Overheard

Los Angeles activists Mary Lucey and Roxy Ventola want to tell you about it

August 1, 1994 By Christopher Petrikin

Mary Lucey and Roxy Ventola think their street in Venice, California, should be renamed from Superba to Positively Superba. This is not, however, the view of two women being lulled into mindlessness by a carefree life in the sunny, laid-back Golden State. Rather it is in response to the fact that on this small residential street there are at least three women living with AIDS; and a fourth just recently passed away from the disease.

Roxy and Mary -- or Old Woman and Sea Hag as they refer to each other, respectively -- make up two of this critical population. But fragile they are not. “While we perceive ourselves as princesses, we have very raw personalities and similar senses of humor,” Roxy tells me on this stereotypically sunny Southern California summer afternoon. “For instance, one of our fantasies is to kidnap [National Institute of Health Director] Anthony Fauci, give him an enema and shove AZT and ddI down his throat.”

Each day the duo plots ways, from the sublime to the terrorizing, of bringing their message to anyone who will listen. “We have to keep AIDS in front of the public, keep them outraged. People have to realize there is no cavalry coming to the rescue,” says Roxy. “This disease is terminal. We’d rather be realistic than in denial. People with AIDS who are in denial end up doing nothing. I don’t have a lot of time. Once you realize that it’s futile, you just try and chip away.”

Roxy notices a surprised look on my face as I watch them smoke half a pack of cigarettes in the first 15 minutes that I have been sitting in Roxy’s living room. “This is how we survive. We hang out, smoke cigarettes, drink coffee and devise ways of exacting revenge. You know when the guys from the tobacco companies testified before Congress recently and they all seemed to be keeping a secret? Well, we’ve theorized that there is a secret ingredient in cigarettes that is keeping us alive,” says Roxy.

“Actually cigarettes and coffee,” says Mary.

At this point, Roxy’s husband, Matthew -- Tall, ponytailed and tattooed -- enters the room and, while looking directly at me, hands Mary a large hunting knife and says he is leaving to run an errand. Wait! I’ve seen this movie before. Asked if the knife is meant for me, both Mary and Roxy -- almost identically outfitted in flannel shirts and denim jeans -- laugh as if the joke worked. Mary

says, “No, no, Matthew was just showing me the knife he made. We share Matthew. He acts as the neighborhood husband.” Still, I’m on best behavior.

Mary and Roxy have been best friends since performing the play *AIDS/Us/Women* last year, which is based on their life stories. Mary tested HIV positive five years ago and Roxy, who lost her first husband and daughter to AIDS in 1991, think she has been HIV positive since 1983. Yet this duo is not about to live their life as statistics or remain in some sort of holding pattern waiting for death. They are buoyed by the anger and frustration over their belief that the AIDS establishment discriminates against women infected with AIDS, that AIDS research is misguided and that most of the highly funded AIDS organizations, in their opinion, are greedy bureaucracies.

“I don’t like any drugs or the researchers’ attitudes toward this disease,” says Mary. “AIDS drugs are prescribed based on dosages for men. We really don’t know what these drugs will do to women and children. If AZT has toxic effects for men, just think what it can do to us.”

Roxy is part of a class action suit brought by the American Civil Liberties Union (ACLU) and a civil suit initiated by Lambda Legal Defense and Education Fund directed against the AIDS Clinical Trials Group (ACTG) and its persistence in basing their research on drugs that have already been researched and approved by the Food and Drug Administration (FDA); as wel as their virtual exclusion of women and women’s infections from clinical trials. “The ACTG, which is supposed to be on the cutting edge of research, is not spending money on new avenues of research. They’re still concentrating on drugs and treatments that have already been approved. For instance, they have trials going on based on AZT vs. AZT and AZT vs. aspirin. It’s absurd. We feel our money shouldn’t be used by the FDA and the NIH on post-research marketing for drug companies with products like ddI and AZT.”

Mary feels that while women are excluded from the focus of AIDS research, everyone is the victim of misguided direction by researchers and AIDS service organizations. “Treatment is more glamorous than prevention. Those in the research and medical communities want publication, money, fame and notoriety rather than the long-term work of finding a cure.”

“And some of the other groups just concentrate on prevention,” says Roxy. “We went to a National Association of People with AIDS (NAPWA) convention in New Orleans and the entire convention focused on prevention. This is supposedly a meeting of people who already have the disease. This gives the people with AIDS no hope so they focus solely on death and dying. And that’s not OK. We’re interested in people with AIDS, not prevention. But we have to get more creative in our activism. Women, drug recoverers, dope fiends and the gay community -- we want to give them all a reason to fight. You have to have a reason to live. We live for revenge.”

“Roxy and I want to mobilize women for a revolution,” says Mary. “Women with AIDS don’t have a thing to lose. We’ve had good role models in the gay community. We’ve learned that we can be angry, fight back and die with dignity. Activism has to escalate as the disease escalates, incorporating all segments of the affected population, if it takes a revolution and extremism such as hostage-taking, so be it.”

In addition to their activism, the comrades continue to work -- Mary is the site coordinator for the first epidemiology study of women at Prototypes Women's Center in Los Angeles and Roxy is a playwright and television scriptwriter -- and contribute to many grassroots AIDS service organizations. Their outlet of choice is *Women Being Alive*, a newsletter to which they contribute. "We do *Women Being Alive* for others not for ourselves. It is run by HIV positives for HIV positives. At *Being Alive* we're working our asses off trying to help the whole family get the help they need," says Mary.

Roxy explains further. "So many heterosexuals with AIDS are in hiding," says Roxy. "They're dying like sheep, taking on assumed names and denying their illness. It's a disservice to the general population because we never see the families or the effect AIDS has on families. This has to be a battle for personal health as well as a battle for the AIDS community. Some of these doctors and organizations are nothing but professional AIDS pimps. Their concern is with money, not in helping people with AIDS, especially women with AIDS and their families."

"Hell, give money to us, not APLA," says Mary. "We can do more good. APLA and the other monolithic bureaucracies don't care about or help families and children with AIDS. They just want your money. Yet, our biggest opponent is the fundamentalists. They don't have a clue about this disease, and they judge us. We're dying and the assholes aren't."

When asked how they think the Clinton Administration is doing, Roxy says, "Clinton talks a good game, but nothing gets done. And Nurse [Kristine] Gebbie is an idiot. She promised us a congressional hearing on women and AIDS, then she reneged. She said it's on the back burner."

The dynamic duos' vision of revenge would not even be interrupted by death. "We want very political funerals," says Mary.

"Well, when I'm ready to go I want to strap a bomb to my chest and roll myself into Fauci's office and let it go," says Roxy. "If I'm going to go, I'll take some of them with me."

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