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ACT UP, other groups provide voice for activists Influence AIDS legislation, awareness, treatment

By Jean Lee

Spectator Staff Writer

Since 1987, the drug AZT has been considered essential, a lifesaver by many infected with the human immunodeficiency virus (HIV). The first approved drug to treat Acquired Immune Deficiency Syndrome (AIDS), AZT was originally the most expensive drug on the market, costing nearly \$12,000 a year, according to the Gay Men's Health Crisis.

Outraged by the inaccessibility of the drug and the ability for the sole provider of AZT, Burroughs-Wellcome, to inflate the price, a group of activists disrupted the opening of the New York Stock Exchange one morning by chaining themselves to the balcony, waving a banner reading "Sell Wellcome," and creating a ruckus.

A few weeks later, Burroughs-Wellcome lowered the price for AZT to \$4000 per year.

The men considered by many responsible for shocking Burroughs-Wellcome into dropping the price and making the drug more affordable were members of AIDS Coalition to Unleash Power (ACT UP), the most visible and vocal AIDS activist group since its inception in 1987.

AIDS has, arguably more than any other disease, fired up people from all ends of the spectrum--gay and straight men and women infected with HIV, celebrities, friends of HIV-infected people--to act, to fight, to demonstrate for both AIDS awareness and funding for projects to combat the disease. Frustration and anger moved the founding members of ACT UP to form a group to end the AIDS crisis through visible, provocative activism, said ACT UP member Robert Getso, a student in the Graduate School of Arts and Sciences.

"In 1987 people were interested in getting the federal government to respond to the crisis," he said. "When more and more people you know are getting ill, treatment and data and the availability of drugs is important."

Since June 1981, when the first cases of AIDS were reported in Los Angeles, the number of AIDS cases has increased to over 140,000 reported infected Americans, according to the Center for Disease Control in Washington--creating an everwidening pool of people affected directly and indirectly by AIDS.

"When you have friends who are [HIV-] infected, it really moves you to do something," said Michael, a Columbia College senior involved with ACT UP, who asked to be identified only by his first name.

Public and governmental awareness of AIDS has been furthered by activist groups like ACT UP, which propel the issue into the spotlight, according to Fiercely political, ACT UP's tactics have included blockading bridges, setting smoke bombs, and holding mass sit-down demonstrations, all of which have garnered attention in the media and helped promote public awareness, Getso said.

"ACT UP has brought the issue to the forefront," Getso said. "We've made people aware of what we're doing and what needed to be done."

An organization which draws over 700 at

its weekly meetings, ACT UP is fast-moving and effective, Michael said.

"They do get things done," he said.

"Ideas are presented at the floor and that same meeting are voted on."

Several members of the Columbia Lesbian Bisexual Gay Coalition (LBGC) said they have at some point attended ACT UP meetings. College students from local schools like Columbia, New York University, and Cooper Union, where the Monday night meetings are held, constitute a notable percentage of ACT UP, members said.

"College students are ideally suited for [activism]," Getso said, since students are in an academic environment and would have the time and energy to devote themselves to activism.

Issues like safe sex education "should be sort of central to their lives right now," he added.

Throughout the week, the dozen subcommittees of ACT UP meet to work on projects such as drug treatment and data, housing for people with AIDS, insurance, women's actions, and fund raising.

Dogged activism and lobbying on the part of ACT UP and other groups, such as the AIDS Action Council and People With AIDS Coalition (PWAC), has been most evident in the world of drugs. Actions taken by such groups, whether through demonstration and confrontation or through lobbying, have spurred the Food and Drug Administration (FDA) to speed up the availability of drugs and the federal government to increase funding and rights.

Formed in April, 1985--when over 10,000 cases of AIDS were already diagnosed--PWAC was the first AIDS coalition created for and by people with AIDS to address issues such as education, outreach, drug testing, and political lobbying.

