

Rude, Rash, Effective, Act-Up Shifts AIDS Policy

By JASON DePARLE

To many parishioners, the recent invasion of St. Patrick's Cathedral by dozens of angry AIDS protesters was an act of desecration. But to Christopher Hennelly, a former seminarian among those arrested inside the church, it was a prayer for self-preservation.

"The strongest prayer I've ever made in my life was on the floor of St. Patrick's," he said.

Mr. Hennelly and other members of the nation's most prominent AIDS protest group rarely see the world the way it sees them. To the businesses, bishops and bureaucrats that they accuse of slowing the fight against AIDS, they often seem rude, rash and paranoid, and virtually impossible to please.

And they are.

'An Enormous Effect'

But at their weekly meetings in a dingy West Village community center, members of Act-Up, the Aids Coalition to Unleash Power, refer to themselves as a despised minority, literally fighting for their lives.

And that they are as well.

Another word helps describe Act-Up: effective. Pressure by the group has not only helped keep the epidemic in the news; it has also helped bring major changes to the way the Federal Government tests and distributes experimental drugs, allowing patients to obtain them much faster.

A Series of Funerals

"There's no doubt that they've had an enormous effect," said Dr. Stephen C. Joseph, the former New York City Health Commissioner who himself has been a target of Act-Up's ire. "We've basically changed the way we make drugs available in the last year."

Act-Up's unusual experiment in the politics of participation — a mixture of the shrill and the shrewd — is being conducted by a group that is predominantly gay, white and male, though heterosexuals, blacks and women are also found within its ranks.



The New York Times/Chester Higgins Jr.

Members of Act-Up, the Aids Coalition to Unleash Power, turned their backs on John Cardinal O'Connor as he spoke at Mayor David N. Dinkins's swearing-in ceremony Monday. The group set off a controversy in December when dozens of its members invaded St. Patrick's Cathedral for an angry demonstration.

Whatever their background, almost all share a personal relationship with the epidemic that has killed 67,000 people in the United States.

While to many people AIDS is an abstract menace, to members of Act-Up, it is a series of funerals — a procession of friends, relatives and lovers given over to painful, protracted deaths.

In the past, Act-Up members halted trading on the floor of the New York Stock Exchange, delayed for two hours the opening of an international AIDS conference in Montreal, and bolted and chained themselves to

the offices of pharmaceutical companies. But they had never set off the kind of controversy that began on Dec. 10 at St. Patrick's when one member crumbled a communion wafer, desecrating what Roman Catholics believe to be the body of Christ.

David N. Dinkins, then the Mayor-elect, and Gov. Mario M. Cuomo said they deplored the demonstration. Andy Humm, a spokesman for the Coalition for Gay and Lesbian Rights, said the demonstration was "stupid and wrong-headed."

Over the last few weeks the group has held several soul-searching sessions to dis-

cuss its past and plot its future. The debate offers a look at the passions that suffuse Act-Up and at the complicated pain of living and dying with AIDS.

Shouting in a hallway as one meeting concluded, Peter Staley, a 28-year-old former bond trader who is among Act-Up's leaders, denounced the St. Patrick's protest as an "utter failure" and a "selfish, macho thing."

Though intended to protest the AIDS policies of the Roman Catholic Archbishop of

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Changes AIDS Policies

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New York, John Cardinal O'Connor, the action failed, Mr. Staley said, because it shifted the focus to the subject of religious freedom.

But Bob Rafsky was just as angry. A public relations professional, Mr. Rafsky argued that the group was becoming too conscious of its image. "My frustration is that we have a room of scared people," he yelled.

From the Nazis, A Symbol

Act-Up began in March 1987, after Larry Kramer, a playwright and advocate for people with AIDS, told an audience at a gay community center that two-thirds of them could be dead within five years — casualties, he said, not only of a virus but also of an unresponsive medical-industrial complex.

"If what you're hearing doesn't rouse you to anger, fury, rage, and action, gay men will have no future here on earth," he said.

In his view that the AIDS crisis was being aggravated by institutional failures, Mr. Kramer was not alone. In June 1988, a Presidential AIDS commission called the nation's drug-development system "unresponsive"; its health-care system "overly burdened and unnecessarily costly," and its health-education measures in "absence."

