The Mighty ACT UP Has Fallen: The Philadelphia Story

But in the depressed city of Philadelphia, one chapter has defied the doomsayers-by changing all the rules. Welcome to the future of AIDS activism

November 1, 2001 By Esther Kaplan

On the morning of June 23, 2001, as United Nations delegates from around the world arrived in New York City for the first-ever General Assembly on AIDS, the rain was pouring down without mercy. It was the sort of storm that makes umbrellas useless, that transforms comfortable shoes into steaming swamps. When the weather finally abated, an hour after the 11 a.m. start time for the Stop Global AIDS march, most of the protesters had scattered with the pigeons. Of the thousands expected, fewer than 100 remained in soggy Washington Square Park, gathering in clumps over watery coffee to hear a few hoarse speakers hold forth. If this assortment of button-clad lefties, onetime elected officials and paid staffers of nonprofits was the new global AIDS movement, its prospects that morning felt shaky indeed.

Then suddenly, the reinforcements thundered in: Chanting “Pills cost pennies! Greed costs lives!” with startling energy, ACT UP/Philadelphia rolled out of 12 packed buses, filling the desolate plaza with banners, signs and tremendous noise. The muted, pale clusters became, at once, an energetic African-American protest rally. Philadelphia may be one fifth of the size of New York, but the City of Brotherly Love had sent the whole march in.

It has become a regular thing for this hardscrabble group to turn out a thousand activists several times a year, to serve as the beating heart of demonstrations in New York, Philadelphia and Washington, D.C. With one foot planted solidly in Philly’s predominately black epidemic and the other in the new movement against corporate globalization, ACT UP/Philadelphia has not only renewed the waning ranks of American AIDS activism -- it may have put AIDS on the agenda of the Seattle generation. And as war-on-terrorism fever grips America in the months to come, ACT UP/Philly’s persistence may prove to be the AIDS movement’s saving grace.

Only a few years after the spectacular birth of ACT UP in 1987, journalists began to pronounce its death. Mostly these reports were false alarms, quickly refuted by another massive sit-in on Wall Street. But, eventually, the movement did lose steam: By the mid-’90s, many of ACT UP’s most dynamic leaders had died of AIDS, the complacency of the Clinton years had set in and the protease demi-miracle gave people a sense that the worst was over. ACT UP chapters around the globe closed up shop, leaving only a few at the barricades (see “Final Chapters”). Yet somehow,

during this same period, ACT UP/Philadelphia recreated itself as one of the most effective activist organizations in the country.

Like many ACT UP chapters, ACT UP/Philly came out of the local gay community. Despite the multicultural vision of PWAs of color like the late Kiyoshi Kuromiya, who helped found the chapter, Philly was a mostly white gay group at its 1988 inception. But even then, there were signs that the group's style was different from the angry, mediagenic culture of ACT UPs in LA, San Francisco or New York (where I joined up for several years). In 1990, when a proposed AIDS hospice faced opposition from the leafy liberal community of Mt. Airy, ACT UP/Philly broke into the former nursing home and camped there for a week, talking up the issue with neighbors. The camp-in ended with a community picnic, where activists played football with local kids whose parents surrounded reporters to express support.

Today, ACT UP's weekly meetings are held in the basement of St. Luke's Church, in Philadelphia's semi-revived downtown, and the atmosphere is more church social than Queer Nation. When I visited last June, activist Melvin White approached me right off, poured me coffee and began to chat. The meeting didn't come to order until another member, Shahid Robinson, arrived with tinfoil vats of food and everyone had settled down with a plate. The evening I was there, the discussion centered on a state names-reporting law and a recent boneheaded remark by Bush appointee Andrew Natsios, head of USAID, that Africans can't handle complex anti-HIV combos because they can't tell time. The meeting ended with a ritual go-around, where each person shared a parting thought.

The crowd of 60 was a pretty even mix of middle-class queer neohippies -- mostly women -- and low-income PWAs, almost all African American, who came to ACT UP through recovery programs or the local needle exchange. That old ACT UP staple, the muscled gay clone, was nowhere in sight. Everyone I've spoken to in ACT UP/Philly has warmly characterized this oddball gathering as a family. Watching them interact, I was reminded instead of Martin Luther King's dream of a "beloved community," in which loyalties transcend race and tribe.