Though today primarily a service-oriented group limiting

political activity to lobbying under other umbrella organizations, the history of AIDS activism can be traced to PWAC, according to PWAC Deputy Director Christopher Babick.

"We have a really lush history [of activism]," he said. "

'Empowerment' came from the PWAC movement."

PWAC efforts include starting the Community Research Initiative (CRI), a program which allows the community to get involved in drug research, according to Babick.

CRI works to widen the availability of drugs being clinically tested, since the government-funded clinical trial groups are limited both in number of HIV-infected persons being tested and drugs available, he said.

Through CRI, people with AIDS can pay cash and obtain certain drugs currently being tested, including Compound Q and Alpha interferon, Getso said.

ACT UP has taken up the movement to widen the availability of drugs by creating the "parallel track," a program allowing those not enrolled in the limited government-funded clinical testing programs to obtain drugs being tested through their doctors.

When the FDA determines that drugs like DDI are not toxic, they are then distributed through doctors to those who are ill and unable to qualify for a clinical trial group. Through the 'parallel track' program, additional data can be provided to federally-funded research, Getso said.

ACT UP and PWAC have also teamed up with other citywide, state-wide, and national coalitions to lobby for AIDSrelated bills and to increase AIDS funding both in New York and in the United States.

The Committee for AIDS Funding, a New York City umbrella coalition combining the efforts of half a dozen New York City AIDS coalitions, helped to bring \$9.1 million in new AIDS funding in Mayor David Dinkins' proposed budget, according to GMHC.

The AIDS Care Bill, a federal disaster relief bill designed to provide federal funding for the 16 U.S. cities hardest hit by the AIDS epidemic, was passed in the U.S. Senate this summer.

The Gay Men's Health Crisis (GMHC), New York's most prominent AIDS service organization, played major role in lobbying for the bill, according to Carisa Cunningham, assistant director of communications for GMHC.

GMHC's policy department, along with ACT UP and other groups, is currently working on the care bill's funding, which provides nearly \$3 billion to 16 cities, including New York over the next three years, she said.

GMHC, founded in January 1982 by six gay men, is one of the oldest and most respected AIDS organizations and boasts an annual budget of \$12 million.

"GMHC is considered an important source," Cunningham said. "We've been very influential for many years."

The organization's political history stretches back to 1983, when GMHC funded the first AIDS discrimination suit, Sonnabend and Callen v. 49 West 12th St.

Most recently, GMHC pushed for the passage of the Americans with Disabilities Act (ADA) through the Senate this summer by working with the AIDS Action Council, a lobbying organization representing over 600 community-based AIDS organizations nationwide, and the New York Citizens AIDS Lobby.

This past July, the landmark ADA was approved by President George Bush and the United States Senate. Taking effect in 1992, the law prohibits discrimination against people--

including those infected with HIV--in housing, employment, and public accommodations.

The implementation of ADA is "core to

since societal alienation of people with AIDS has kept those infected away from AIDS testing and care, she said.

Pushing the FDA to speed up their drug approval trials, which Getso said can take years, has been a main priority of ACT UP's Treatment and Data Committee, the group's largest committee.

Getting the FDA to pay attention to ACT UP and the urgency of speeding up drug approvals takes attention, ACT UP members said. In 1988, smoke bombs helped ACT UP members shut down the FDA for a day.

"ACT UP has been instrumental in getting drugs to people more quickly," Getso said. "In cases where it was about impossible to get drugs, [ACT UP has] negotiated with

government officials [to speed up the process.]"

The FDA, the federal government, and the public all have had to take notice of ACT UP, and since 1987 the group has gradually been afforded more attention and respect, Getso said.

For the first time, ACT UP took part in last year's annual international AIDS conference of doctors and researchers held in Montreal, Canada. The conference had been criticized in the past for not including people with AIDS, for limiting discussion of therapies, and for alienating groups like ACT UP, which were left demonstrating behind closed conference doors.

