POZ Annual Givers Guide

1998 was the year of the AIDS backlash. ASOs and HIVers need each other now more than ever.

December 1, 1998 By Greg Lugliani

“I’ve joined the club,” a friend from the old ACT UP days recently told me about just getting a positive test result. Stunned by the news and too ashamed to talk to others, he called me because I’ve been positive for a long time and work at Gay Men’s Health Crisis. “How do I find a good HIV doctor?” he asked. “When should I start the treatments and what are they? I don’t know any of this stuff.” My answer -- that he call GMHC’s hotline about a physician, attend our treatment forums and check out the one-on-one counseling for the newly diagnosed -- reminded me of some things that many HIV veterans may take for granted. One is how devastating the news that you have HIV still is. Another is how many people still turn to AIDS organizations for succor and sanctuary in a world grown weary of the epidemic.

It’s good to remember this right now. With better drugs, plummeting death rates and few hospital stays, AIDS in 1998 can seem like the best of all possible worlds. But for AIDS service, education and advocacy groups nationwide, it was our annus horribilis -- a year that saw the demise of at least one, the drastic downsizing of others and enormous difficulties for all. The problem? Money, or rather the lack of it. Whatever the cause of evaporating private giving [see Liz Galst’s report, next page], an alarming irony can’t be ignored: Donors dug deep into their pockets when AIDS meant certain death; now, in the age of “chronic, manageable disease,” philanthropy is flagging. This fiscal downturn comes at time when HIVers need to rely upon our strength as never before.

Yes, people with HIV are living longer. One irony of this -- at least for AIDS service organizations (ASOs) -- is that more of us are lining up at their doors, and we need service for longer too. As demand expands and dollars dry up, ASOs have no alternative to cutting budgets, laying off employees and deciding which clients are expendable.

Politically, there couldn’t be a worse time to have to make these choices: 1998 was “the year of the backlash.” The past 12 months witnessed the gravest legislative threats to the AIDS community since the epidemic’s earliest days. Despite valiant resistance, names reporting and mandatory contact tracing became the law in New York, paving the way for adoption by other states in the future; conservative members of Congress introduced similar federal legislation immediately afterward. In the wake of the Nushawn Williams case, bills criminalizing HIV transmission stand a real chance of passage in New York, California and 14 other states. Nearly twice as many have already created criminal penalties for people who knowingly transmit HIV, 10 in the past two years. “We’ve moved from a period where civil rights and civil liberties for a person

with HIV prevailed to a compulsory and punitive approach," Lawrence O. Gostin, director of the Georgetown University Johns Hopkins Program on Law and Public Health, told The New York Times in September. Clearly, the bloodiest battles lie ahead: More HIV criminalization laws, moves to abolish anonymous HIV testing and worse.

Once-unthinkable laws may be the result of a public increasingly intolerant of people with HIV. More than half of the respondents in a recent survey of 1,700 U.S. adults believed that most PWAs are responsible for their illness. Almost 30 percent agreed that people who got AIDS through sex or drug use deserved it, compared to 20 percent in 1991. One-quarter said most PWAs don't care if they infect others. As if those numbers aren't bad enough, about half of the respondents believed AIDS can be transmitted by sharing a drinking glass, being coughed or sneezed on or using a public toilet. More than one in four feels uncomfortable even being around a PWA.

These troubling statistics reveal how much HIV prevention and "AIDS 101" work still needs to be done by community-based groups. The terrible new anti-HIV measures spawned by such attitudes indicate how crucial our lobbyists and activists are in the corridors of power. The tragedy is that the AIDS community is losing its political grip: Undetectable viral loads and rising CD4s don't inspire protest. Last spring, the Clinton Administration determined that needle exchanges work to stop HIV transmission but refused to lift the ban against funding them, despite the outcry of advocates and scientists alike. When the president came to New York City the day his decision was announced, fewer than 100 turned out to demonstrate -- and it was deemed a good showing. Most rallies draw even fewer, a far cry from the early '90s, when a good demo easily commanded hundreds, even thousands, of protesters.

Politicians respond to numbers. Without them, the advocates deployed by ASOs offer the only bulwark against cynical office-holders with an eye to reelection, the AIDS-phobic agendas of conservative crusaders and the parsimonious public health officials who require persistent prodding in order to fund critical prevention programs.

That such efforts don't get the funding they deserve is one reason that my friend and some 40,000 other Americans got HIV this year. If ASOs are forced to close their doors, both the newly infected and those of us who have long been positive will have a far harder time making sense of the complexity of HIV treatments and health care benefits. The very fact that my friend has options is the direct result of the dogged determination of treatment-focused groups like ACT UP, GMHC, Project Inform and TAG. Were these institutions to vanish, the future of AIDS treatments is almost unimaginable. As bitter experience has taught us, leaving it all to government and industry is a recipe for disaster.

As is leaving health care to insurers. With better drugs restoring many to health, access to treatment and other medical services takes on ever-greater importance. And while managed care may meet the needs of the disease-free many, it can drive people with chronic conditions such as HIV infection to madness -- or away from care. In New York this year, the health care giant Oxford tried to hike premiums by 70 percent for people in the direct-pay market -- some 100,000 people, most with HIV and other serious medical conditions. AIDS and other health advocacy groups

successfully mobilized to block the move, but the victory is bound to be short-lived as Oxford is certain to try again in 1999.

Medicaid, the health care provider for most Americans with HIV, poses an even greater threat to the well-being of those who rely on it. Current Medicaid policy provides protease inhibitors to the HIV positive only once they are sick enough to be diagnosed with AIDS. The Washington, DC, lobby AIDS Action Council, which likens this to installing airbags in an automobile after the crash, sees Medicaid as the biggest battle for the AIDS community in 1999.

AIDS organizations have been around for some 16 years -- long enough to have dramatically lowered HIV infections among urban gay men, long enough to have become the model for people battling other diseases, long enough to have grown from grass roots and regarded by many as a noble enterprise to an industry some dismiss as “AIDS, Inc.” and careerist, long enough to grow and to shrink and, in increasing numbers, to disappear. But none has been around long enough to accomplish what they were all started to do: stop AIDS.

As we close 1998, there’s no end in sight to the epidemic, but there may be for the organizations built in response to it. True, AIDS organizations aren’t perfect. They’re only as good as the people who work at them and who support them. Unless we rouse ourselves from our cocktail-induced complacency and unconditionally rush to their rescue -- with a check, with some time, with our presence at a protest or simply with renewed faith -- their extinction may make debates about their merits and failings moot. And if the future of the AIDS organization is imperiled, so is the future of all of us who count on them.

To read the POZ Givers Guide, click here.

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