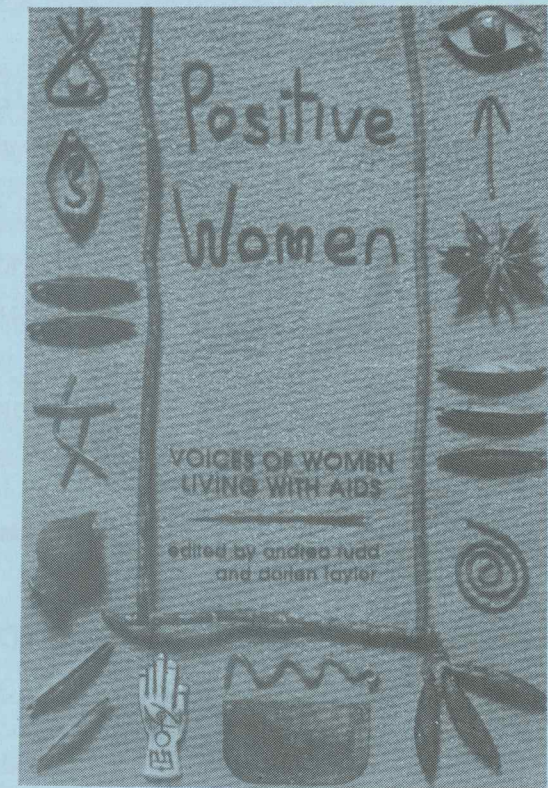
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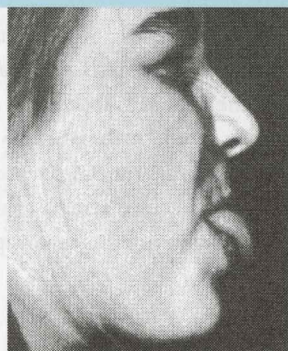
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ing for the marks and the other eye on the door, looking for the King.

RIIINNG, COOP CABS, MAY WE HELP YOU? YES, PLEASE SEND ONE SWEET CHARIOT OVER TO ROOM 2000, 7 KING'S COLLEGE CIRCLE.

The drive to speak it can only be intensified when I'm reading, with my students, such passages as I've quoted here from Twain, Dickinson, Cather, Hurston. How wasteful, I think, to deny whatever voice my experience has in enjoying and deconstructing those/my deathbeds. Slave narratives are ringed with death by violence; the Pequod is a three-year deathbed; did you ever notice how often death and dying comes up in comedy, from Mark Twain to—say, the Golden Girls?

I've engaged several strategies. Last summer, I taught ENG 103, and said during our round-robin of unique introductions, "I have AIDS." The silence of awe, of course. But the next class, one student raised his hand: "May I ask you something personal?" "Go ahead." "If you have AIDS, as I think you said last class, then why are you so happy?" Perhaps my answer should have been "mood elevators, 20 mg b.i.d.," but instead I gave my best Mr. Chips reply, with a touch of Miss Dove thrown in for the genderblend. But that's true too. Several students, as a result, felt freer to talk about ultimate matters such as vulnerability of grief, the fear of infection, etc. Towards the end of the course, one woman asked to see me after class to talk about the positive test results a friend had just received. That's what I thought she said. It turned out, as we spoke on the slope outside University College in the July dusk, that she was speaking of her test results. Would she ever have spoken had I not spoken first? Was it good, or weak, pedagogy?

Another example. Last December 5, at the last meeting of the Willa Cather seminar where I had flirted and skirted the announcement all term, I wanted to announce this talk. But I could only bring myself to announce the first half of the title. How could I hit them with the second half, the AIDS-marker half, when they were just about to write their course evaluations? This concealing/revealing and hinting/coding



may remind us not just of the basic structures of teaching, but also of the structures of the closets that pervade our culture.<sup>7</sup> In a culture of identities, the textures of withholding and revealing can become all-emcompassing. So can the textures of wanting to guess, and wanting, above all, not to see.<sup>8</sup>

## VI. Who's Talking Here? Part II

I'm hardly the first man to treat the classroom as deathbed. If Emmeline Grangerford slipped your mind, you surely have been remembering Socrates. In the Phaedo, where our philosopher, about to down his poison, holds forth about philosopher and the deathbed. His watchers are his students, his last words a lecture. I cathect not at all on the dear gorgeous nonsense he speaks, but on Plato's playsome construction of the scene. Some very odd goings-on go on.

First, Plato, who twice elsewhere says he was present for Socrates' deathbed, has Phaedo explain that Plato was not present.<sup>9</sup> Further, that he was not there because of illness, playfully destabilizes the eye-witness report.

Second, Socrates can babble on as he does because there was an unusually long time between his trial and his execution, so long that Phaedo is called to explain the delay. It has to do with Athen's annual ritual remembering King Minos' annual ritual murders of Athenian youths and maidens, and Theseus's slaying of the Minotaur which ended all that. On the day before Socrates' trial, the ritual ship departed for Delos, and until its return, his execution cannot take place because of a law that the city must keep pure during the ship's absence. So Socrates, who must die for corrupting the Athenian young, cannot die just now because of a ritual recalling the murder of other Athenian young. Odder yet, Socrates, who must die to purify corruption, must for a long while not die so that the city will remain pure.

Third, Xanthippe is excluded from the deathbed dialogue because she says, as Phaedo puts it, "the sort of thing that women usually say." And what is that? "Socrates," she says, "this is the last time your friends will talk to you and you to them." Because of that line, Socrates orders her taken away. Later, his sons and some women from his household are brought in briefly and then sent away. At the great sunset moment, when his students/watchers break into "noisy tears," Socrates upbraids them: "I sent the women away, to avoid such unseemliness . . . so keep quiet and control yourselves."

Fourth, Socrates' legs hurt while in chains, but when the chains are removed he feels pleasure from stroking them. To



explain that one cannot feel pleasure and pain at the same time, he imagines a Aesopian fable about two creatures with one head—bodily pain and bodily pleasure are linked only at the somehow nonbodily head.

Fifth, Socrates on his deathbed has been visited by dreams which say to him, "Socrates, practice and cultivate the arts." He is indecisive about which ones to cultivate, shifting from philosophy to poetry and then to the versification of Aesop, much as Emmeline shifts from tributes to crayons.

Sixth, As he argues for the immortality of the soul and the instability of the body, and derives his philosopher's calm from talking through these concepts, Phaedo becomes distressed. Socrates heals his distress not by argumentation but by stroking the youth's hair. "He was in the habit," says Phaedo, "of playing with my hair."

Seventh, There follows some really curious stuff about hair-cutting, which I'll not go into here.

Eighth, The poison-monger keeps sending word that Socrates should shut up, because if he babbles on like this it may take extra swigs to produce death.

Ninth, One of Socrates' penultimate acts is—to take a bath, "to save the women the trouble," he explains, of washing his corpse.

. . . but here, at midnight last night, 10 mg. of Serax kicking in, Lynch turned off his computer. His great lecture remains incomplete; it's because he has AIDS, you know. But it will be continued in a talk entitled "The Bodies in the Classroom," planned for the English-Philosophy symposium on March 10, 1990. That is, if I live that long.

## Endnotes

1. Richard, Howard, *Preferences* (New York: Viking, 1971), 23.
2. I have in mind Frederick Douglass' imagining the death of his grandmother, and Harriet A. Jacobs' account of her grandmother's death.
3. According to J. W. Wallace's account in "Last Days of Walt Whitman," they were "Warry, shift." See *In Re Walt Whitman* (Philadelphia, David MacKay, 1893), 131.
4. Willa Cather, *Death Comes to the Archbishop* (New York: Knopf, 1927), 170. The passage appears in the account of Padre Lucero's death; the Archbishop's deathbed culminates not in the imaginable scene, but in the remembered one: his bonding with Joseph to escape their fatherland.
5. The self-help books that lard the shelves these days with techniques for death and dying problematize speaking only for some of the people some of the time. Dr. Robert Buckman's *I Don't Know What To Say* (Toronto: Key Porter, 1988), for example, bears the subtitle "How to Help and Support Someone Who is Dying." What to say is a problem for vigilants, not for the invigilated.
6. On 6 January 1990 British actor Ian Charleson died of, as the press put it, "complications from AIDS." Nine weeks earlier he had been playing Hamlet at the National Theatre, even as he was receiving daily chemotherapy treatments.
7. See Eva Kosofsky Sedgwick, *Epistemology of the Closet*, slated for publication in 1990 by University of California Press, Berkeley.
8. Obituary columns have become a primary site for such hide-and-seek texts during the HIV epidemic. For example, this notice appeared in the *Toronto Globe and Mail* on 19 January 1990:

CAMPBELL, Graham Craig—On Wednesday, January 17, 1990 at the Toronto General Hospital. Beloved son of Donald and Eileen Campbell. Descendent of Alexander Campbell, United Empire Loyalist, Schoharie, New York, 1776. Friends may call at the Rosar-Morrison Funeral Home, 167 Sherbourne Street, Toronto (near Wellesley) on Friday after 4 p.m. Funeral service in the Coach House Chapel of the funeral home on Friday at 7:30 p.m. Cremation to follow. Interment of cremated remain in Mount Royal Cemetery, Montreal. In lieu of flowers, contributions to the charity of your choice would be appreciated. Parking adjacent to the funeral home.

