Alive and Kicking

ACT UP's still fighting-and it's more needed than ever

March 1, 1997 By Maxine Wolfe

Ever since a group of ACT UP/New York members left to form the Treatment Action Group in 1992, some self-defined AIDS movement spokespeople have spread the word that ACT UP is dead. How was it, then, that on October 14, 1996, *The New York Times* ran a photo of ACT UP's 1000-strong political funeral demanding *real* presidential leadership against the AIDS epidemic, with activists "tossing urns with ashes over the [White House] fence before being dispersed by police officers on horseback"? Was it a mirage? Or was it, as the late activist Iris de la Cruz once wrote, that "our screams are heard and our tears fall on your head even from the grave"? It was neither. ACT UP is beginning its 11th year, and its basic premise-the need for direct action to end the AIDS crisis-is as relevant today as when it began.

Direct action *still* works. Just three recent examples:

Stadtlanders Pharmacy reduced the price of Crixivan (indinavir) by 20 percent the day after ACT UP/NY members plastered one of its storefronts with posters protesting profiteering.

Four major Los Angeles AIDS organizations retracted their public support for mandatory testing of pregnany women after a "fax zap" organized by the ACT UP Network Women's Caucus.

The protease inhibitor ritonavir (Norvir) was allowed into France only after ACT UP/Paris stopped production for six hours in an Abbott drug plant.

Yet in this country, it's a difficult time for direct action. Many ACT UP chapters have folded; existing ones are small and underfunded. While demoralization due to continuing deaths is an oft-cited reason, the pattern of decline is not unique to AIDS activism; it has occurred before in the labor, civil-rights, women's and lesbian/gay movements. The common thread is a shift in strategy to insider politics.

Bill Clinton's election in 1992 convinced many that the White House would take care of us. Some former direct-action activists and supporters were given administration jobs or named as "our representatives" to federal committees. Now on the "inside," they claim the "outside"-direct action-is no longer necessary and even detrimental, that lobbying and behind-the-scenes negotiating are sufficient. Many believe them, and we hav allowed them to become our AIDScrats.

But without bringing *public* pressure to bear, there is only politics-as-usual (read: backroom dealing). Experience shows we don't get very far very fast this way. Bill Clinton has failed to implement most of the 1991 recommendations of the National Commission on AIDS. Instead, he waited until 1995, then appointed yet another advisory council and held a White House AIDS Conference, both peopled with AIDScrats. More recommendations, more inaction. How many commissions, councils and reports will it take to fund needle exchange, end immigration restrictions, require testing drugs in women and study alternative treatments?

Then we have our "AIDS thought leaders," invited by pharmaceutical companies to give "our perspective" on drug development or working with government and university researchers to fine-tune research designs. Though self-taught and having gained access through direct action, they now tell us that "AIDS is complex," "Scientific discovery can't be rushed," and "We can't alienate researchers." We have allowed them to become our "experts." Protease inhibitors have given many hope that such an approach will soon produce a cure, but the rising tide of treatment failures reminds us how far corporate medicine is from that goal.

Our experts distinguish between "treatment" issues, which their strategy supposedly addresses, and "social" issues, which they claim are not central to treatment research. Yet this false division does not challenge some basic premises of science-as-usual. For example, they say having enough women in clinical trials is simply a matter of equity, a "social" issue. However, hormonal and liver-function differences between men and women can affect proper dosing. Fifteen years into this epidemic, only one AIDS clinical trial has *ever* recruited enough women to analyze gender differences (a result of direct action). That trial's result, reported last year in Vancouver, was that women who self-lowered doses of ddI had the same outcomes as men who didn't. So we must ask: Is the male-defined dose of protease inhibitors too small for women, and could this allow resistance to develop? Or is it too large to be tolerated? This *is* a treatment issue, as is the need to develop medications that PWAs with impaired livers-especially drug-users-can tolerate.

Maybe no one you know has died recently. Maybe you're not an HIV positive pregnant woman pressured to take AZT and give it to your newborn. Maybe, despite the lack of government-funded research, you know how much vitamin C to take. Maybe you can afford, tolerate and easily stick to the prescribed regimen of protease cocktails. Hope is wonderful, but for many it's not enough. Where is your rage?

When you find it, join ACT UP. Or participate in a demonstration. Support us verbally or financially. Our AIDScrats and experts alone aren't enough to get us through. Even in a right-wing period, small groups of committed individuals can accomplish a lot. Direct action may no longer be glamorous or the in thing to do. But it's still a crucial part of fighting the AIDS crisis.

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