Two days after Mr. Kramer's speech, several hundred people reconvened and took a name. They also took a symbol — a pink triangle set against a black border and inscribed with "Silence = Death." While many gay rights organizations had invoked the pink triangle — which Nazis affixed to homosexuals in concentration camps — the Act-Up triangle was different: It pointed up.

"We were trying to disavow the victim role," said Avram Finkelstein, who designed the triangle while the group was silent.

One thing that Act-Up has never been is silent. Two weeks after Mr. Kramer's call to arms, 17 members of the group were arrested at its first demonstration, held on Wall Street to denounce the business and government response to AIDS. At that time, a year's dosage of AZT, the pre-eminent AIDS drug, cost as much as \$10,000.

A few months later, Act-Up countered the festive spirit of the annual Gay Pride march by striding behind a truck float decorated as a concentration camp. Protesters with AIDS were trapped within its barbed wire boundaries, evoking the group's vision of the epidemic as an act of extermination.

Act-Up now has chapters in about 40 American cities as well as in several cities abroad.

A Fellowship Linked by Death

Act-Up's weekly meetings are an exercise in creative anarchy. There is no board and no paid staff. Anyone who shows up can vote. Some say the group's antiergonomic ethic is a source of its strength since it generates new ideas, people and energy.

Thirty minutes before a recent meet-

ing, the several hundred seats at the Lesbian and Gay Community Services Center on West 13th Street were filled and the crowd lined the walls.

The agenda sprawls: proposed demonstrations and leafletting campaigns, reports on the newest AIDS drugs, reports from committees on housing and insurance. The meetings are steeped in the political grammar of the left but spiced by Robert's Rules. Calls for "empowerment" compete with cries like "point of order."

There is a bit of carnival, too. The meetings are run by four "facilitators" — three women in pants and a man in a skirt. A transvestite named Rollerena is typically in ostentatious attendance.

With no official membership, Act-Up's demographics are hard to gauge. Most members seem between the ages of 25 and 45; at age 54, Mr. Kramer plays the role of elder statesman. The group is making a conscious effort to recruit more women and minorities.

Some men arrive in business suits. More come wearing earrings and black leather. Rough guesses by Act-Up members estimate that about half have tested positive for the HIV virus.

"I don't think anyone can understand what life is like for us unless you're one of us," said Mr. Kramer, who learned last fall that he was infected with the virus. "There's not a week goes by unless someone you know dies."

Eric Sawyer is among those brought to Act-Up by a lover's death, and like a sizable minority of the group, he had little experience with political activism. "I was on kind of a typical yuppie materialistic trip," said Mr. Sawyer, 35, a business consultant with a large Manhattan company.

He spoke of the anger he felt at not being allowed time away from work as his lover, Scott, was dying of AIDS. "I felt, damn it, that I deserve the same kind of consideration that anybody else deserves whose spouse is dying at home," he said.

While Mr. Sawyer is open about his homosexuality and his work with Act-Up (though he seeks anonymity for his employer), there are others who disguise their participation.

"There's always a tendency for gays and lesbians to be a little apologetic about ourselves," said one gay man, who attended his first Act-Up demonstration in sunglasses, to keep business contacts from recognizing him in photographs. "But the position we should be coming from is, 'This is who we are and we've got nothing to apologize for.' Act-Up is very self-affirming."

Mr. Hennelly, the former seminarian arrested inside St. Patrick's, also spoke of affirmation as part of the group's appeal.

"I would see 'Silence = Death' and think, 'I've been silent about who I am for too long,'" said Mr. Hennelly, who is 26 and gay. "I'm fighting for my life in a social way, for acceptance of who I am, my sexuality."

The number of members with backgrounds in business, law, medicine, the arts and other professions gives Act-Up a rich pool of talent, which it puts to effective — and frequent — use.

The list of those deemed insufficiently devoted to the eradication of AIDS has included, among many others, officials at the National Insti-



The New York Times photo by Chester Higgins Jr.

