

creating a radically democratic politics. But for the space of movements to be more than a refuge for the politically correct, we must also create a third space of mediation that attempts to shift that bizarre mass-mediated virtual public sphere in truly democratic directions. Those who believe that the "new world order" of Presidents George H. Bush and George W. Bush looks all too much like the imperial world order of King George III (the one we Americans fought a revolution against) have much work to do.

Just as mobilizing is surely not enough in itself, any social movement that is serious about extending its constituency beyond the margins needs at some level to contest for and with the realm of mass-mediated messages. That kind of politics, as I have been arguing, may need some global counter-spectacles and more than a little of that transnational language known as rock music.

The energy set in motion by Live Aid continued nearly two decades after it began. When Bob Geldof's protégé, U2's Bono, addressed the U.S. Senate on the Third World debt crisis and traveled to Africa with Secretary of Treasury O'Neil in 2002, debating policy all the way, he was building on that legacy. At a time when there are millions of people in Africa with AIDS, and when a new, possibly even more devastating famine is emerging in southern Africa, finding ways to harness the power of global pop culture to assist popular global movements has never been more urgent.

## SEVEN

## ACTing UP against AIDS

*The (Very) Graphic Arts in a Moment of Crisis*

In this chapter I explore one of the most dynamic and successful social movement groups of the late 1980s and 1990s, the AIDS Coalition to Unleash Power, or ACT UP. One key argument of this book—that all movement politics involves a degree of *cultural* politics—owes much to recent activist groups like ACT UP, which have made such an insight difficult to ignore. ACT UP, as much as any movement yet invented, has made self-conscious cultural struggle part of its core work. Those of us who now see culture everywhere, even in movements from earlier centuries, owe a great debt to groups like ACT UP, which have brilliantly highlighted the impossibility of fully separating cultural from political dimensions of movement activity.

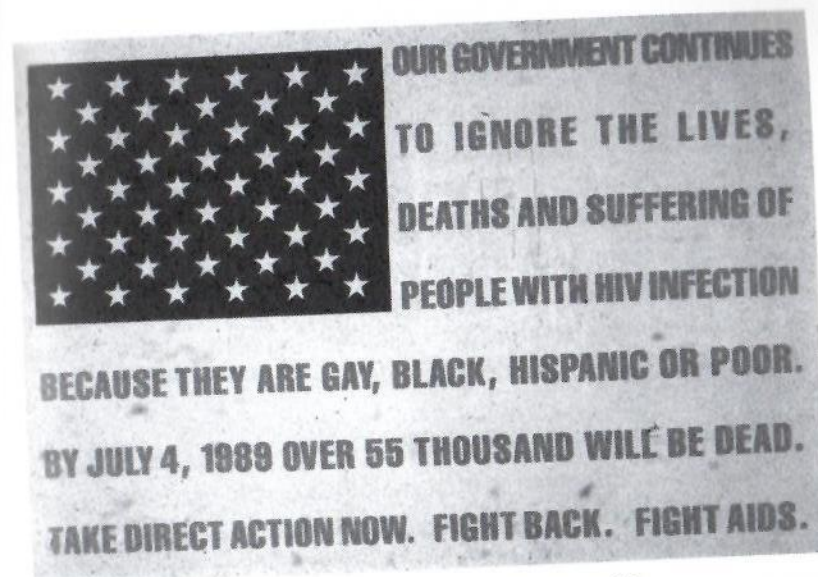
In examining ACT UP I tell its story as, among other things, an attempt to reinvent the politics of protest in the face of the changed political, economic, and cultural conditions often given the label "post-modern." While I think that claims to a unique, postmodern condition are often exaggerated, they do point to certain cultural developments that have reshaped the terrain on which movements function, and no group has done more to address those developments than ACT UP. Post-modern perspectives call attention to the notion that the cultural landscape is now so media-saturated and commodified, it is hard to tell the real from the virtual, past from present, entertainment from news, resistance from cooptation. One of the many ways in which this media-saturated environment has had an impact on social movements has been through the trope of decade segregation. How often does one hear



the media use a phrase like “sixties-style demonstration,” which at once trivializes movements as a “style” and suggests that the movement in question is an anachronism (as though it had missed the one decade when movements were apparently allowed, the 1960s). This attempt to ghettoize movements as a phenomenon of one decade forms part of a larger trend in which it has become more and more difficult for movements to get the attention of the public. Part of the genius of ACT UP has been the group’s amazing creativity, particularly through use of the visual and performing arts, in challenging the media’s packaging of protest and trivialization of movements. As we will see, it did this most effectively through the use of striking, aesthetically rich images, accompanied by witty, sound-bite-worthy slogans. Drawing heavily on *AIDS DemoGraphics*, a remarkable book by Adam Ralston and Douglas Crimp that covers the work of New York City’s branch of ACT UP, I will trace the major themes, foci, and actions of the organization primarily through a trail of graphic—sometimes very graphic—slogans and images emblazoned on signs, posters, banners, stickers, t-shirts, buttons, bumper stickers, and other paraphernalia.

### Protexsts and Contexts

The disease of acquired immune deficiency syndrome, which came to be known as AIDS, emerged in the United States in the early 1980s. By historical accident, in the United States the syndrome arose initially primarily among gay men, a fact that forever colored the response. For the first couple of years of the epidemic, very little attention was paid to it outside the gay community. This was due in no small part to homophobia, a social disease on the rise in a time of right-wing ascendancy in national politics. The far less virulent infection called legionnaires disease, which was identified around the same time when an outbreak occurred among a group of older, white male war veterans, received far more medical attention. When AIDS was first identified, it was given the name gay-related immune deficiency (GRID), a name that obviously reinforced an association of homosexuality and the disease. The religious right, recently emboldened by the election of President Ronald Reagan, quickly seized on the situation to deepen their attack on homosexuality and their promotion of an antifeminist agenda that sought to return sexuality to the control of patriarchal heterosexual men.



ACT UP reworks the U.S. flag. Courtesy of AIDS DemoGraphics.

The response in the gay community moved quickly from confusion and panic to self-organization. In the face of neglect from government and the medical system, service organizations like the Gay Men’s Health Crisis (GMHC) emerged in many cities. The GMHC took on the monumental task of lobbying for medical research, while also seeking to attend to the needs of those afflicted with the mysterious disease. GMHC and groups like it gradually became institutionalized as vitally important AIDS service organizations, in effect filling in for the neglect of local, state, and federal governments. They provided the latest medical information, disseminated “safer sex” guidelines, and organized care for those with the disease. By the mid-1980s, with the death count rising, and during the administration of a conservative president who had yet to utter the word *AIDS* in public, let alone offer a policy on the disease, a growing sense of crisis was being felt. In this context, the GMHC and other service organizations seemed too tame, too overworked, and too tied to bureaucracies that still had done far too little to address AIDS. As has happened in so many areas of contemporary society, economic slowdowns and conservative antigovernment politics have forced voluntary, largely self-sustaining organizations to provide the services governments should provide. In providing those services, however, these



organizations inadvertently help the interests of a political system that has shown its unwillingness to help them. They thus insulate governments from the demands of those in need. In the case of AIDS, the government's (in)action of pushing responsibility onto impossibly underfunded service organizations like GMHC was having a deadly impact. Sensing the injustice of this situation, a new generation of activists sought to tear away the insulation, provoking confrontation, not compromise, direct action, not accommodation, in the face of government and corporate indifference.