A week later, 25 January 1990, this notice appeared in the same obituary column:

CAMPBELL, GRAM—January 17 1990: at noon on that fateful day your friend and comrade told you that you could go if you wanted to, that he would be alright, and by the end of that evening, you were gone, providing one more demonstration of the deep love you both shared. Your creative spark, enthusiastic approach to life, and wonderful sense of humour, will be deeply missed and never forgotten by Alan, your family, friends, and caregivers. To celebrate your life, and to relive some of the memories, your friends are invited to a gathering in your honour. It will take place on Saturday, Jan 27, 2-5 pm, at Ontario Crafts Council, 3rd Floor, Chalmers Bldg, 35 McCaul St, Toronto. Contributions in the form of words and images towards the compilation of Gram's 1990 journal are welcome at the celebration.

They refer to the same legal person. The first was placed by parents, the second by lover and friends. Neither factors in HIV or AIDS as significant, though the latter encodes more cues than the first.

9. I draw on the translation by G. M. A. Grube in *Five Dialogues* (Indianapolis: Hackett, 1981), 89-162. A remark made by Elizabeth V. Spellman in a lecture suggested these observation on Socrates' body in the Phaedo.

EXCERPT FROM PERSONAL JOURNAL, NOVEMBER 1989

Now I know my initial blood "picture" and it's not normal, in fact it's fairly seriously outa whack. My T 4s are low and T 8s high. I was depressed upon learning the results and have slowly adjusted to the knowledge. At the moment my tension is related to the decision to start AZT, wait, or not take it. My naturopath strongly suggests not to, while my doctor urges me to begin soon. I feel caught and anxious.

After a revealing and cathartic weekend spent in the AIDS Mastery workshop I finally confronted my main fears of love and rejection and strong fear of intimacy. I realized it stemmed from never revealing myself or my feelings to my parents. I had never told them I loved them nor did I know if they loved me—no matter what. Well I finally, after all these years, went home to talk to them and confess and offer the true picture of myself. I told them I was HIV+, they were of course very worried and anxious about my health and my status now and for the future. As I explained that situation wasn't hopeless, but was actually full of hope and optimism, we finally confronted the issue of my homosexuality. No reproaches or recriminations, they both listened very quietly with wide open eyes that were moist. No tears, no sighs, they were open. I didn't falter, I felt calm, determined but careful. My father said, No matter what happens to you, or who you are—you are still our son and we love you. I said, Thank you, I love you both too. How great—what a relief—I finally let it out. I felt sad, but quiet, no exhilaration or heart-felt release, just a silent satisfaction. Not quite numb but still reserved. It was all very usual, or normal. We were all very even-tempered, there were no emotional flares. We had dinner.

ROBERT FLACK



HOW IT WAS &  
HOW IT WILL BE  
BY ROSEANNE

# POSITIVE WOMEN

It was a Tuesday morning I believe, in mid-February of 1987, when the call came. Ten days before this, I had found out that we were going to have our first child. We were both so happy at that time, so completely happy.

Then the nightmare began. This is Dr. Smith's office calling, the voice on the other side said. I have been asked to book you an appointment for this afternoon, Mrs. R. Could you please come in to the office about, let's say, 4:00 p.m.?

I had no idea at that time how drastically that call would change my husband's and my lives. The happiness we had come to know just a short time ago was about to be shattered into a thousand little pieces.

I arrived promptly at 4:00 p.m. In about twenty minutes, I was called into Dr. Smith's office.

Hello, Mrs. R, he said. How are you today? After some preliminaries, he got right down to the reason I was called. I hear from your family physician that you have just been handed a positive pregnancy test result, he said.

Yes, I replied.

I wish the news I have could be good news, but unfortunately it isn't.

What is it? I asked. Is it the baby?

No, he said, but I have some test results here that I should tell you about.

But I haven't had any tests done in about ten months aside from my pregnancy test. I said.

Not so. According to this, you have tested positive for the HIV antibody.

What is that? I asked.

Have you ever heard of AIDS, Mrs. R? Have you ever heard of Rock Hudson?

Then it was suddenly clear to me what this man was telling me. It was as if a sharp knife sliced through me right to the very core of my being. My life was being shattered in front of my eyes. I couldn't speak. The fear overwhelmed me. For me, for my unborn child, for my husband, for us. I wished he would just shut up. I wanted to scream but no sound came.

for better

in sickness

till death

I suggest that you contact your physician and discuss the details of an abortion. You will in all probability pass the infection on to your child and the baby will die.

How dare he suggest that I was going to kill my baby before it had a chance to live! How dare he tell me I was going to die! I was only twenty years old and someone had just handed me a death sentence.

I don't know how I made it home. I know I sat there and cried until there were no tears left, until I felt emotionally drained. And then my husband came home. How do you tell the man you love that someone has just sentenced you to death, and how do you explain that his unborn child may be born with AIDS? How do you explain that he himself could already be infected? There is no easy way. But I did, and somehow I survived. The next three days passed in a haze of shock. I slept alone. He hardly slept at all. Locked away from each other, we both tried to contemplate what was happening to us. When we finally faced each other, we wouldn't touch. We just sat there and talked. We talked for about six hours and slowly through the anger and shock we decided,

For better and for worse  
In sickness and in health  
Till death do us part

We had so much believed in those words, so young yet so confident that nothing bad would ever touch us.

But that was then, and it all seems so long ago. My husband went for a test and it came back negative. Through the discrimination and fear and people urging us to abort our baby, we stuck together. But for better or for worse became mainly for worse. But when the labour and delivery room was ready two months ahead of time because I was a special precautions case, we managed to love each other.

Then one beautiful Friday morning at 8:45 a.m. our baby came into this world, screaming her will to live for all to hear. How proud we were and how scared for this little child, so tiny, so defenseless. We were so scared to love her, for we feared that if she should die, we would perish along with her. But she made us love her, more than life itself, for she was the continuance of life personified. She was life long-ing for itself and a new hope for us.

I was discharged two days later because the hospital was afraid the news of an HIV positive mom might spread around. I wasn't allowed to use the same bathroom as the other women and even had to use a completely different shower. My baby girl was with me all the time, as she was not allowed into the nursery and was an infectious disease case with special precautions labels all over. We loved her dearly and yet every time she would get a childhood disease or infection, we would fear that this might be the last time we would hold her.

In the beginning, she tested HIV positive, but we were told that those were just the maternal antibodies passed on to the child from the mother. And with each subsequent test they went down. When our little girl was barely two months old, I decided to defy the doctors and death and I became pregnant again. Call it risky, stupid, even downright dumb, I wanted another child. It was an act of defiance. It went against everything we were told. But we had faith.

This time the pregnancy was hard. I had a baby to care for and another on the way. I had numerous colds, pelvic infections. I bled early in my pregnancy and I was worn out to the point of total exhaustion more than once. Then we got the news of work in northern Ontario and decided to go where our prospects were good. Or so we thought. What a mistake!

In the beginning things were hard but beautiful. We lived in a small town. Clean air and lots of sun was always available. Everything was expensive and we didn't make much money, but we were happy.

At least until I became sick and my doctor ordered me hospitalized in the small town hospital. Then the parade of red stickers began again. One day I learned that while I was in hospital nobody would babysit for my husband or help him with our daughter. As a result he had to skip work, and since there were lots of contractors in the town, he lost the job. How I blamed myself those days and how I hated myself for putting him through this hell!

One day we took our little girl to the only doughnut shop in town and met up with a surprise. When we entered, the place fell silent and only whispers could be heard from behind our backs. Someone spit on the floor in front of us. At this point I was nearly in tears. They knew! There must have been a confidentiality leak at the hospital. We bought our daughter her doughnut and left. Thank God she was only nine months old.

