Working in the worst of times

The decimation caused by the AIDS epidemic on the gay men's community is taking a terrible toll

▼

by Rachel Timoner

PROFILE

Eric Rofes is the executive director of Shanti Project, a large non-profit agency serving people with AIDS in San Francisco. He is also a board member of the National Gay and Lesbian Task Force.

Rofes attended the June '92 International Conference on AIDS in Amsterdam and took the time to talk with Just Out *about his impressions of the conference and thoughts on the epidemic.*

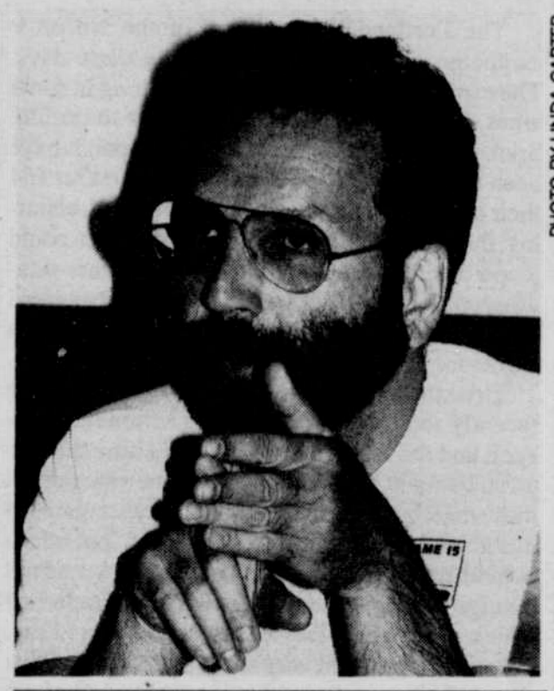

PHOTO BY LINDA CARTER

What are the primary functions of the International Conference on AIDS?

Speaking from my own perspective, I find the International Conference helpful because it's one of the few times during the year that researchers, doctors, community-based organization representatives, people with HIV infection and activists come together in one place. There can be a very powerful cross-fertilization there. There can be a lot of education that takes place. Sometimes what happens is the medical researchers and the doctors don't really talk to the activists, the people with HIV or the community-based people, but ideally than can really be a rich mix.

We heard a lot of news about the reported cases of AIDS that are not *accompanied by HIV. What do you think of those findings?*

Well, I am probably one of the few people heading up an AIDS institution in this country who will say it on the record, but I do not believe that anyone has ever proven at Amsterdam or before that HIV causes AIDS.

I believe that this will nag on the United States and AIDS research until people begin to investigate some of the alternate theories. To me this report called up years' worth of low-level discussions that refute that HIV alone causes AIDS or that HIV itself can cause significantly anything.

Anecdotally, for all the years I've been doing this work (since 1985), I have known people with AIDS who are HIV negative consistently, both for the antibodies and the virus.

So what does that mean? To me it means that in the rush to make progress on AIDS research, I am scared that questions may have been answered that we weren't ready to answer yet, and I'm scared that there might be some wasted years when we should have pursued some alternate theories.

fensive and didn't answer the question.

Another big story coming out of Amsterdam was about gp160, the new vaccine therapy that early studies show may stabilize T-cell counts. What do you know about that?

I went to the panel on gp160. This year there were the preliminary results of six studies in different parts of the United States. They were simply supposed to be reporting on whether gp160 was toxic –whether they died, this kind of thing.

I was very heartened by the fact that all the reports showed that it wasn't toxic, that it didn't seem to cause any problems. But more important, there were significant signs of stabilization of T-cell counts. In two reports there was evidence of diminishing of the viral load, meaning there's less active virus, HIV, in people's bloodstreams. One of the studies showed that of people who were on gp160, none of them became symptomatic who weren't symptomatic already.

This seemed like really good news to me. I talked to a lot of the doctors, and they also were excited and optimistic. It was the one medical presentation I attended where there was any hope, any excitement, where we were talking about extending life more than two or three months. That made me happy.

You mentioned before that you felt the working relationship between doctor and researcher types and activist and community organizer types was better at this conference than in past conferences. Could you elaborate?

I feel like this was the conference that was most successful at bringing both community-based service providers and activists into the running of the conference. More people were part of key panels and key planning committees. We were still outnumbered by the docs and researchers, but it certainly felt like we had more.

I do not believe that anyone has ever proven at Amsterdam or before that HIV causes AIDS.

I'm not saying that HIV is not the cause or that people don't need to be safe around sex. I'm not a scientist, but as a lay person, I have not read anything that convinces me that that story's over with.

What do you think of the U.S. government's immediate response that the report did not have sufficient evidence to cause alarm?

People who have nothing to hide should be able to deal with challenge more calmly. Why, anytime anyone speaks about alternate theories, you have either the federal government, an AIDS doctor or the AIDS medical research establishment jumping down their throat as if it's heresy. In fact simply saying what I'm saying will make some people think that I'm crazy, but I really believe in science as an open field of inquiry. The U.S. government response was inappropriate, de-

You gave a presentation at the conference that was cited in U.S. magazines about the issue of relapse in HIV-negative gay men. Can you explain your ideas?