### New York Stories

ACT UP was founded in New York City in March 1987 amid a deepening sense of the horrifying extent of the HIV/AIDS epidemic. The group declared themselves a "diverse, non-partisan group united in anger and committed to direct action to end the AIDS crisis."<sup>1</sup> In myth, ACT UP springs up spontaneously during a speech by AIDS activist Larry Kramer. The speech and Kramer's passion were certainly important inspiration. But the origins of ACT UP are multiple and complex, drawing from various elements of the women's health movement, earlier AIDS activist groups like the Silence = Death Project, disgruntled members of the more moderate Gay Men's Health Crisis, and various gay and lesbian liberation groups. ACT UP eventually grew to national and international dimensions. By early 1988 chapters had appeared in various cities throughout the country, including Los Angeles, Boston, Chicago, and San Francisco. By the beginning of 1990 ACT UP had spread throughout the United States and around the globe, with more than a hundred chapters worldwide.

While this growth led to great diversity, ACT UP's New York origins left an indelible mark on the group. One can chart much of the activity and cultural shape of ACT UP via a social geography of New York City. Four of the major targets of ACT UP have a strong historical presence in the city: the mass media (Times Square, home of the national TV networks), corporations (Wall Street, the New York Stock Exchange), advertising (Madison Avenue), and the arts (Soho, Greenwich Village, Broadway). Two other favored targets of ACT UP activists, the Catholic Church and government bureaucracies, also have major New York sites that proved convenient points of focus. And proximity to Washington,

D.C., made a host of federal government sites accessible to ACT UP NYC as well.

ACT UP had an unusual, if not unique, set of material and cultural advantages, as well as substantial disadvantages as an organization. On the negative side, especially in the early years it was lobbying on behalf of several highly stigmatized communities, including gay people, intravenous drug users, and prostitutes. Add to this the stigma of working on the terrain of a disease about which little was known and around which much fear of contagion circled, and formidable obstacles confronted the group. On the positive side of the ledger, the organization drew much of its membership and support from middle- and upper-class professionals and semi-professionals, including people employed in some of the very sites the group would target. This provided unusual amounts of material resources, and unusual kinds of intellectual resources. Of particular relevance for this analysis is that ACT UP's membership included visual artists, advertising copywriters, and media professionals who knew intimately what would and would not work, what would or would not sell in contemporary U.S. culture. They understood, for example, that modern mass-media news most often takes narrative form; thus, ACT UP's dramatic demonstrations always sought to tell good, carefully plotted stories.

### Theorizing in an Epidemic of Words and Images

ACT UP's somewhat atypical constituency also included an unusually large number of academics, artists, and others who were conversant with, if not enmeshed in, contemporary cultural theory. Cultural critic/AIDS activist Cindy Patton claims that:

ACT UP, especially the New York City group . . . provides an interesting example of emerging postmodern political praxis using deconstructionist analyses and tactics. A number of key people in the group are artists or intellectuals with deconstruction politics. To many people actively involved in gay and now AIDS anarchist politics, deconstructionist, cultural marxist, and post-structuralist methods and jargon are fairly familiar, whether coming directly from Derrida, Gramsci, or Foucault, or simply as part of a zeitgeist. In addition, particular postmodernist texts form the reading list of the ACT UP New York group, which holds discussions of the relationship between their particular praxis and their experience/politics.<sup>2</sup>



Allowing for the likelihood that Patton is exaggerating the influence of her own preferred theoretical-political style in the organization, it is clear that ACT UP is informed by postmodern theory in some significant ways. This is manifested particularly through a stronger than average sense that, in Michel Foucault's terms, power and knowledge are inseparable. This leads to great sensitivity to the ways in which even the most factual, scientific knowledge is a cultural construct caught in politically inf(1)ected webs of language. This has aided ACT UP especially in taking on socially constructed medical knowledge, and in analyzing and using mass media framings of the "real."

In the same year as the founding of ACT UP, cultural critic Paula Treichler published an essay that did much to bring theory into the orbit of AIDS activism. Treichler noted that AIDS was not only a disease of epidemic proportions, but a phenomenon that had spawned an "epidemic of signification." Her essay offered a kind of primer for a postmodern understanding of language as implicated in the process of creating AIDS: "The name AIDS in part constructs the disease and helps make it intelligible. We cannot therefore look 'through' language to determine what AIDS 'really' is. Rather we must explore the site where such determinations really occur and intervene at the point where meaning is created: in language." Treichler quickly refutes the common misunderstanding of postmodern theory that sees it as claiming that nothing is real, or that any story is as good as any other. Rather, she writes: "Of course AIDS is a real disease syndrome, damaging and killing real human beings. Because of this, it is tempting—perhaps in some instances imperative—to view science and medicine as providing a discourse about AIDS that is closer to its 'reality' than what we can provide ourselves. [But] try as we may to treat AIDS as 'an infectious disease' and nothing more, meanings continue to multiply wildly."<sup>3</sup>

After demonstrating brilliantly how even the most elemental scientific "facts" about AIDS are infected with cultural assumptions, Treichler calls for an approach to the medical knowledge about AIDS that is neither dismissive nor submissive: "We need to use what science gives us in ways that are selective, self-conscious, and pragmatic ('as though' they were true). We need to understand that AIDS is and will remain a provisional and deeply problematic signifier."<sup>4</sup> This understanding of knowledge about AIDS as "provisional" and "problematic" was crucial to giving ACT UP the power to challenge the proliferation of questionable cul-

tural meanings imposed on the disease by the medical community, the government, and the media.

What became clear, with the aid of cultural theorists like Treichler, Michel Foucault, Jan Grover, Cindy Patton, Simon Watney, Douglas Crimp, and many others, was that homophobia, racism, and sexism were deadly social diseases that needed to be fought along with the virus, not only in the outside world but inside ACT UP as well. Prejudice against gays, people of color, drug users, and women set back the process of treating and seeking a cure for AIDS and its causative agent, the human immunodeficiency virus (HIV). The country's longstanding puritanical sexual attitudes made it difficult to talk publicly about a sexually transmitted disease. It became clear that in an "information age" and a "knowledge economy," more than ever knowledge was power, power knowledge. The war over HIV/AIDS was going to be very much a "discursive" battle, a battle over the meaning of words and images. This was surely not something wholly new in a social movement, but the extent to which "semiotic" warfare became self-conscious and central to the work of ACT UP was unprecedented.