The next day we found out more devastating news. I wasn't going to be able to have my baby naturally, or in town. I was to be scheduled to be induced at a hospital in the city five hours away. I was told when to go to the city and to report to Dr. X to be induced.

The next day, while my husband waited, the doctor broke the amniotic sac of water. We spent the rest of the day wandering through the hospital. I had to carry my little girl on my hip, leaning on the wall to breathe through the contractions.

When the pain of my labour got so strong that I could hardly stand, we were faced with the problem of what to do with our little girl. It looked as if my husband and I were going to have to be apart while I had my baby. But then a small miracle



happened. A woman approached my husband and told him that she had an HIV positive friend and that she was this person's nurse. She offered to babysit for us right there in the hospital. We were absolutely ecstatic. We wanted to be together when our child came into the world.

The delivery came two hours later and as our younger daughter entered this world we cried tears of joy. We were now complete. The four of us would face whatever life would bring and nothing would stop us. In the short moments after our child's birth, we decided that we were going to leave this city, the town we lived in, and take our family back home.

Our joy was premature though. The doctors miscalculated the dates and our daughter was born too early. She was a big girl at seven pounds, nine-and-a-half ounces, but there were other problems. Her bottom eyelids were turned inwards, eyes not quite ready for the outside world.

Ten days after her birth, she came down with a respiratory infection. She had to be hospitalized in the town hospital and there she suffered inhumane treatment. During the five days she was there, she was in a large metal crib, separate from the other babies. She was left to cry and at feeding time her bottle would be propped up on a blanket. How cruel to deny a ten-day-old baby human touch. The nurses only changed her when it was completely

necessary. And then, they wore rubber gloves, masks, and gowns with hats. They tried to tell me that this was for my baby's protection. But if that was so, why was she plagued by a bleeding diaper rash from not being changed often enough? And why was her voice hoarse from crying? Her diaper rash cleared up when she got home, but her lungs and chest have always been sensitive and remain that way. She remained a shy and insecure child until the age of one, and to this day is afraid of strangers.

After we arranged an early release, we thought we could finally leave town. But life had other plans for us. I was so physically and emotionally exhausted by all the events and with caring for an eleven-month-old and a newborn, I came close to a nervous breakdown. I came down with severe migraines and was told that I couldn't be treated in the town hospital. I was sedated with Demerol, against my wishes, and flown to the city. There they performed a CAT scan to make sure that it was a migraine. Afterwards, still heavily sedated with Demerol, I was approached by another doctor. I remember talking with him about permanent sterilization and I know that in my state I wasn't hard to convince. The surgery was done the following day. It made me feel awful and I wondered how come they didn't want me to have babies so much. They caught me off guard and weak. I was plagued by a pelvic infection and severe bleeding after the surgery. I was also told to leave my room ten hours early and spent my time waiting for my husband in the hospital sitting room, while the staff scrubbed the room I had been in twice over, from top to bottom including the ceiling.

When the time came to leave northern Ontario, we had to sell just about everything we owned and worked so hard for. Everything went at a charity price. The town people didn't hide that they were happy to see us go. My microwave that my husband had bought me to make it easier to heat two babies' bottles had cost him 475 dollars of his hard earned money. It was

still wrapped and 18 days old. They offered us a hundred dollars, and we had no choice but to accept. How much hurt I felt at this insensitive cruelty! My babies were the only bright things in our lives. We were literally run out of town. When we left, the only possessions we had were our vehicle, two baby cribs, some clothes and our dishes. We had our pillows, blankets and 980 dollars to our name to show for our move.

We have since closed a door on that chapter in our lives. Our love for each other is stronger than the hate we face. My husband remains HIV negative and our two beautiful daughters, aged two and three, are also negative. We just recently got the test results on our two-year-old with a big congratulations from our doctor. Our faith has paid off and our lives will continue in our children. We will

teach them to love as we love and to respect life as we do. So maybe one day they will be able to say they were proud to be my children. I gave them life and in turn they brought hope into mine.

Back then, we lived in fear. Now we live with hope for a brighter tomorrow and we will never be sorry that we didn't listen to the doctors. For it was not their right to take a life that I had given. And I will never be sorry that I chose to do so.

Roseanne was raised in Czechoslovakia and came to Canada as a teenager. She lives in Western Canada with her family.

Some information about mother-to-fetus transmission of HIV: All babies born to HIV positive women carry maternal HIV antibodies. Within 18 months the maternal antibodies clear, and, according to the latest research, 70 to 87 per cent of babies are then free of HIV.

We

need

to

talk

### KECIA LARKIN

The following is a speech Kecia Larkin gave to the Native community in Toronto.

I grew up in Alert Bay, which is on the northern tip of Vancouver Island. It's a very small isolated fishing community of about 2,500 people. When I was growing up, a lot of things led to my becoming HIV positive. I see and hear about these same things in different communities.

I grew up with alcoholism in my family. I was sexually abused and exploited as a child. These experiences gave me a very distorted view of myself, about who I was and about my life. They basically screwed me up. These things are normal to us on reserves. We breathe them and live them, and sleep with them every night. We pretend bad things

aren't happening and that's denial. There are very scary things that I lived through and people I loved went through them, too. I ran away to Vancouver at fifteen to deal with the sexual abuse, hoping that things would get better. But it didn't quite happen that way.

Because I was sexually abused, it was easy for me to become a prostitute. I didn't care about my body anyway, so why not get paid to have sex?

When I hit the streets of Vancouver, I was like a little country bumpkin who just fell off the cabbage truck. I didn't know left from right. I had the knowledge that was given to me as a child, why I bled every month and where babies come from. But you go to Vancouver and there are things like sexually transmitted diseases and AIDS that I didn't know about. It was too embarrassing, too intimate, too touchy to talk about them.

I got a job at the Downtown Eastside Women's Centre and at first I thought I was doing them a big favour by being there. The women told me that they had been raped and they had been hurt and abused. They couldn't deal with it, so they ran away. And then I realized, well geez, they're just like Kecia. She had to run away because she couldn't

deal with it. And nobody was talking about it. I really felt comfortable dealing with these people because they were real. They didn't have anything to hide behind.

The reason I felt safe on Hastings Street was because there were so many people with the same coloured skin as mine – so many people like the people at home. The sexual exploitation, the abuse, the anger, the bitterness, the denial was screaming out every day on Hastings Street. It was just like being at home again, like my little reserve, only in the big city. A lot of kids run away and end up there because they identify with the others, people who've been abused and left home because nobody wanted to talk about it. Because they felt bad for talking about these things. All my life, I'd heard respect your elders, but they never showed me any respect.

I fell into prostitution, and heroin and cocaine really fast. I was an alcoholic by the age of 15. I felt I had no options. I didn't want to go home and deal with that stuff. I was having fun. I heard about AIDS but I was like everybody else. Oh, it's never going to happen to me so I don't have to worry about it. I figured there was some way to tell by looking if someone was HIV positive.

I found out I was HIV positive after I decided to get off the streets. I met this person who helped me. I didn't know he was from the same background. I knew that he'd been a pimp and a junkie in Toronto. I figured that he was in Vancouver trying to straighten out his life. Just like I wanted to do, but I couldn't, because nobody else wanted to do it with me.

This man contracted the disease in Toronto. Somebody gave it to him. He knew about it, but he didn't tell me. I trusted him, so we never used condoms and we shared needles. He looked healthy. He got into an accident and that's when I found out that he was HIV positive. At that point, I knew that I had it. And then it was easy to blame myself and judge myself because I was just another poor little Indian from Alert Bay who had run away, gotten into drugs and became a prostitute. I felt I deserved it.

When I found out I had it, I said, Fuck this nonsense! I don't want to deal with this.



I pretended it wasn't happening. I felt very dirty inside, very ashamed. I went back to the street, shooting up, sharing needles, working. I didn't care that maybe I was giving this disease to other people the way that I had gotten it. It just didn't seem important because I didn't admit it was happening to me. I was very alone and very afraid. And it's very hard for me to deal with it today because I'm not a murderer. But I see myself that way sometimes when I'm feeling really shitty. I did it because I didn't feel that I had anybody there to support me.

I knew my family was screwed up. I didn't want to go home and say, Here I am, I've got AIDS, deal with me. Because I thought that they couldn't. I figured they wouldn't welcome me. I kept it a big secret just like all those secrets I kept about sexual abuse. I was taught that you don't talk outside your family anyway, because it's disrespectful, it's wrong. Finally, one day I got really tired. I got really sick. I got really lonely and scared, because I was wired on coke.