Take Robinson, 46, a bear of a man sporting a full beard and an ankle-length black caftan. Released from prison a year ago after serving 23 years, Robinson is a leader of ACT UP's Prison Working Group. A practicing Muslim, decades in recovery and straight, Robinson has nevertheless found a sustaining support network among ACT UP's many young white lesbians, such as Asia Russell, 24, a former student activist who dropped out of college to devote her energies to AIDS.

As an inmate, Robinson was cut off from the heyday of AIDS activism, unable even to be open about his HIV status; Russell was only 12 when, she says, "you could call a demo on a week's notice and hundreds of people would show" -- the ACT UP she heard about on the news. Each came to AIDS activism only *after* its legendary death -- ready to rebuild the movement the hard way, one conversation at a time.

"A lot of people thought we'd have won the AIDS fight 10 years ago," says Kevin Conare, director of Philly's largest AIDS organization, Action AIDS. "ACT UP/Philly sees that we're part of a much

longer struggle.” Action AIDS may often play good cop to ACT UP’s bad, but Conare and staff still show up at demos.

In this and other ways, Philadelphia is an unusual town among American AIDS epicenters. While elsewhere the AIDS movement is sharply divided into “street activists” and “bureaucrats,” Philadelphia’s strong Quaker tradition of dissent has helped to create a more fluid relationship between service and protest. And unlike multiethnic New York or LA, Philadelphia is almost Deep South in its racial composition -- about half black and half white, with only tiny numbers of Latinos and Asians. It was early to develop a black AIDS infrastructure, with BEBASHI (Blacks Educating Blacks About Sexual Health Issues) founded in 1985.

These circumstances have allowed ACT UP/Philly to bloom as AIDS activism elsewhere has wilted. But its success is also rooted in what activist-training guru John Sellers, founder of the Ruckus Society, calls “great organizers, who are willing to challenge their class background, look at the fabric of inner cities and build unity.” These include Paul Davis, 32, once a tenant organizer; Kate Sorensen, 38, a union rep; and Asia Russell, a former rape-crisis worker, all of whom emphasize door-knocking over flashy graphic design. Many of these activists share homes and kitchens, where a phone number for the DA’s office is scratched on the wall near canisters of couscous, or work a few cubicles apart from one another at such AIDS agencies as Philadelphia FIGHT. And most of them, including the top treatment specialists, are women, a rarity in the AIDS world. They all found themselves through activism and share a passion for transmitting the skills and ideas that can transform a life.

None failed to notice that, by the mid-’90s, AIDS had moved way beyond the white gay community, and that the gay and lesbian social networks that had sustained the movement for so long were now inadequate. As other chapters struggled to survive, ACT UP/Philly “made a conscious effort to prioritize impacting low-income people with HIV,” according to Julie Davids, 33, a treatment specialist and one of ACT UP’s leading strategists. Most AIDS organizations did come to embrace addicts -- as clients. ACT UP/Philly’s critical insight was that recovering addicts were a potentially explosive activist force. In the years since the group took this turn, it has become a familiar presence at black AIDS organizations, community corrections programs and, especially, recovery houses. In fact, activism and recovery make such a tight fit that Philly has managed to funnel thousands of PWAs into activism.

I witnessed this myself one hot day last summer, when I followed John Bell out to a former church in North Philadelphia, an area of falling-down porches and abandoned storefronts. Bell, 54, a war vet and PWA, was scheduled to address a recovery meeting sponsored by One Day at a Time (ODAAT), a group founded by Rev. Henry T. Wells, a prominent black minister who still lives in a small brick house in the community. “ACT UP is glad to be where they can exercise their muscle,” Wells told me. “Down here where the rubber meets the road, they are seen as angels.”

The meeting was in a stultifying room on the church’s top floor, yet it was packed. Bell began his recruitment effort for the Stop Global AIDS march by saying, “Hi. My name is John, and I’m an addict and an alcoholic.” As he went on to talk about his gratitude for his lifesaving meds, it

seemed only natural that he'd invite the 100 or so assembled to stand up for HIVers worldwide who don't have access to the same meds. "For addicts, this is 12-step work," he said. "This is a chance to put away your own issues and help the lives of those less fortunate."

Later, Bell told me that ACT UP's direct-action tactics intimidated him at first. "As an addict, I'd interacted with the police and it was ugly," he said. But after observing Russell's dignity as she was hauled off by police, he finally took the risk, at a demo outside of a pharmaceutical lobby. What he remembers most is the look of admiration he got from his arresting officer. "I do this because it's the right thing to do," he said. "But the results, they sometimes floor me."