The postmodernist element in ACT UP politics reinforced a strong preference for decentralized, antihierarchical organizational forms that the group inherited from other movements, most directly from the antinuclear direct action movement of the late 1970s and early 1980s. ACT UP was structured in a set of "affinity groups" (typically consisting of five to fifteen individuals), each of which maintained a strong degree of autonomy within the organization. Few rules or overarching ideas, other than a general commitment to nonviolence and a desire to bring an end to the AIDS crisis, limited ACT UP activists. Mobility and flexibility were deemed crucial resources in a cultural environment constantly in motion.

ACT UP's postmodernist tendencies are also manifested in the group's complicated relation to so-called "identity politics"—the efforts of groups to organize around specific racial, ethnic, gender, sexual, or other characteristics. On the one hand, the group understood the necessity to deploy a "gay" identity at times as an organizing tool. But even as it demonstrated a willingness to use "identity" politically, members incessantly questioned the assumptions through which identities often devolve into static, homogenizing essences. ACT UP put into play the complexly ambiguous identity, "queer," an identity that at once reminds those using



it of its oppressive origins as a homophobic epithet, resignifies it as a positive identity, and articulates a queering (blurring) of the lines between gay and straight, normative and oppositional. Thus ACT UP members learned to see identity formation as an ongoing collective and strategic practice, not an unchanging essence.

Postmodern perspectives on the instability of identities also proved useful, as Joshua Gamson has argued, in dealing with one of the central contradictions faced by ACT UP: the need to challenge the mainstream, homophobic view that AIDS was a "gay disease," on the one hand, and, on the other hand, the need to mobilize the gay community to see the AIDS crisis as a community crisis tied to the politics of lesbian and gay liberation. Rather than becoming stymied by this seeming double-bind, ACT UP was able, thanks to its postmodern critique of such easy dichotomies as gay/straight, to treat this contradiction as a useful one that could challenge dangerous oversimplifications perpetrated by the mainstream media.<sup>5</sup>

More generally, ACT UP's theoretical understanding means that its members recognize that in addition to fighting government bureaucracies, media bias, and corporate self-interest, they are also fighting, as Gamson phrases it, an "invisible" force: social norms that define what is normal, natural, and appropriate versus what is abnormal, unnatural, and deviant. The power of these norms lies precisely in their invisibility, their deep embeddedness in culture such that they are taken utterly for granted. ACT UP developed several strategies for bringing these invisible norms out of the closet and into the open where they could be challenged.

### Cultural Que(e)ries

While it was never an exclusively gay organization, the movement culture of ACT UP drew heavily upon institutions, forms, and styles within gay male and lesbian communities. In turn, ACT UP played a significant role in transforming those communities. A gay culture that had previously remained largely underground had been strengthened, extended, and moved above ground by successive waves of movement activity from the 1950s onwards. Three overlapping waves of activism preceded the emergence of the ACT UP generation: a "homophile" phase in the late 1950s and early 1960s that established baseline positions in a style reminiscent of the NAACP; a more radical "gay liberation" and "lesbian-

feminist" phase in the late 1960s to mid-1970s, shaped by revolutionary models provided by feminist and ethnic radicals; and a "gay and lesbian rights" phase from the mid-1970s to the mid-1980s that consolidated and institutionalized what the radical movement had begun. In this context, ACT UP and spin-off gay groups Queer Nation and Lesbian Avengers represent a fourth phase, a reradicalization aimed at both the AIDS crisis and assimilationist elements in lesbian and gay communities. As the rise of AIDS fueled a new demonization of gays that showed signs of reversing the modest but important gains of the gay rights era, ACT UP pushed back on the political and cultural fronts simultaneously.

Each movement phase not only strengthened semi-autonomous gay culture(s), but also contributed to a process that brought greater visibility to elements of queer culture that were deeply embedded in key terrains of U.S. high and popular culture. Even as each emergent wave created new, interwoven institutions for gay people, it also complicated gay/queer community life by revealing internal differences in race, class, gender, political orientation, and sexual practices. As waves crash against the shore, they dissolve and re-form into new configurations; just so, lines between radical and reformist, integrationist and separatist are seldom neatly traceable in highly fluid situations. Thus, ACT UP emerged at a highly complex moment, and its actions were never less than controversial across various lesbian/gay/queer subcultures.

Despite and because of this complexity, it is clear that queer cultural connections and styles enabled and shaped virtually all dimensions of ACT UP, from the social networks that it recruited from, to the sites chosen for meetings, to fundraising sources, to, most pertinently, its graphic images, slogans, costumes, and highly theatrical demonstration style. The rise of gay, lesbian, and queer studies in the universities; the creation of gay bookstores, coffeehouses, movie theaters, and health clinics; the expansion of the gay press: all these provided material-intellectual resources of great importance to ACT UP. These institutions made more available a set of gay cultural codes that could be deployed positively in organizing and parodically used against a mainstream "white, male, heterosexual" world.

A sense of how a playfully gay cultural coding worked in the movement is apparent in the group's name itself. The acronym *ACT UP* has multiple meanings. It clearly signals a sense of the need to act, to act defiantly, and to stand up against oppression. At the same time, this



rather macho sense of activism is undercut both by an echo of the phrase *acting up* (in the sense of not working right) and *acting up* (in the sense of a child behaving badly). And, of course, the emphasis on *acting clearly* signals a sense of performing or pretending that is supposedly the opposite of serious political action. The name thus suggests a characteristic political seriousness in ACT UP that was entangled with an equally serious and equally political playfulness (for example, wrapping antigay Senator Jesse Helms's home in a giant yellow condom).

A pointed example of how gayness played politically appears in one of ACT UP's first demonstrations. During the Washington demonstration in June 1987, District of Columbia police officers displayed their homophobia and hysteria about "catching" AIDS (or gayness?) through casual contact, by wearing bright-yellow rubber gloves as they arrested several dozen ACT UP members who were engaging in civil disobedience. As Crimp and Ralston report it, the "activists, many looking unusually respectable in conservative business clothes, raised a very queer chant, 'Your gloves don't match your shoes! You'll see it on the news!'" Amid the campy humor, the chant is perfectly designed to "out" the police hysteria. The point is made more memorable through its catchy, rhymed phrasing. It was just the kind of chant (connected to a visual image) that would make sure that not just the police, but also the protesters, would see themselves "on the news."

Another contribution of gay culture to ACT UP actions is hinted at by the reference to "conservative business suits" in the passage above. This particular costume in part reflects the professional class and business world in which many members spent their "day jobs." Some activists sometimes used this mode of dress straightforwardly, as it were, to reflect their class similarity to those they were protesting against. At other times, however, group members used this costume as a disguise, as what they called "Republican drag." This ability to "pass" sent a message about the ubiquity of gayness and the contingency of "normal" identity. It also served activists well in such efforts as "zapping" the New York Stock Exchange or "crashing" international AIDS medical conferences. In conservative drag ACT UP could infiltrate the audience, for example, and pepper gathered scientists with the kind of troubling questions from which they were often insulated in their academic or corporate ivory towers. At still other times, the drag employed was the more traditional, cross-dressing kind, and was used to express an unrepentant otherness

in gay culture and gay humor, symbolized by the favorite chant of ACT UP's cousin Queer Nation: "We're here, we're queer, get used to it."