ACT UP delegates have been invited to the 1991 AIDS conference to be held in Florence, an indication of ACT UP's growth and influence, Getso said.

"They're paying more attention to us. In 1987 [ACT UP's activism] didn't necessarily fall on deaf ears," Getso said.

but when we kept the heat up, people were eventually embarrassed and said, 'include these people and see what they can contribute.' They've realized we're experts, too,' he said.

The attention given to ACT UP has not all been positive, however. Following a demonstration at St. Patrick's Cathedral last December, many leaders, including former Mayor Ed Koch and the four New York dailies, criticized ACT UP's behavior.

Protesting Cardinal John O'Connor's position on sex education and the use of condoms, ACT UP and Women's Health Action and Mobilization (WHAM) members chained themselves to pews, chanted slogans, and tossed condoms in the air, disrupting the High Mass service. One ACT UP member threw the Communion host, considered in Catholicism representa-

tive of the Christ's body, to the floor.

Extremism was necessary in the case of Cardinal O'Connor and the Catholic church, according to ACT UP members, who consider opposition to AIDS and sexual education akin promoting death.

"Compare that [protesting at St. Patrick's Cathedral] with what the Catholic church does day to day by forbidding safe sex education," Getso said. "Their actions directly contribute to the death of a lot of people."

However, ACT UP demonstrations are generally "peaceful," said Michael, the Columbia College senior involved in ACT UP.

"[ACT UP demonstrations] may offend people, but they are never violent," he said, adding that strong activism is necessary. "It's really a life and death situation as it is. You have to do what you have to." Several members of the Columbia LBGC said they did not necessarily approve of all of ACT UP's actions.

"It is the gay community that goes off and sits in and demonstrates--their voices are stronger--but I only agree with it to a point,"

said LBGC member Anastasia Kedroe, SEAS '91, who said she would probably turn to other groups attending to her needs before getting closely involved with ACT UP.

Kedroe characterized ACT UP members as "predominantly male and white."

"I definitely agree that concerning AIDS the only way to be heard is to sit in the street and block traffic--[ACT UP] wouldn't be as large as they are if they weren't successful-but they can sometimes miss the point," she said.

Support for ACT UP is not universal, Kedroe said.

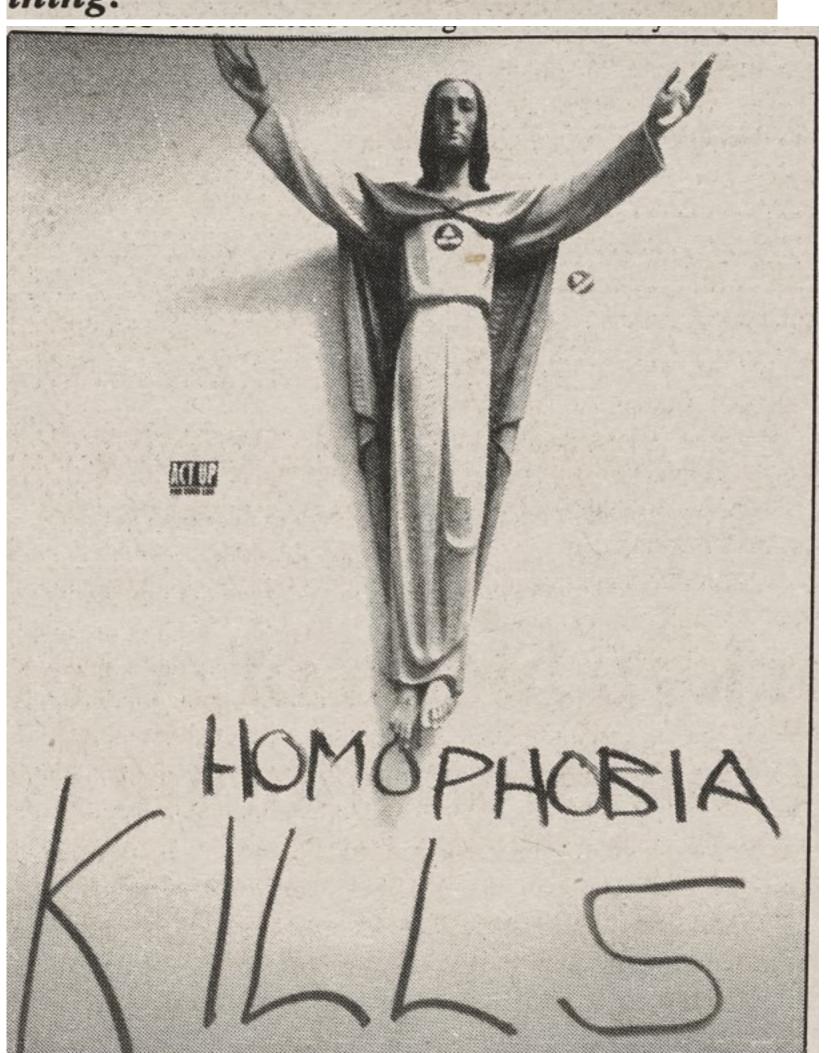
"Within the gay community, everyone doesn't necessarily agree with their ways," she added. Following the incident at St. Patrick's Cathedral, "there were a lot of people in the gay community who thought they were wrong," she said.