They include, in recent years, a decision by the city of Philadelphia to oppose names reporting; the state ADAP's addition of every protease inhibitor to its formulary; the right to an HIV specialist for people pushed into Pennsylvania's new Medicaid HMO plan (here Philly led a large coalition); and the one that most impresses Robinson, a new prison policy to release HIV positive inmates with a month's supply of meds, the culmination of a campaign with the AIDS Law Project. Along the way, ACT UP has gained the support of the city's most prominent labor and religious leaders, not to mention every major AIDS agency in town.

Just as ACT UP/ Philly had consolidated its base in late 1999, labor and environmentalists launched a new movement. By its sheer size and scope, the Battle in Seattle threatened to relegate '80s AIDS activism to a historical footnote. While AIDS activists in South Africa and Brazil fought drug-patent laws, a cause that meshed well with the new spirit of global anticorporatism, AIDS advocates in the U.S. mostly stayed focused on issues here -- drug side effects, say, or Ryan White renewal.

Well before Seattle, in April 1999, ACT UP/Philly bused 500 people down to Washington, D.C., to protest the free-trade-oriented Africa Growth and Opportunity Act -- also a target of environmentalists -- which they said benefited big business, not PWAs. The following summer, Philly joined in a high-profile series of zaps, hitting dozens of Al Gore's presidential campaign appearances. By the end of June, Gore, who had threatened sanctions against South Africa for legalizing generic drug production, declared his support for the measure.

More Philly actions followed, often with the newly formed Health GAP and ACT UP/New York, against fluconazole-maker Pfizer, then-U.S. trade rep Charlene Barshefsky and others. By the time antiglobalization forces targeted the Republican National Convention, slated for Philadelphia in early August 2000, ACT UP/Philly was a known player in the new movement.

According to Medea Benjamin, director of Global Exchange, a nerve center of antiglobalization forces, AIDS was invisible just two years ago in Seattle. Now, she says, due to militant AIDS groups such as ACT UP/Philly, "'Patients before patents' has become a rallying cry for the whole movement. AIDS is now in the top three issues, along with sweatshops and genetically modified food."

Yet ACT UP/Philly has its critics. Several longtime New York AIDS activists say the group's tendency toward chaotic improvisation -- which aligns it with the decentralized, anarchic approach of the

antiglobalization crew -- hampers them in working with the bureaucratic arm of the AIDS drug-access movement, from Doctors without Borders to UNAIDS. They cite a few debacles, such as a Health GAP conference-cum-protest at last June's UN Assembly on AIDS, which ACT UP/Philly helped to organize. Members staged a walkout, shaking pill bottles filled with pennies, but when dozens of Asian and African delegates joined in, security guards snatched away their conference badges. Several AIDS advocates had to play mop up, politicking to get those credentials restored. The support that Philly enjoys may have taught them that if they take chances, they can finesse the consequences later -- a feat that's not so easy away from home. Still, one critic, ACT UP/New York's Kate Barnhart says, "They have tremendous risk-taking energy, and this knack for grass-roots mobilization, so they get a hell of a lot done."

While some advocates fret that attention paid to AIDS in Africa distracts from the crisis at home, the Philly squad has embraced the epidemic's global dimensions totally. As Davids asked at a recent teach-in: What's the difference between user fees imposed on Philadelphia inmates by a for-profit health provider and those imposed on Africans by the International Monetary Fund?

And so it goes like this: In August, ACT UP/Philly invaded city hall to protest negligent health care in the city's jails; by late September, they planned to be in D.C. again, to protest the IMF's role in gutting health-care infrastructure in the developing world. Of course this and countless other best-laid plans crumbled on September 11 along with the gleaming towers of the World Trade Center. The IMF meeting was canceled, and so was the demo. But the uncertainty that grips many in the AIDS field as the threat of war eclipses the epidemic, hasn't rattled the beloved community at St. Luke's Church. Bell, a veteran of that other "low-intensity conflict," Vietnam, says his work with ACT UP made more sense than ever that Tuesday. "We were already making the connections between local and global in terms of health care and AIDS," he says. "We have been preparing people for some time to be not only U.S. citizens, but citizens of the world."

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