Campy humor informed other dimensions of the organization as well. Affinity groups, the core units used to organize ACT UP, have a long history of clever self-naming. In ACT UP, this self-naming frequently took on a decidedly queer quality. For example, one group's acronym was CHER, in homage to one of the favorite divas of a segment of the gay male community. The meaning of the acronym changed frequently, but one explication is particularly rich: Commie Homos Engaged in Revolution. This version of CHER at once sends up homophobia and expresses solidarity with the long-suffering American left against which the label "commie" had been hurled to dismiss anyone so "deviant" as to question the U.S. political system. In similar fashion, another colorful affinity group called themselves the Pinkos. Both names hint at the hysterical connection drawn during the "un-American activities" witch hunts of the 1950s between deviant politics and deviant sexuality, between the allegedly "contagious" "spread" of communism and sexual perversity.<sup>6</sup>

The campy humor of ACT UP underlines the impossibility of separating "political" from "cultural" dimensions of a movement. The group's humor was both an effective tactic and a mode of defiant assertion of identity. And even the "expressive" mode was political in that it deepened solidarity in the movement. ACT UP understood that humor could be disarming and used wit strategically to counter half-witted messages circulating in the mainstream (when protesting the Catholic Church's deadly stand against condom use, members chanted, "Curb your dogma"). Sometimes, as in the acronym ACT UP itself, they used humor to make fun of their own emerging ideological rigidities. They also used it just for fun. But as Crimp and Ralston put it, "ACT UP's humor is no joke. It has given us the courage to maintain our exuberant sense of life while every day coping with disease and death, and it has defended us against the pessimism endemic to other Left movements, from which we have otherwise taken so much."<sup>7</sup>

### Silence = Death

ACT UP's media savvy and aesthetic sophistication combined to form a series of remarkably catchy images and slogans, texts to catch both the media's and the public's attention. The group understood that in an image-saturated, sound-bite culture, getting people's attention was no



easy task. But many ACT UP activists were media veterans, and their expertise helped the group gain an unprecedented amount of media coverage.

While the slogan and image "Silence = Death" precedes the birth of ACT UP, the group quickly adopted the phrase and its accompanying image, a pink triangle on a black background, which became its most identifiable image-text. As political slogans go, it is certainly a strange one, alerting us that there was from the beginning something different about this particular group of activists. While most traditional activists would view as a liability the lack of immediate clarity about what the phrase might mean, to ACT UP that ambiguity was precisely the point. ACT UP created many brilliantly clear, pointed slogans. But the group also understood the importance of strategic ambiguity. In this case, the equation was meant to, and on countless occasions did, evoke the question: "What does that mean?" As such, it became an invitation to a prolonged discussion of the AIDS crisis. Various answers to the question were possible, but many would begin by saying that the pink triangle was fastened on gay prisoners as they were marched to Nazi concentration camps. Silence about those camps led to millions of deaths. By analogy, fearful silence about the extent of the AIDS crisis, including fearful self-silencing by gays and other stigmatized groups, deepened a crisis they believed would soon reach Holocaust proportions. But this pink triangle inverted the one gays were forced to wear by the Nazis; this one pointed up in hope, not down in despair. If silence equaled death, speaking out and acting up could equal new chances for life.

### Art Is Not Enough

The Silence = Death graphic eventually found its way into an exhibit at the New Museum of Contemporary Art in Soho in 1988. By that time the Silence = Death collective was metamorphosing into the key ACT UP graphic collective, Gran Fury (named after the kind of cruising car favored by the gay-harassing police). Entitled "Let the Record Show," the exhibition demonstrates both ACT UP's early targeting of some and support from others in the art community. As noted above, the presence of many visual artists, advertising professionals, actors, and playwrights in ACT UP seeded the group with aesthetic powers and a visual-theatrical orientation that proved crucial to its successes. And a particular, "postmodern" aesthetic then prevalent in part of the art world lent itself

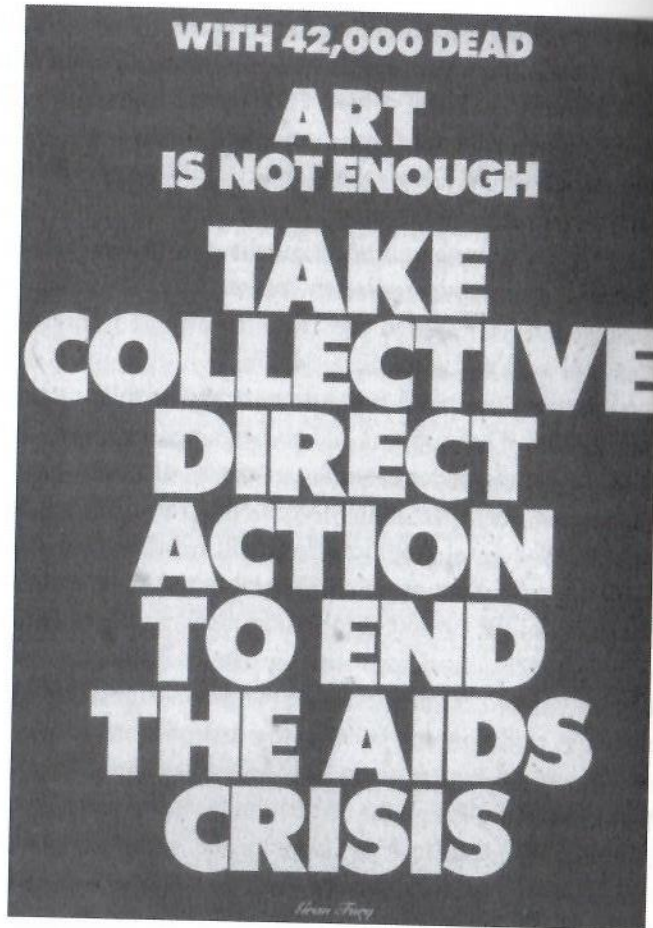
well to activism. Much postmodern art and criticism was deemphasizing the individual artist of genius in favor of a sense of art as a social process embedded in political contexts. This attitude assisted ACT UP in quickly recruiting artists and appropriating whatever aesthetic styles the group believed would further the visibility of the movement. Appropriation itself had the imprimatur of the avant-garde, since "appropriation art," in which the myth of utter originality was being challenged by artists deliberately imitating or directly copying works by earlier artists, was all the rage. ACT UP shifted register to the other, emotional definition of *rage*, but kept the aesthetic possibilities.