I had nowhere to go so I put myself into a detoxification centre. I had to make the hardest decision: whether I was just going to let myself die or whether I would fight. So I phoned my mom and told her where I was. I told her that I was HIV positive. She didn't know what that meant. In small communities, they don't know about it, if they've never had AIDS education. You see it on television — AIDS, AIDS, AIDS — but you change the channel because it's not your problem. That's only in the city.

I explained to my mom what it was. She cried and cried and I could feel her pain. I was really scared and she was really scared. Somehow we came together and she told me to come home because she needed some help to deal with this. I knew that I did, too, but I was afraid to ask for her help.

I went home and that's where I stayed. If I hadn't, I wouldn't be here talking to you. It scared me to go home, because I didn't know how the rest of my family would react. So we kept it a big secret for a long time since Grandma is pretty judgemental. She likes to criticize.

I didn't talk about this really openly until

about eight months ago. My mom disclosed to certain family members that I was HIV positive. I'm really happy and really lucky because I have my family, people who just accept Kecia. I've never really been shown that before. And this is what I'm being shown with my work.

It makes me sad to know there are a lot of people out there who will never have that family support, people who will die alone. I put myself in their predicament and say, What would it be like if I were alone, if my family had rejected me? I know that I wouldn't be able to make it alone. I wouldn't be able to sit here and say what I am saying. Because for a lot of us, our families are all we've got.

We all have our little piece of hell, but not enough of us talk about it. It's not just Kecia who has AIDS. There are a lot of things that we need to start working on together.

It's really frustrating because it always comes down to those things that happen: the alcoholism and sexual abuse that nobody wants to talk about. That's why we're running away. That's why we don't want to be at home. That's why we're going out and getting high so we can't feel anything, so we don't have to think about those things. That's why we're not where we're supposed to be. Because of that little piece of hell that we carry around inside that we don't want to talk about because nobody else knows how we're feeling. Yet everybody feels the same way.

We need to talk. We need to yell and scream rather than just sit and suffer in silence, because it's not doing anybody any good. And if anybody's in a position of power, if they're being quiet about these things, it ain't doing their people any good because it's really phoney, it's very fake. And we can see that.

I got into trouble a lot when I was growing up because I have a big mouth. But I love my big mouth. I go to communities to talk about my experiences. I see a lot of people sitting in their chairs, listening to what I have to say. I can feel if it's affecting them to hear me talk about sexual abuse. And I'm not going to stop talking about it.

Kecia Larkin is a young Native woman who grew up in a small fishing community on the west coast of Canada.



Illustrations by Mirinda Lafaye



# LESSONS FROM THE

BY LLOYD WONG

STEFAN COLLINS TESTED POSITIVE for antibodies to the HIV virus in 1982. That puts him in the honoured elite of long time survivor. "Or does it?" The test used to detect the antibodies was first made available in 1982. We have only been able to test for it since then, but that doesn't mean it wasn't around before that. The entire medical industry would have you believe in the importance of HIV as the sole cause of AIDS. The multi-billion dollar AIDS industry is, by and large, organized around this notion. Critics, and there are many, claim that there are co-factors that actually cause AIDS, rather than the single agent theory of HIV.

Living in Winnipeg in 1982 left little to be desired for Stefan, an out gay black man who had just tested positive. "There was no kind of support system. I had post-test counselling that lasted about five to ten minutes and then joined a support group that met four times. It was eight men with different phases of this illness. That was it. They weren't organized very well." Winnipeg had no lesbian or gay community centre at the time, except for Giovanni's Room, a bar for gay men. This is where Stefan found his support group. This bar is where I looked for post-test counselling. That was the extent of the support systems they had then.

It didn't take much time for Stefan to exhaust the resources available to him. "I had to be around people who were infected as well. 'Where were they?' I had this game where I couldn't tell anybody. I told a few people and some family. I got very negative reactions so I was silenced and was afraid to tell people. I couldn't tell them because of where their head was at."

Testing HIV positive is stressful in and of itself, but to cope with the associated emotions over a ten-year period is another issue. So little is known about AIDS and there is so much new information to keep abreast of that one's whole existence quickly becomes organized around AIDS. It is a long time and I've seen a lot of changes and I've gone through a lot of changes. I've seen a lot of people come and go. Everything I do is affected by HIV. I can't get away from it and sometimes it angers me. Fuck, sometimes I would just like to tune it out. No matter how much positive thinking or visualization I do, it doesn't touch the depth of the realities I have to face and deal with. Your whole lifestyle becomes [centered around HIV]. It's just a

lot of work to stay on top. It's just a lot of work. And it's scary, scary in the sense that you don't know. This disease is so unpredictable. Even after ten years, one minute you're in and the next minute you're out. It's hard to maintain your sense of hope and strength when you see everything around you deteriorate, like friends, lovers and just people—multiple losses."

Needless to say, racism has also affected Stefan's experience of HIV—from the very beginning in Winnipeg with an all-white support group to his work today as a community health worker and activist. "I would listen to these men in Winnipeg talk about the issues they had to deal with other than HIV, like homophobia, and it was okay to name it and talk about it. And then when they were so blatant with their own racism, I would try to name it. But when I tried to do that as an HIV positive black man talking about other issues that come into play, not just HIV and AIDS, all of a sudden SNAP! 'Oh no, we're only talking about AIDS here. We're not talking about racism.' And it was tiring. It was me having to educate them. It took me away from my own self-healing and it made me very angry. Here I am dealing with these fucking bigots and I'm calling them on their racism and they deny it. And being the only black person reinforced my isolation. So a lot of my time was spent educating them. 'What happens to me? Where does my support come from?' And then when I came to Toronto, it was like that all over again. It's like 'Oh my god, when does this stop?' These are supposed to be educators that are educated. I'm not supposed to be teaching them! And they're not even interested in my concerns. It's still happening."

We know that racism exists and that it is merely reflected back in the organizations and institutions we use, create, and even work for. So it is easy to understand how Stefan's experience happens. However, this implies that there is an abun-

dance of support for people like Stefan within the gay black community. Not true. While there does exist small informal social circles for gay black men, the denial around sexuality makes it difficult for Stefan to find the support that he wants. "It's a denial thing. They don't want to deal with it. When are they going to deal with it? When a crisis faces them? There so many factor that come into play for them. It's the internalized stuff that they have to deal with themselves. Everything society has done to them, the drug problem and the housing problem. With all these problems it's just another thing until a disaster happens and then it becomes a priority."

In Toronto, racially-specific AIDS service organization have been created to fill in the gaps where others leave off, namely the Alliance for South Asian AIDS Prevention (ASAP), the Black Coalition for AIDS Prevention (BlackCAP), and the Gay Asian AIDS project. "All these groups have to organize themselves just like the women's groups because they have to address their own issues; mainstream society is not going to. Let's face it, they've made it quite clear where they stand on the issues. Having groups like BlackCAP gave me a sense of solidarity and strength. I belong and I'm not alone. I can go there and not have to feel like I'm isolated and have to explain or educate them. I can express my issues and they can understand. And then again, within these same groups, you deal with homophobia, sexism, and internalized racism."

While these groups are much smaller than most other AIDS service organizations, they find themselves having to do just as much work with a small core staff of three where other mainstream organizations work with upwards of 50 staff. Racism delineates parameters in curious ways so that many of the services an organization like BlackCAP must provide are already available. Systemic exclusion works to prevent these services from reaching all populations. There is also the need for culturally- and racially-specific service and ways of outreach. Stefan comments, "They [BlackCAP]

fuck,  
I would  
just  
like to  
tune it  
out



# no more crocodile tears

started off doing basically education and prevention within the Black community and specific groups, that is, youth, heterosexuals, lesbians, bisexuals and drug users. Groups we are trying to target are the IV drug users because that is very prevalent in the Black community and we are trying to target heterosexual men because they're in heavy denial. We're not perceived as a gay organization but we have lesbians and gays on our Board of Directors who give it focus and make sure we are not left out. Lesbians and gays are doing all the frontline work. More Black HIV positive men and women are starting to surface so we have to implement strategies and programs that deal with them."