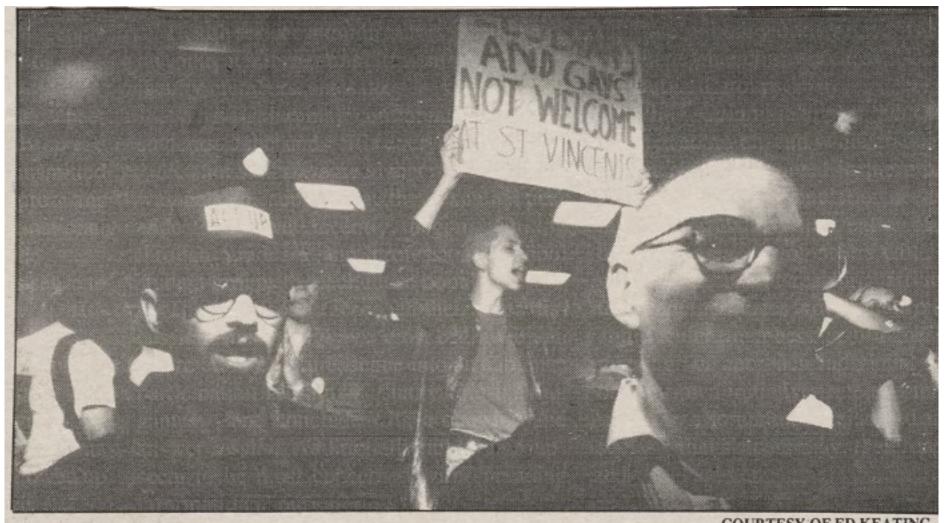
ACT UP needs a self-evaluation, Kedroe said. "As [ACT UP] grows and gets stronger, I really think there's a tendency to say we're right and you're wrong," she said. "Sort of, we can't be wrong."

"They're paying more attention to us. In 1987 ACT UP's activism didn't necessarily fall on deaf ears. We were making a lot of noise and were widely publicized, but when we kept the heat up, people were eventually embarrassed and said, 'include these

people and see what they can contribute.' They've realized we're experts, too."

"When you have friends who are HIVinfected, it really moves you to do something."





COURTESY OF ED KEATING

The AIDS Coalition to Unleash Power (ACT UP) has placed itself at the forefront of aggressive campaigning for AIDS awareness, medical care, and fair treatment. ACT UP has held numerous rallies and protests, and has targeted the Catholic Church for perpetuating anti-gay views.

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