But the art community did not automatically or fully embrace the fight against AIDS. That support had to be gained by organizing and acting. ACT UP protested, for example, an exhibit of protest graphics at the Museum of Modern Art (MOMA) in New York that included no examples of AIDS activist graphics. They believed the museum exhibit perpetuated a sense of art as above the political fray by emphasizing formal elements of the protest graphics on display, and by embalming art objects while excluding living activist-artists like the Silence = Death/Gran Fury Collective. "Let the Record Show" was a counter to this more mainstream art tradition and became the first of many shows raising awareness of and, in benefit form, raising money for AIDS activism. The exhibit title itself plays on the distinction between "mere" documentation ("the record") and "true" art (worthy of a "show"). This counter-exhibit and the MOMA protest both challenged the sense that real art was about form and abstract, universal human experience, and sought to break down the complacent distinction between art as representation and art as action: acts of representation were held politically accountable, and political acts were celebrated for the terrible beauty of the crisis they brought into view. At the same time, as seen in a Gran Fury ACT UP poster produced near the beginning of the crisis, art, however useful, is "not enough." In striking white letters on a mournful black background, the poster declaims: "WITH 42,000 DEAD, ART IS NOT ENOUGH. TAKE COLLECTIVE DIRECT ACTION TO END THE AIDS CRISIS."

### Medicinal Civil Disobedience

The central targets on ACT UP's initial agenda were the intertwined issues of health education, medical research, drug availability, and disease treatment. Following the kind of position articulated by Treichler





Art Is Not Enough. Courtesy of AIDS DemoGraphics.

and others, ACT UP members became skeptical medical consumers and, often, amateur medical researchers themselves. The group's professional membership included doctors and medical researchers, but beyond that many other members took up the task of learning about the process and substance of drug development, testing, and distribution. Their understanding of the social construction of disease and their analysis of the corporate-government process of drug approval led them into several kinds of civil disobedience. This included what we might call medicinal civil disobedience in the form of publicizing, making available, and using illegal or not-yet-legal medicines. It also took the more traditional form of demonstrations against pharmaceutical corporations and the federal

drug bureaucracy, and aggressive actions invading medical conferences. It also took the form of imagining theatrical actions like wearing lab coats and presenting "guerrilla" slide shows that parodied conference presentations, or doctoring real slide shows by inserting slides stating, "He's lying" or "This is voodoo epidemiology."<sup>8</sup>

ACT UP actions also challenged health educators, from the surgeon general on down. The group called for education about AIDS that was frank, not euphemistic, unprejudiced, not homophobic, and targeted in culturally sensitive ways to particular communities, rather than blandly generic. This included challenging the dominant model of medical expertise in which the opinions, experience, and cultural location of the client-patient had been deemed largely irrelevant. Drawing inspiration from the women's health movement that grew out of second-wave feminism, and wielding the privilege embodied in their highly educated constituency, ACT UP had grudging but substantial success in changing attitudes and practices inside and outside the medical establishment.

ACT UP's basic strategy might be called the politics of shaming. Through demonstrations, flyers, posters, informational media actions, newspaper advertisements, letter-writing campaigns, civil disobedience, and sit-ins and small "zap" actions in corporate, government and media offices, the group sought to draw attention to shameful government sluggishness, shameful corporate profiteering, and shameful media bias. Faster drug approval, lower drug costs, community-targeted health information, more humane treatment programs, easier availability of experimental drugs, more money for medical research: all these goals were furthered by ACT UP action and negotiation, and all prolonged or saved lives. These victories had ramifications beyond the context of AIDS, benefiting all users of the health care system.

### **AIDS: It's Big Business, But Who's Making a Killing?**

Given these concerns, it is no surprise that the first major ACT UP "demo" (demonstration) targeted pharmaceutical corporations and their allies in the federal government. Specifically, the demonstration was aimed at Burroughs Wellcome, maker of the first important anti-AIDS drug, AZT, and its relationship with the federal Food and Drug Administration (FDA). Burroughs Wellcome had proposed to charge more than \$12,000 per year for this critical drug. For ACT UP, in a country without universal health care this was tantamount to condemning





AIDS Is [still] Big Business! Courtesy of AIDS DemoGraphics.

to death all but the wealthiest people with AIDS. Noting the heavy subsidizing of medical research by the federal government, and the exclusive contract given Burroughs by the FDA, ACT UP argued that there was outrageous price-fixing collusion between government and pharmaceutical companies. ACT UP descended on Wall Street at 7 a.m. on Thursday, 4 March 1987, to protest the alliance between the FDA and Burroughs Wellcome. Protesters tied up busy commuter traffic for several hours. "The demonstration made national news, and several weeks later, when [the FDA] Commissioner announced a speed-up of the FDA's drug approval process, CBS anchor Dan Rather credited ACT UP's pressure."<sup>9</sup> The action also proved a recruitment device; stock trader Peter Staley, for example, was so impressed by the demo and so disturbed by the homophobic reaction to it by his fellow traders that he started "living a double life, trading by day, going to ACT UP meetings at night," till eventually he devoted himself to the group full time. He became a stalwart member of ACT UP, and later a founder of the spin-off group TAG (Treatment Action Group).<sup>10</sup> Corporate targeting included a brilliantly innovative use of the sticker graphic. ACT UP designed small stickers with the words "AIDS Profiteer" that members affixed to cold care medicines and other medical products from Burroughs Wellcome Corporation as they moved through pharmacies. A later continuation of this action included a poster with a slogan that at once called for a new

type of boycott, selling stocks, and paid witty homage to the tradition of campaigns to free political prisoners: "Sell Wellcome, Free AZT." ACT UP took on other pharmaceutical corporations as AIDS medicine evolved; one effective tactic was backing up the label "AIDS Profiteer" with strategically placed ads detailing the price of particular drugs and the yearly profits of the company making them. This politics of shaming often proved quite effective as in the dip in Burroughs stock that had followed the demonstration against the firm.

### The Government Has Blood on Its Hands

As part of its targeting of government inaction, ACT UP went after the FDA itself, and the agency's cumbersome process for getting new drugs and treatments approved. Activists challenged what they saw as the deadly neglect entailed by long-delayed approvals of experimental drugs. In the group's inimitable style, an ACT UP graphic proclaims: "Time Isn't the Only Thing the FDA is Killing." A tactic developed to dramatize this problem and used in numerous ACT UP actions was the "die-in." Adapted from antinuclear activism, ACT UP's version is interpreted by Gamson as not only a direct commentary on drug policy, but also a swipe at normalizing: "A 'die-in,' in which activists draw police-style chalk outlines around each other's 'dead' bodies, gives death another meaning by shifting responsibility: these are deaths likened to murders, victims not of their own 'deviance,' but shot down by the people controlling the definition of normality."<sup>11</sup> Moreover, these "living dead" protest their relegation to the hospice and the cemetery or to the silence that equals death. By moving "death" out into public space, they resist the death sentences written by normative discourse and social indifference to the search for treatment and cure.