As a part of his own healing process and coping, Stefan is also an activist, spokesperson, and community health worker. There are costs to pay beyond the obvious for being so vocal and identifiable. He has encountered hostility on the street from strangers that have recognized him from a television appearance, but beyond that, he must deal with the never ending responsibility of being "the HIV positive representative." This is true for anyone who decides to cross the line into a public identity whether it is about being of colour, HIV positive, queer, or female. "There's a burden when you become visible. Everybody expects you to do things. They call you the day before to give a talk and when it's over, they give me bus tokens! They assume I have no needs, but meanwhile I'm dealing with unemployment, housing problems etc. . . . bus tokens are not enough. I have to re-evaluate my

whole support system. Where is my support? When it comes down to the crunch, where are they? I'm getting used and abused. No more crocodile tears. I'm tired of crocodile tears."

Stefan began his community work by volunteering as a buddy for people that needed help. You would think that being the caregiver would have its share of rewards. Instead, racism rears its ugly head. "I've had this experience a few times. I was told quite frankly that the person who was sick didn't want someone who was black, or I would go to meet somebody and they freak out 'You're black! You didn't sound black over the phone!' Like what the hell is this? You're sick, you're on your way out and what difference does it make what colour you are if someone is going to give you the support, care, love, and respect that you need. Like get over that dear! It hinders my relationship because I don't want to play that role with them. I'm giving a support care service to this person and helping them out whenever I can and they're giving me this kind of racism. I can respect and understand that you have that choice. But when you're in the process of dying and you can still have that crap, that angers me!"

More recently, Stefan works as an education and prevention officer at a suburban community centre. From his personal experiences as well as his work, he has learned to understand where people are coming from and as hard, and wrong as it may be, respect where they are at. "I was putting up a poster as this black African man was watching. Before I even left he had torn it

down, so I went to him and starting talking to him. I was trying to connect with him and talked about his wife. 'I can always get another wife,' he said. So I had to try another route and so I started talking about his children and he started to listen. Another time, I had a client who was straight and he wanted someone who was straight or who didn't act or look gay. This guy was an IV drug user. He said 'Well you don't look gay and you don't act it.' We both had cowboy boots on and that's how we connected. Still I felt powerless because I always had to be on guard. He could justify his sexuality and explain to me how he felt, but when it came to mine, it wasn't justified. He didn't want to connect or talk about it."

In the final analysis, it's about respect. In this case, it's not the respect we need to give to those that are HIV positive, but the lessons here are about the different kinds of respects necessary for the complexities of AIDS. "We have to face the realities of what we can do and accept the things we cannot do because we can't be there for everybody within our communities. We know how they work. A lot of them are bisexual or gay but they don't identify with their sexuality or refuse to. They come over to these groups and we have to educate them and respect the denial and where they're at. If BlackCAP was just a gay organization, we would lose a lot of the population because the homophobia is so rampant and so hyped. So many people are in denial anyway it's easy to distance themselves from it."

# it's about respect

by Andy Fabo

EARLY IN THE AIDS PANDEMIC a false polarity was created between activist artwork and more subjective, emotional artistic responses to the loss of loved ones. In time, however, it was generally recognized that the anger of activism was not the only appropriate reaction. A community does not only organize, mobilize, demonstrate, and lobby together; a community also celebrates and mourns together.

In Canada there has certainly been, and continues to be, a lot of political work to do. It wasn't until the International AIDS Conference in Montreal in 1989 (nine years into the epidemic) that Prime Minister Mulroney first addressed the AIDS issue in public. It took great lobbying efforts on various governmental agencies in order to release such vital AIDS-related drugs as Pentamidine, Gancyclovir, and DDI. The cost of drugs not covered by drug plans can be financially crippling for HIV patients. Our systems of socialized medicine and a broader social net (housing, hospices, access to disability pensions, etc. . . .) for those in need, however, has produced a substantially different circumstance than in the the U.S., and art dealing with AIDS in Canada reflects that difference. The pressure-cooker situation that created the agit-prop response of *Gran Fury* in New York is not nearly as intense in Canada. Also the gulf between the activist response of artists like John Greyson, Werner Arnold, Michael Balsler, David Tuft and HIV-positive artists making personal responses (Stephen Andrews, Rob Flack and myself) is less polarized here. Most of these artists are working on both sides of the illusory fence.

Similar to the U.S., artists in the video community have made the most extensive, varied, and informative responses to the AIDS crisis. This is largely because the time-based nature of the medium is amenable to didactic purposes. One exemplary project that came out of the art community was the Toronto *Living With Aids* cable television series that aired in the

1990-'91 season. Initiated by Michael Balsler and John Greyson and produced by Michael Balsler, it included programs by Debbie Douglas and Gabriella Micallef, Glace W. Lawrence (for BlackCAP), Gita Saxena and Ian Rashid (for the Association for South Asian AIDS Prevention), Ted Myerscough with Anishnawbe Health, Greg Wight and Jim MacSwain, Richard Fung, and Coleman Jones. Unlike the numerous ACT UP-related video projects from New York, these tapes were not documents of actions responding to immediate issues;

ed in the mid-'80s, had its inaugural display in Washington on the Mall in the fall of 1987. The Quilt has travelled extensively throughout North America since then. The initial showing had almost 2,000 panels, although now The Quilt is too large to be shown in its entirety. When a portion of it is displayed in a city the local panels predominate, but they are augmented with additional panels from the rest of North America. The most recent showing of The Quilt is reflective of how this gesture has been co-opted by the mainstream, appear-

# OF MEMORY MEMORIALIZING RESPONSES TO THE DEVASTATION AIDS

rather, they were carefully written and produced investigations of the longterm concerns of various targeted communities. Canadian responses have been meditative and considered while maneuvering the treacherous terrain of the AIDS crisis and its contradictions.

The highest profile memorial project is The Names Project, better known as "The Quilt". It consists of sewn panels memorializing those who have died of HIV-related complications. Created mostly by loved ones, the panels tend to be highly personalized and therefore surprisingly revealing of the personality of the deceased and how she or he was regarded. This project, start-



ing in the windows of The Bay on Queen Street as well as in several galleries of the Textile Museum in the fall of 1991. Few can deny the continuing emotional impact of The Quilt, especially when we see the names of past lovers, friends, or relatives, but increasingly The Quilt is presented in such a way that gay and lesbian communities are rendered nearly invisible. This is apparent in recent literature, publicity, and video documentation related to The Quilt project. The early grassroots video document by David Thomson has frequent images of gay men and lesbians embracing and grieving together; in one recent "slick" documentary, this aspect of the



Photo Jake Peters

**THE NAMES PROJECT  
AT THE  
TORONTO TEXTILE MUSEUM**

epidemic is totally eclipsed by the sorrow and anger of mothers, as if the deceased could only be worthy of mourning within the embrace of the traditional family. Certainly the AIDS crisis is hitting with a vengeance communities that believed they were not at risk, particularly in the lower income strata, but this does not justify ignoring both the terrible toll and incredible contribution of the gay community.

To counter this increasing oversight as well as many others, Nan Goldin and the Visual Aids Caucus initiated a project in 1990 that attempted to reveal more completely the face of AIDS in New York City. Titled Electric Blanket: AIDS Projection Project (with an obvious reference to The Quilt), this project consisted of slides projected onto a screen mounted on the exterior of Cooper Union, an art school in the heart of the East Village, on the evening of A Day Without

Art, December 1st. The slide selection was edited by Nan Goldin with Alan Frame, and a conscious effort was made to represent a broad spectrum of those affected including women, the homeless, blacks, Hispanics, gays, bisexuals, and families. As well as portraits of people living with AIDS, there were also memorial portraits and documentary photos of political actions around AIDS issues.

In Toronto this project was first mounted in 1991 by a lesbian and gay collective that later came to be called Clamorous Intentions. The members of this new collective are Frederick Peters, Sharon Switzer, and Claire Sykes. The initial contact with the New York originators was made by Toronto artist/curator Robert

Windrum. He asked Clamorous Intentions to curate and organize the project, recognizing their capability, energy, and commitment. With only a few months to organize, they found a suitable site, did the fundraising, and gathered a large selection of slides. The site of the projection screen was the Club Monaco billboard on Queen Street. Conveniently the artist watering hole and club venue the Rivoli Café was directly across from this ideal screening surface. A benefit at the Rivoli featuring Toronto bands Fictive Kin, The Pardon Beggars, Mother Tongue, and Sunforce coincided with the street presentation of slides, while video monitors inside and loudspeakers outdoors brought the two components of the event together on that chilly December evening. The event was simultaneously moving and celebratory, wrenching and empowering, contemplative and mobilizing.