I believe that significantly large numbers of gay men are seroconverting right now. And they're not seroconverting because they're drunk or because they don't know what's safe or not safe or because they're not educated, empowered people.

I've had 10 friends since the start of this year, in San Francisco, go from negative to positive status. Most of them feel a tremendous amount of relief.

I don't believe this has been documented yet. I believe that people are underestimating how much it's happening, and I believe people don't want to look at what's going on.

I think that when we look at prevention efforts targeting homosexual men in the United States we need to look at those things. While most AIDS prevention work today still focuses on getting information to gay men and supporting gay men in using that information, very little deals with the psychological factors that might lead us to seroconversion and the mental health stress we are under.

I was disappointed at the conference that so few of the prevention panels acknowledged that people have a subconscious or unconscious mind. It's like Freud never existed; it's the concept that if HIV is out there, explain what condoms are, tell people to use condoms, and they'll use condoms. That doesn't factor in the subconscious or unconscious desire not to survive, survivor guilt and the tremendous stress that gay men in high-impact areas are under.

What is one's mental health state after 11 years of watching your contemporaries die; watching a community you helped to build fall apart around you; taking care of sick people and wiping the shit off your best friend; burying your lover? What is your mental health state when you realize it's not over, it doesn't look like it's going to be over soon, and you've got 10, 20, 30 more years of this kind of life?

Well, we really don't know, because no one's looking at the mental health state of uninfected gay men.

I think if you ignore the mental health state of HIV-negative gay men, those men are going to become positive. Why are so many HIV-negative gay men killing themselves? Why are so many HIV-negative gay men who have been sober relapsing? Why are they going out drinking again and shooting up again? It's because we're living through something as severe as what people lived through in Vietnam, what people experienced when the United States bombed Hiroshima, what people survived in historical situations that are very concentrated on one population and involve repeated loss, repeated trauma beyond what the human spirit is able to cope with. Except in the case of AIDS, we have the chance to look at it and see it while it's happening; but no one's looking and no one's seeing.

What I see is a community of men who are depressed, who are anxious, who are suicidal, who are manic, who are hypochondriacs, and all of these I see in myself and I see in other uninfected men. These are conditions that can lead to not taking care of yourself and becoming infected.

When we [HIV-negative gay men] talk about it, we are shamed by HIV-positive gay men often or by ourselves. You know, "What are your concerns, you're not infected, why do work on that?"

It's a very hard issue to deal with, but I actually believe that this explains the condition of the gay community in most cities right now. You have a gay male population of infected people who are scared and angry and have every right to be scared and angry. And you have a bunch of uninfected people who are scared and guilty. That creates organizations and communities that are very difficult to be in.

When you look at some issues (like the *Advocate* recently raised about cannibalism in the community), I am struck by how many people simply say, "Well, all fringe groups destroy their own." No one looks at what's in front of our faces. The gay community in the last 10 years has been decimated, and we continue to be decimated. Those of us who are "survivors" may be walking around and still in our bodies, may have survived physiologically, but on a spiritual level, on an emotional level, on a functional level, we are severely wounded.

What is it like when a group of wounded people try to work together and do a project together? Very, very difficult.

I think new organizing efforts have a very difficult time in high-impact cities, and not just because of the issues that are already there; the issue of race, the issue of racism, the issue of gender, the issue of sexism, but because so many people are desperate and fried and guilt-ridden and angry and have no place to put it. We don't have access to George Bush, so we put it on ourselves. I think organizing efforts are really hindered, and I think the participation of gay men as community leaders is really at risk. And not, as everyone always says, because so many of our leaders have died, but because so many of our leaders who have not died are so scared and so angry and so guilty and so under attack that it's not necessarily productive for us to continue in those roles.

How can the Oregon Citizens Alliance be attacking a population that's already under such attack? How can people allow that to occur?

I really feel there needs to be a focused community effort on HIV-negative gay men's survival. It is important for some gay men to survive another 30 or 40 years simply to be able to report historically what these years were like. There needs to be an embracing of that identity, not in a divisive sense, not in a sense that says, "I'm going to ignore AIDS," "I'm not going to be a caregiver," "I'm not going to volunteer," "I'm not going to give money"–but a part of what gets gay men in trouble these days is that we confuse our gay identity with HIV status. And I'll tell you, in the minds of people in the United States, gay equals HIV-positive. I think that operates in gay men's subconscious. It's easy to confuse the two.

I would like to add for Oregon–I really do feel that 50 years from now, when people look back on this epidemic and understand that the gay male population is the population most infected, most vulnerable, most dying and grieving, and they look at what government did and what the church did and what politicians did, people will be amazed, just like they were amazed at the people who sat there when the Nazis marched through Germany and Western Europe and Eastern Europe.

They'll be amazed at how the Oregon Citizens Alliance can be doing this at this time. How can you be attacking a population that's already under such attack? How can people allow that to occur?

That is not separate from our mental health. We like to say it doesn't have any impact–we can beat the OCA and we'll be stronger for it–but the fact is that the message that the OCA gives and the message that homophobes give and the message that the Vatican gives says you're expendable. You don't deserve to live.

It has to be implicated. When we look at the villains of the AIDS epidemic, they have to be right up there, in Oregon.