The AIDS Coalition to Unleash Power has complained about government's and science's responses to AIDS. Act-Up members blocked Broadway in lower Manhattan during a 1988 demonstration; 105 were arrested.

tutes of Health, the Food and Drug Administration, many pharmaceutical companies and most news organizations — particularly The New York Times, which has been the target of several Act-Up protests.

Rarely are Act-Up's adversaries seen as well-meaning people working in a complicated world.

In Act-Up's eyes they are liars, hypocrites — even murderers.

In 1988, Dr. Joseph, then the city's Health Commissioner, reduced by half his estimate of the number of city residents infected by the virus. While Dr. Joseph accompanied his study with the warning that no one should think it "in any way reduces the services needed," Act-Up members accused him of a plot to accomplish that and other nefarious purposes. They splashed paint and posters on his house, occupied his office and called him a Nazi.

While no one really knows how many New Yorkers carry the virus, a panel of outside experts found the Commissioner's estimates to be "in the ballpark."

In becoming "too aggressive, too closed minded, as they sometimes are," Dr. Joseph said, "you become the very thing you're fighting against, which is intolerance."

Mr. Kramer said the group adopted its incendiary tactics only after quieter lobbying failed.

Leading the Fight to Get Safe Drugs Faster

Perhaps Act-Up's clearest imprint has been its role in speeding the dissemination of new drugs, a change that may affect treatment of many diseases in addition to AIDS.

At the outbreak of the AIDS epidemic, the Food and Drug Administration would typically allow the distribution of drugs only after testing both their safety and efficacy, a process that kept many promising but unproved drugs off the shelves for years. Many AIDS patients argued that they did not have time to wait.

Act-Up conducted a two-front assault to get the Government to release safe drugs faster, even if their medical benefits were still not completely known: It gained enough expertise to second-guess the experts. And it threw HHS, seeking congressional hearings of the Food and Drug Administration, and calling a key official a murderer and a Nazi. "We were beastly to her," Mr. Kramer said.

In the last year, Act-Up members say, their pressure has played a significant role in making available faster than usual two new drugs — ganciclovir and DDI — and in lowering the price of an old one, AZT.

Dr. Anthony Fauci, director of the National Institute of Allergy and Infectious Diseases, is among those officials previously reviled by Act-Up — in 1988 Mr. Kramer wrote an article calling him "an incompetent idiot" and a "monster." Dr. Fauci now credits the group with playing a constructive role.

"Did Act-Up play a significant role in the whole idea of expanded access to experimental drugs?" Dr. Fauci said. "The answer is yes."

Some worry that the pendulum may swing too far — that with too many drugs distributed too quickly, effective ones may be dismissed and ineffective ones embraced. While Dr. Joseph, who resigned as Health Commissioner as of Dec. 31, shares those concerns, he credits Act-Up with helping change aspects of a system that had been "unfair and constricting."

Issues of Scope And Priorities

As Act-Up grows up, it joins the list of institutions that must contend with its militant impulses.

Among the issues being debated is how broadly Act-Up should define its mission. It now encompasses 22 committees, including a "youth brigade," a "women's caucus," a "women's action" group and one to work on issues affecting racial minorities.

Some Act-Up members argue that AIDS cannot be eradicated without addressing what they see as underlying political issues of discrimination against homosexuals, drug addicts and others.

But some Act-Up members worry that the group is stretching itself too thin. "We need to find a rudder," Tom Cunningham, 29, the group's unpaid administrator, said at a recent meeting. He said in recent months five proposed fact sheets had neglected to mention AIDS at all.

And just as Act-Up has charged the world with discriminating against homosexuals, many of its gay men have had to face charges from the group that they are inconsiderate of the concerns of its other members.

"I'm constantly being told we're a gay white male organization," Mr. Cunningham said. "Let me tell you, I'd like to apologize for the fact that we got hit first with this disease, that we have a lot of savvy in AIDS politics because we've buried so many of our friends."

For now, even in frustration and anger, many Act-Up members describe the group as a cherished association. "Personally," Mr. Kramer wrote in a recent letter to the group, critical of its blurring focus, "Act-Up gives me my greatest energy and my greatest reason for being alive."