The Toronto visual component that was added to the the New York selection included the well-known activist documentation of Jake Peters, archival photographs from Casey House Hospice, Xtra!, Buddies In Bad Times Theatre, BlackCAP (mainly from Dionne Falconer), Rites magazine, and the Walk for Life (Stephen Spera, Jeff Woods), along with contributions from individuals like Claudia Converse, Phillip Hannan, Alan Miller, Claire Sykes, and Sharon Switzer, to name a few.

The franchise aspect of Electric Blanket was problematic because the New York organizers insisted on the final edit of the Toronto material and they eliminated some images that had particular resonance in Toronto. Also, there were many American

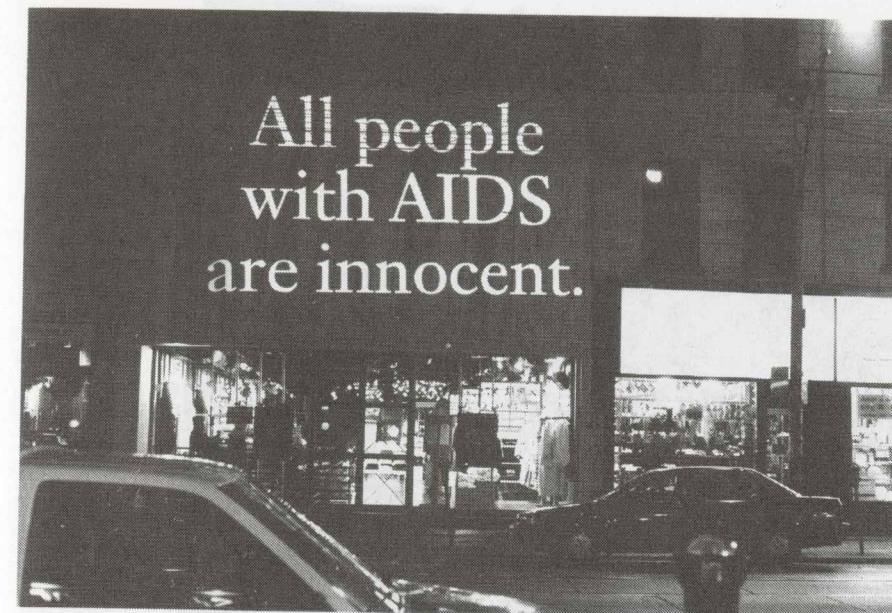


Photo Jennifer Gillmor, courtesy Clamorous Intentions

**ELECTRIC BLANKET  
ON QUEEN STREET**

images that gave distorted notions of the effects of the AIDS epidemic locally, if you didn't know their origin. For example the preponderance of blacks in the AIDS and Homelessness section does not reflect urban reality in Canada. Clamorous Intentions recognized these problems and worked up to the last minute substituting text cards with Canadian information and statistics, and recontextualizing the images that were the most troublesome in a Toronto milieu. The job would have been easier if the New York organizers of Electric Blanket had actually understood that a New York view is far from universal and entrusted this intelligent young trio with more autonomy, giving them more leeway to address the particulars of the local.

Facsimile is the name of a current memorial project by Toronto artist Stephen Andrews. The genesis of this project occurred while Andrews was in France on an extended visit where he received a fax

from a friend of the year-end Proud Lives column from Xtra!, Toronto's gay and lesbian bi-weekly. Proud Lives is an obituary listing of those who have died of AIDS-related complications, most of which are accompanied by a snapshot of the deceased. Finding the multi-page spread of friends and strangers wrenching, Andrews wished to convey this strong sense of loss in a new body of work. He began hand-replicating the portraits by coating wax tablets with graphite and carving away the white areas of the digitalized images. These portraits were pointed tropes for our memories of those who have died: seemingly so tactile and concrete, and yet disintegrating within every stage of recall. He has now completed almost 100 of these laborious portraits on which he stamps the name of the individual on the side of each mounting frame. The images are accompanied by a scroll listing all the names and installed at an angle beneath the portraits. Closer inspection reveals the scroll to be a piano roll, a musical analogue of the modern-day fax. The brilliance of Facsimile is that it is cool and mediated, inviting reflection and analysis while simultaneously being rough, hand-hewn and heart-felt, providing an emotional safe-space for mourning.

The Memorial Wall was spawned by the late Michael Lynch in 1988 when, with a firm belief that remembering was political, he organized an ad hoc public memorial in Cawthra Park for Gay Pride Day. The first version, made of cardboard, letraset and buttressed plywood panels, listed names under each year of the epidemic. This temporal monument proved to be a cathartic site of community, grieving and a committee led by Lynch negotiated with the city to hold a competition in order to choose a plan for a permanent one for the park. In the fall of 1991 a young architect, Patrick Fahn, won the commission and his granite and steel naming project should be installed in the next year.

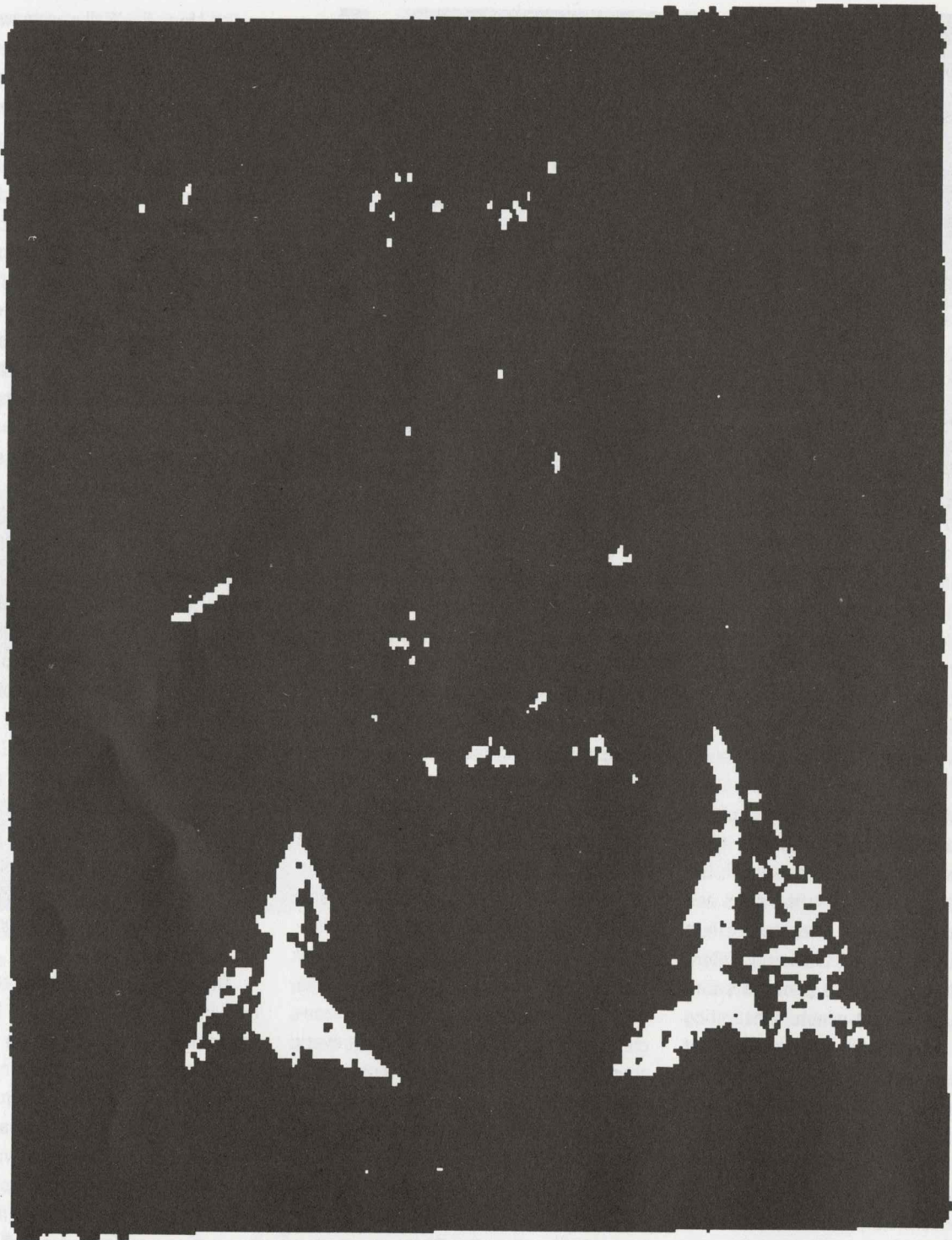
Another initiative that Clamorous Intentions has undertaken for the future is an extensive exhibition at A Space, culled from work done by artists remembering lovers and friends lost to AIDS. This memorial show is intended to survey all media and be representative of the broad spectrum of communities that have been touched by AIDS in Toronto. It is scheduled for late November and early December in order to coincide with A Day Without Art. The fact that this show is the first mixed-media group exhibition dealing with AIDS that has been mounted in Toronto is a shocking reflection of curatorial biases in the city.