In a similar vein, a good deal of the cultural struggle around AIDS has focused on blood. Where "contaminated" blood was used to separate the innocent from the guilty, an ACT UP graphic declares that "the government has blood on its hands," above a huge bloody handprint. A still more dramatic and imaginative use of blood symbolism was embodied in the infamous "Dannemeyer Vampire." Rep. William Dannemeyer was a California politician whose Proposition 102 would have required all doctors to report to authorities all those infected, or even suspected of being infected, with HIV. In response, San Francisco's ACT UP chapter built a huge puppet effigy of Dannemeyer, with a vampire head,



black cape, and blood dripping from its fangs. As Gamson reads it, "ACT UP activates another popular code in which blood has meaning—the gore horror movies—and reframes blood testing as blood sucking. It's not the blood that is monstrous, but the vampire [politician] who would take it."<sup>12</sup>

The issue of blood testing and violation of patient confidentiality led ACT UP to take on another corporate antagonist, the insurance industry. The actions against the insurance industry, sometimes including throwing blood or bloodlike liquids at corporate offices, opened out to a host of efforts to guarantee the privacy of people with AIDS, secure their rights to employment and housing, and force the extension of other basic human rights to these individuals.

### Reading the "New York Crimes"

Many ACT UP activists were in the media or had friends in the media, and they understood that the mass media are not neutral reporters of reality, but active agents in the social creation of what counts as truth, reality, and news. Not surprisingly, given their location, the nation's "newspaper of record," the *New York Times*, early became a target. ACT UP undertook a prolonged struggle to get the *Times* to cover the AIDS crisis more fully, and to reshape the discourse used in that coverage. In the process, the group used some of their more inventive techniques and slogans. They created, for example, a mock-up of the *Times* front page, renamed the *New York Crimes*, in which they detailed how the paper had neglected to cover the crisis. They noted, for example, that during the first year and a half of the AIDS epidemic, when close to a thousand cases had already been reported, the *Times* carried only seven articles about it, none on the front page. In contrast, ACT UP counted fifty-four articles about a Tylenol contamination scandal over a three-month period, despite only seven reported cases. The group traced this neglect to a longstanding, deep-seated homophobia in the paper.

The last straw for ACT UP in relation to the *Times* came in June 1989, when the paper published an editorial suggesting that AIDS activist groups were exaggerating the seriousness of the disease. According to this editorial, at a point when a hundred thousand cases had been reported, the disease was "leveling off" because AIDS is "still very largely confined to specific risk groups. Once all susceptible members are infected, the numbers of new victims will decline." ACT UP's translation

was "Soon all the fags and junkies will be dead, and we'll be rid of AIDS." Outraged, ACT UP organized a demonstration in front of *Times* publisher "Punch" Sulzberger's Fifth Avenue residence that included painting white outlines of bodies and the inscription "All the News That's Fit to Kill" (an allusion to the newspaper's motto, "All the News That's Fit to Print") on the street in front of the apartment. The organization also launched a boycott of the paper that included the brilliant touch of placing stickers on newspaper vending machines that read: "*The New York Times* AIDS Reporting is OUT OF ORDER," with the last phrase printed large enough to discourage potential users of the machines. Another sticker read: "Buy Your Lies Here. The New York Times Reports Half the Truth about AIDS. ACT UP FIGHT BACK FIGHT AIDS." In addition to the typically catchy, sound-bite-length slogans, ACT UP handed out a flyer with statistics on the paper's (lack of) coverage, and raised specific questions about AIDS issues the paper had not addressed. In a comparison clearly designed to embarrass the prestigious newspaper, ACT UP pointed out that the *Times* had sent only one reporter to cover the twelve-thousand-delegate Fifth International AIDS Conference earlier that year, while even the tabloid *New York Newsday* had sent five. Not only that, the *Times* reporter failed to attend the most exciting event of the conference, the opening ceremonies, which were taken over by hundreds of international AIDS activists.

ACT UP's media assault often focused on terminology, keywords in the AIDS cultural battle. Perhaps because ACT UP's core constituency of gay people had been historically sensitized to the power of negative labeling, the organization quickly zeroed in on issues of naming. The first and strongest assault was on the expression "AIDS victim," common in the media. The group argued persuasively that the term *victim* not only implied passivity but encouraged a fatalistic sense that the inevitable result of AIDS was death. ACT UP countered with two alternative phrases: the more neutral sounding "people with AIDS," and the more pointed "people living with AIDS." This second expression emphasized that dying was not the sole occupation of those infected with the HIV virus—people were "living with" the disease.

ACT UP understood that images spoke as loudly as words in this context. A year after the founding of ACT UP, the Museum of Modern Art once again became a target when it exhibited a collection of photographs of AIDS "victims" taken by Nicholas Nixon. Nixon's images were



almost invariably of emaciated, darkly lit figures in late stages of AIDS-related diseases. From the point of view of ACT UP, they evoked at best pity, not activating anger, and rendered the "victims" complacently silent. They reinforced the message that one died from but did not live with AIDS. Picketing the exhibit once again raised the level of awareness in one of AIDS activists' most sympathetic communities, the art world.

A similar struggle surrounded the expression "risk groups." Given the environment of prejudice surrounding AIDS, the Centers for Disease Control's designation of certain people, in particular gay men and intravenous drug users, as members of "high risk groups" was bound to deepen the stigma. ACT UP argued that such labeling not only increased stigmatization but also worsened the health danger by misdirecting attention away from the source of HIV infection—certain practices, not certain people. As an alternative, ACT UP and other activists promoted the phrase "risk behaviors." This move helped force a break through the censorship that made it difficult to talk about such things as unprotected anal sex. Over time and through numerous demos, boycotts, press releases, articles, and direct pressure on reporters, medical professionals, and bureaucrats, ACT UP succeeded in changing the discourse around AIDS, and that in turn changed the climate for research, testing, and treatment.

ACT UP also took on the way in which even the term *victim* was dichotomized. Well-publicized cases like that of Ryan White, an adolescent hemophiliac who contracted HIV through blood transfusion, led the media to invent the category of "innocent AIDS victim." The phrase inevitably if subtly suggests its opposite, the "guilty" victim. Given the social prejudices unleashed by the epidemic, it was not hard to figure out who these other, not-innocent victims were—queers, drug abusers, and sex workers. The religious right was the most extreme force in this construction, arguing that AIDS was God's vengeance on sinful people: deviants, the promiscuous, and drug-addled criminals. But in ACT UP's analysis, mainstream America embraced an only slightly less vicious version of this kind of thought whenever people unquestioningly accepted wording like "innocent victim." ACT UP's assault on this kind of discourse is epitomized by the slogan and graphic: "All people with AIDS are innocent." Designed by the Gran Fury collective for a nine-day campaign of actions in spring 1998, this graphic appropriated the caduceus, the image of twin serpents encircling a staff that symbolizes the medical

profession. Use of this symbol at once targeted the way victim prejudice had infected the medical community and associated ACT UP's position with the Hippocratic medical model of treating all patients equally.