The explosion of lesbian and gay culture in the past decade has been overwhelming. We are asserting our voices during this crisis, countering the lies, myths and distortions of the mass media. Memorial projects and elegiac artworks are part of a multiplicity of vital cultural expressions but they are best tempered with a sense of committed activism, thereby creating a radical subjectivity.

Andy Fabo is a Toronto artist whose work in painting, drawing, installation and video over the past 17 years has explored the construction of the gay male subject. He was diagnosed HIV-positive in 1986 and remains asymptomatic to date.

A community does not only organize, mobilize, and lobby together. A community also celebrates and mourns together.



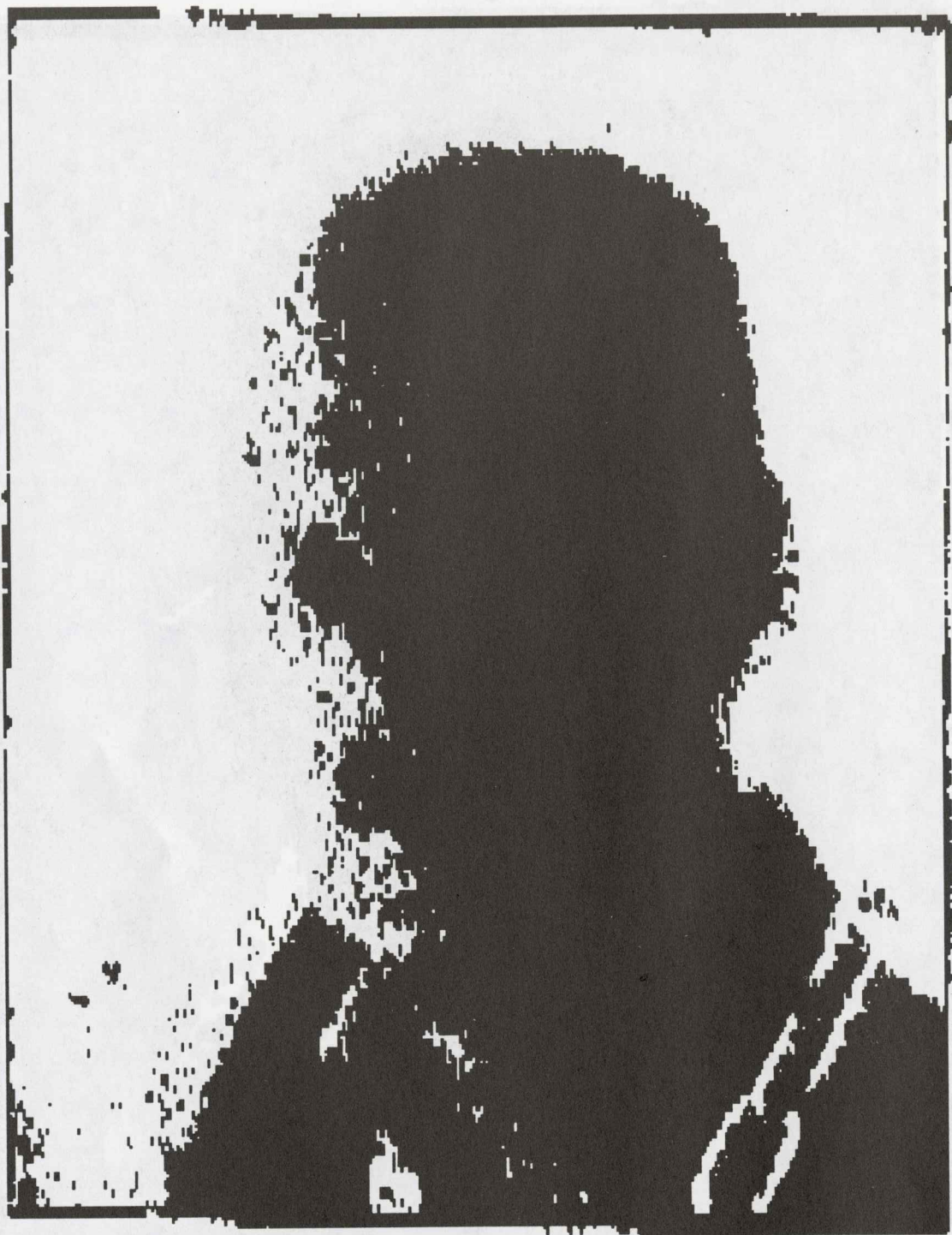


≈ Emperor XII Teddy Bear ≈ Michael Rowlin ≈ Peter Richard MacEachern ≈  
Arthur G Ladson III ≈ Dan Wanamaker ≈ Michael J Levin ≈ Louis Aguiar ≈ Peter  
Georgantis ≈ Frank Seta ≈ Brian Covert ≈ Chris Ackley ≈ Howard Rose ≈ Norman  
Smart ≈ James Alexander Denholm ≈ William W Palmer ≈ Dan William Wordock  
≈ Angela Spalding ≈ Larry K Dawson ≈ John Steer ≈ Frederick Gordon Gilbertson  
≈ Craig Russell ≈ Ian McIntyre ≈ René Gilles Pellerin ≈ Rene Highway ≈ Clyde  
Anthony Paisley ≈ Thomas Robert White ≈ Vito Russo ≈ Marty Miller ≈ Miguel  
Angel Solana ≈ Gordon K Stone ≈ Michael E Plank ≈ Leonard Holden Krause ≈



Bryan Fisher ≈ Tony Brady ≈ Liz Lyons ≈ Michael R Taylor ≈ Ron Niebrzdowski  
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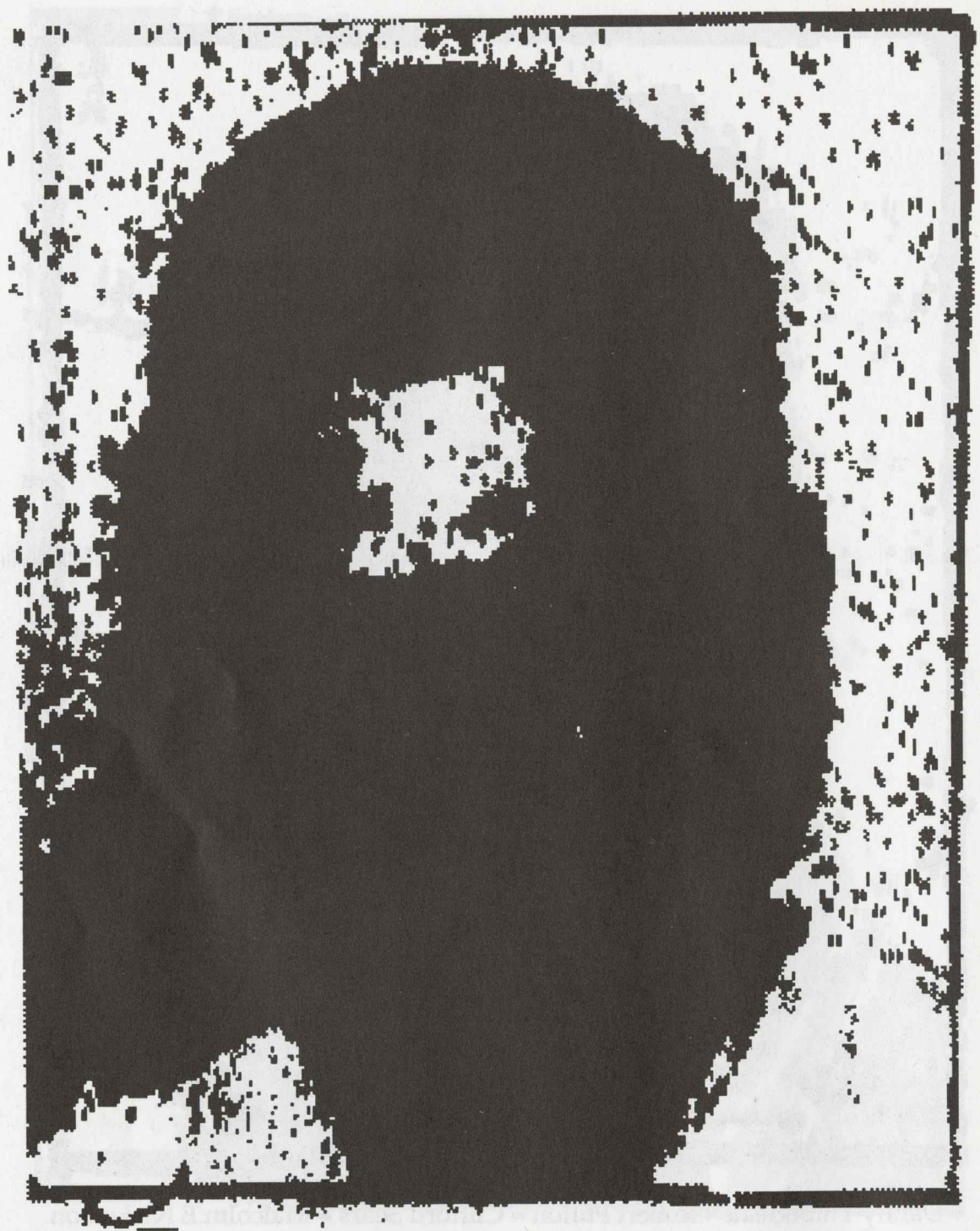