### Not So Cosmopolitan

A different kind of media action was directed against a specific article in a well-known women's magazine. *Cosmopolitan* published a piece in January 1988 entitled "Reassuring News about AIDS: A Doctor Tells Why You May Not Be at Risk." In addition to furthering the notion of AIDS as a "gay disease," the misinformation contained in the article was potentially deadly to women or anyone else taking it as truth about HIV/AIDS. Clearly aimed to soothe a presumed female readership, the article by a psychiatrist named Robert E. Gould offered the lethally misinforming advice that straight women had little to worry about, even if they had unprotected sex with infected partners, unless they had vaginal lacerations. Adding racist assumptions to baseline homophobia, Gould dismissed the high incidence of heterosexually transmitted HIV/AIDS in Africa as the result of brutal, near-rape sexual practices claimed to be typical on the continent.

The actions against *Cosmo* were led by women and marked the emergence in ACT UP of a stronger female and feminist presence. Women in the group, especially lesbians, had been meeting informally for some time, but the *Cosmo* event catalyzed the formation of a women's committee in ACT UP. Although they were among those least at risk for contracting HIV/AIDS, lesbians had gotten deeply involved in AIDS activism from the beginning, for reasons ranging from personal connections with gay men to solidarity in the face of the homophobia that had done so much to worsen the crisis. But the solidarity of women in ACT UP was not always fully reciprocated. Larger numbers, louder voices, and bigger egos had often made ACT UP a male-dominated, sexist organization. Thus, in attacking sexist assumptions in mainstream media, the women's committee was also addressing ACT UP itself.

The women's committee turned out more than a hundred fifty demonstrators at the headquarters of *Cosmo* in the Hearst Magazine Building on a cold January day in 1988. They called for a boycott of the magazine and its advertisers (handing out a list of the latter), and they followed up with a national media campaign, using the particular issue to raise a wider set of concerns regarding poor coverage of women and AIDS.



After being ejected or blocked from appearing on some mainstream talk shows, the women's committee turned to direct media action, producing their own video, "Doctors, Liars, and Women: AIDS Activists Say No to *Cosmo*." The video was widely shown on cable television and at video festivals, museums, and universities, and included information on a range of AIDS issues affecting women. It even gave tips on how to create a demonstration. Like all ACT UP activities, the video stressed a sense of "do it yourself" organizing, free from stifling desire for central control.

At the time of the *Cosmo* action, the Gran Fury collective produced the poster, "AIDS: 1 in 61," which reads in part, "One in every sixty-one babies in New York City is born with AIDS or born HIV positive. So why is the media telling us that heterosexuals are not at risk?" This arresting statistic on HIV-positive babies arose overwhelmingly from black and Latino neighborhoods. Done in both English and Spanish, the poster addressed both neglect of women with AIDS and the racism that often accompanied that indifference: "Ignoring color ignores the facts of AIDS. STOP RACISM: FIGHT AIDS." Both because of its ideological complexity and its proximity to the crisis, ACT UP was among the first groups to notice the changing demographic of the disease, and to act upon that knowledge. But the group's ability to address the impact of HIV/AIDS on communities other than the gay community ran up against serious challenges.

### Kiss-ins, Ball Games, and Other Invasions of Public Space

Like the artists of the mural movement, ACT UP graphic artists and theatrical demo designers sought to reclaim public space. This reclamation was crucially important because the longstanding, puritanical practice of keeping sex talk private was proving deadly. While American culture is one of the more sex-obsessed cultures in the world, using sex to sell everything from cars to household cleansers, certain kinds of sex talk are taboo in certain public arenas. The most obviously relevant silence concerns "deviant" same-sex relations. Beyond this, America's sex phobias were limiting delivery of crucial information about HIV/AIDS. ACT UP's assault on public spaces ranged from politicizing baseball games to crashing medical conferences to its most notorious variation on the sit-in tactic, public same-sex "kiss-ins."

Same-sex kiss-ins also demonstrated the continued link within ACT UP of gay/lesbian liberation and HIV/AIDS activism. The first large-scale kiss-ins were held in conjunction with the 1987 March on Washington for Lesbian and Gay Rights. The materials handed out at the public kiss-ins clearly articulated their motivations, including their intent to confront that invisible force of normalization: "We kiss to protest the cruel and painful bigotry that affects the lives of lesbians and gay men. We kiss so that all who see us will be forced to confront their own homophobia. We kiss to challenge repressive conventions that prohibit displays of love between persons of the same sex." The handout goes on to link this general homophobia to the AIDS crisis: "The Helms Amendment, preventing federal funding for any AIDS educational materials that could be construed to promote lesbian or gay sex, passed in the Senate by a vote of 96 to 2. The federal government has been unconscionably slow to react to the AIDS crisis, a slowness tantamount to condoning the deaths of tens of thousands of gay men."<sup>13</sup>

The essence of the kiss-ins found its way into public space via a different vehicle as well. Gran Fury produced a take-off on a famous Benetton clothing advertisement. The ad, placed on buses circulating throughout the city, carefully mimicked the style and content of Benetton ads that featured kissing couples, making only two slight alterations: two of the three couples kissing were same-sex couples, and the accompanying copy was not from Benetton but from ACT UP and read: "Kissing Doesn't Kill, Greed and Indifference Do. Corporate greed, government inaction and public indifference make AIDS a political crisis." With characteristically brilliant brevity of wit, the images and copy counter the notion that HIV can be transmitted by casual contact, assault homophobia, and separately target pharmaceutical corporations, the government, and the general public reading the ad.

A different invasion of public space took place during a baseball game in New York's Shea Stadium. Like the *Cosmo* demo, it was aimed especially at correcting misinformation about putative heterosexual immunity to AIDS, and, like the *Cosmo* demo, it was organized by the women's committee. Activists bought out four hundred seats in three large sections of the stands from which they could unfurl banners with typically ACT UP-pity but site-appropriate slogans like "No Glove, No Love" (that is, no condom, no sex), "AIDS Is Not a Ball Game," "Strike Out AIDS,"



"Don't Balk at Safe Sex," and, most graphically, "AIDS Kills Women" and "Men: Use Condoms or Beat It." ACT UP also handed out informational "score card" flyers that also utilized baseball metaphors: "Single: Only one woman has been included in government-sponsored tests for new drugs for AIDS. Double: Women diagnosed with AIDS die *twice* as fast as men. Triple: The number of women with AIDS has *tripled* as a result of sexual contact with men in New York City since the 1984 World Series. The Grand Slam: Most men still don't use condoms." Aiming to hit its target audience in their ball(s)park, the action was directed at straight men who refused to take responsibility for safer sex. ACT UP purposely chose to be inappropriate, to coopt a space from which politics is supposed (or presumed) to be absent. But in cultural war, symbols like "America's pastime" are precisely the points where (hetero)normativity is constructed, where the lines between normal, innocent victims of tainted blood get distinguished from virus-spreading sissies who probably never even played baseball!