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Bernard Courte ~ Robert Lennox ~ Stephen Eric Pugsley ~ Warren Kent Rattray  
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~ Paul LeClerc ~ James E Jefferson ~ Robert W White ~ John P Ellis ~ Peter Bruce  
MacNaughton ~ Hugh Conroy ~ Tim Jocelyn ~ James Valentine Quixley ~  
Gregory A Wight ~ Michael Lloyd Boschman ~ (John) Paul Black ~ Paul Vale



~ Danny Thibodeau ~ Robert Fulton ~ Clifford Sears ~ Malcolm E Nickerson  
~ Leo Bujold ~ Peter Ackerman ~ Alan Orenstein ~ Chuck Grochmal ~ Stan  
Goodwin ~ Bill Lane ~ Wayne (Sacha) Voce ~ Clark ~ Wayne Thompson ~  
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Michael David Hersco ~ Doug Bonnell ~ Daniel Grenier ~ Raymond A  
MacDougall ~ Leo Bertrand ~ Gordon Montador ~ Ezeikel Garcia Murillo ~  
Michael Noel Yow ~ Robin Bush ~ Leon Young ~ Michael James Smith ~  
Lawrence Hardcastle ~ Angel (Felip) Vila ~ Susanne Frost ~ Mary Margaret  
Hanson ~ Leon Scobie ~ Richard Bender ~ Bruce Burnham ~ Julene Spurrell ~  
Laird Sagetcheway ~





Glen S Todd ~ Michael J Leclair ~ Harvey Maurer ~ Jean-Louis Paquette ~ Pat Evans ~ Mark Denny ~ Gordon Condy ~ Bill Affleck ~ Michael Pitz ~ Rene J LeBlanc ~ Michael Martin Smith ~ James King ~ John (Josh) Powell ~ Marcel Aucoin ~ Stephen D E Schell ~ Doug Price ~ Maurice Flood ~ Carl Watson ~ Albert M Paradis ~ Thom Barns ~ Robin Boyd ~ Glen Franz Gatz ~ Thomas (Geoffrey) Beldom ~ Lance Von Platen ~ Peter Priestley ~ Peter H Rachl ~ Wayne Hughes ~ Stewart Trafton ~ Tony Brady ~ Billy (Denny) McKenzie ~ Michael Clark Broughton ~ John C Retford ~ Jacques Dignard ~ Grant Finch Jr ~ Paul Fairley ~

AIDS is an  
extra-ordinary  
crisis  
which has  
challenged  
human  
potentials to  
new heights.  
only time will  
tell if we can  
live up to this  
challenge.  
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We are presently providing a forum for education, resource sharing, development, liaison, outreach and support for our members in order to create a coordinated and effective strategy against HIV/AIDS within ethnocultural communities.

### LOGO CONTEST

We are looking for a logo that reflects what we are.

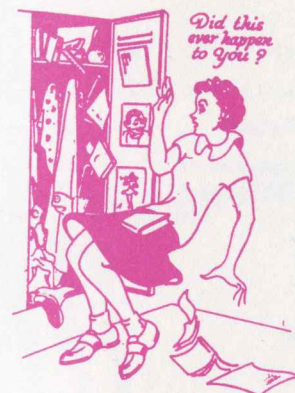
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The deadline is 12 June 1992.

For more information please contact us.

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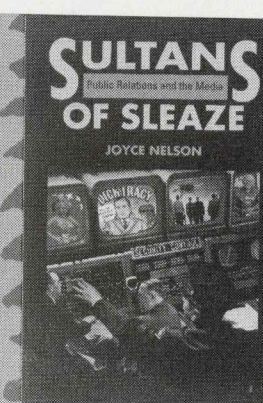
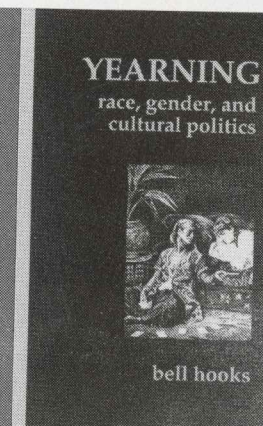
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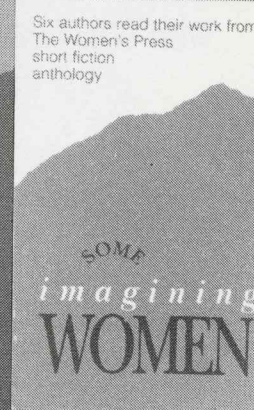
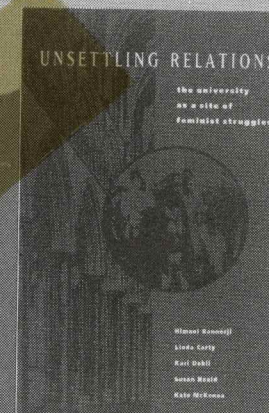
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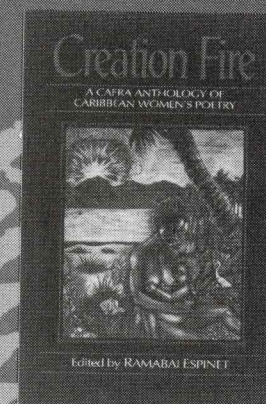
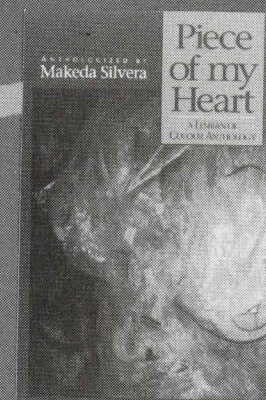
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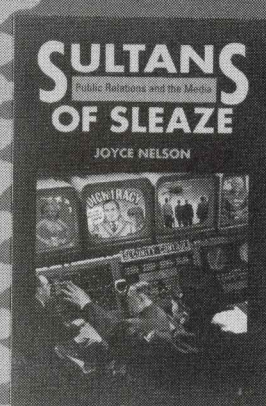
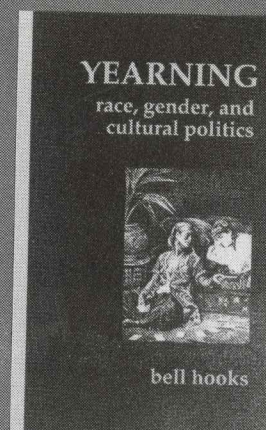
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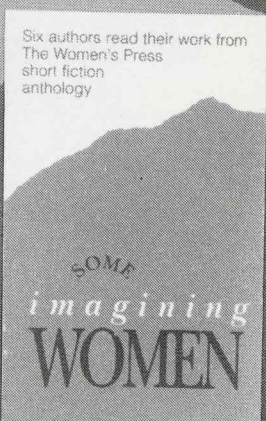
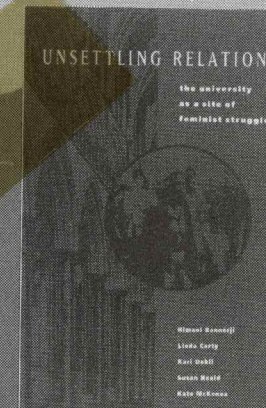
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