These are merely a few among the dozens of actions ACT UP has performed over the years, from single-person or small-group "zap" actions to elaborate demos with hundreds of people committing acts of civil disobedience.

### "Facing" the Crisis

One of the key questions facing a social movement is how to represent the forces against which the movement is struggling. As sociologist William Gamson points out, this process entails a paradox. On one hand, if the forces against which the movement is arrayed are portrayed too abstractly, both potential recruits and movement members may find it difficult to identify with the struggle. On the other hand, if a movement personalizes the struggle too much by naming particular individuals as the opponent, the important insight that structural factors, not just individuals, are the ultimate target is lost. A parallel problem exists on the other side of the equation. If a movement imagines itself too fully in collective terms, the sense of agency in the individual members of the group may wane; they may feel they are replaceable. Conversely, placing too much emphasis on individual commitment plays into the process by which the dominant society undermines collective opposition by personalizing and individualizing all social problems. That pro-

cess, of course, is the very thing against which movements are organized. ACT UP dealt seriously and creatively with both of these dilemmas.

A significant part of ACT UP's power came from the mobilization of anger; recall that its self-definition included the phrase "a group united in anger and committed to direct action to end the AIDS crisis." Direct action is a collective activity, but anger is a very personal emotion. While one may analyze a structure to the point of anger, it is far easier to express anger toward a person than a system. ACT UP graphics suggest a very balanced approach to the dynamic of personalization versus emphasis on structural causation. Their targeting suggests an understanding that while political and bureaucratic systems function abstractly, they also depend in part upon the decisions of individuals in authority. ACT UP posters present the faces of opponents, associating them through written texts with various "crimes" contributing to the AIDS crisis. President Reagan ("AIDSgate," "He Kills Me"), Cardinal James O'Connor ("Public Health Menace"), New York mayor Ed Koch ("10,000 New York City AIDS Deaths: How'm I Doin?"), New York health commissioner Stephen Joseph ("Deadlier than the Virus"), and Burroughs Wellcome CEO A. J. Shepperd ("AIDS Profiteer") were among those singled out in the early years of ACT UP. That singling out took the form of using the faces of these individuals, but in ways that made them more abstract.

Because a straightforward photolike representation might risk humanizing the opponent in ways that made it more difficult to sustain anger, the images were variously colorized, blurred, or rendered grainy in ways that abstracted the individual. The "AIDSgate" poster by the Silence = Death Collective, for example, which is credited by some with recruiting many new members to ACT UP at the national demonstration for lesbian and gay rights in the summer of 1987, featured a head shot of President Reagan done in a garish green with demonic red where the whites of the eyes would normally be. Another poster of Reagan made in the same year by Donald Moffett images a head and torso shot of a smirking president in sepia tones on the right side, juxtaposed to a red and black targetlike set of concentric circles on the left. Over Reagan's chest, in the same color as the red in the target, are the words "He Kills Me." The phrase at once evokes and trashes the public image of Reagan as an allegedly charming, old-boy humorist, and pointedly suggests that Reagan's indifference to the AIDS crisis is deadly. The deadliness is at



once general and concrete; the phrase "He Kills Me" personalizes the threat. Where superimposing the target over Reagan might have seemed a violation of the nonviolence code (if not a provocation to the Secret Service), separating the two images makes ambiguous the question of who is the targeted and who the targeter. The implication that "he," the president, is targeting "me," the person with AIDS, at the same time evokes an anger that is retargeted at Reagan and his policies.

Two uses of pharmaceutical CEOs offer a contrast in regard to giving and not giving a face to the opposition. The first image features "Mr. A. J. Shepperd, Chairman—WELLCOME PLC." Once again a head shot, the face is rendered in abstracted, very grainy black and white, with Shepperd's name and title given in a subliminally threatening diagonal slash across the chairman's necktie. Stamped in larger letters across his receding hairline are the words "AIDS Profiteer." A second, quite famous poster eschews giving face to the "enemy." Again a black and white image, this one features several petrie dishes and a syringe held by a gloved hand in the foreground, and a medical masked head. Presented with *noir*-style contrast, the lab technician's facial features are washed out totally into a black backdrop. On the head of the shadowy figure the following quotation appears: "One million [people with AIDS] isn't a market that's exciting. Sure it's growing, but it's not asthma." Below the quote is the attribution "Patrick Gage, Hoffman-LaRoche, Inc." This contrast of facelessness with the facefulness of the Shepperd poster makes perfect tactical sense. Where Burroughs Wellcome was a direct target of ACT UP, a company whose policies the group specifically wanted to change, Hoffman-LaRoche, as the quotation suggests, was not interested at the time in the "AIDS business." Thus the point of the attack here was to represent the callous indifference of the pharmaceutical industry in general, so that abstract, faceless indifference was the point. At the bottom of the poster are the words "This is to enrage you." This direct evoking of emotion was a common technique in ACT UP posters, and it again embodies a kind of postmodern complexity: it at once tells viewers what to feel ("rage") and tells them that they are being manipulated, "This is [engineered] to enrage you." Through such complicated yet direct image-texts, ACT UP posters managed to personalize and generalize, attack individuals and target the structures in which they are embedded, while simultaneously evoking a collective but personal "you."

### Acting Out: Extending the Issue Frame

ACT UP has shown amazing adaptability when the contexts of AIDS as disease and social construction have shifted, partly in response to its own efforts. While remaining a predominantly white male organization, ACT UP has developed, with much pushing by others inside and out of the organization, a rich analysis of the intersections of race, class, gender, sexuality, and nationality. The list of issues it has taken up includes housing for homeless people with AIDS, free needle exchange programs for intravenous drug users, issues of AIDS in prison, underfunded public hospitals in the inner city, the spread of AIDS in the Third World, health insurance for low-income people, and treatment protocols for women, for lesbians, and for people of color (and for people fitting two or more of those categories). Some of this work has been done via ACT NOW (the AIDS Coalition to Network, Organize and Win), a national, and later international, forum created to extend the range of issues addressed by ACT UP and to offer widespread coordination while maintaining a decentralized structure. But coalition building has been far from easy.

One way to mark the shifting forces in and around ACT UP is to compare two major national marches in which the group was a significant force. The first, the 1987 March on Washington for Lesbian and Gay Rights, attracted six hundred thousand people and was, among other things, a coming-out party for ACT UP and for the wider field of AIDS activism. The march was led by people with AIDS, and the event included the first public display of the enormous AIDS Quilt, another, differently inflected part of AIDS cultural activism that marshaled mourning and remembrance as effectively as ACT UP mobilized anger.<sup>14</sup> It was also the moment when ACT UP received national exposure through its colorful graphics, dancing dragon mobile picket line, and large-scale civil disobedience. AIDS was on the agenda in various other ways throughout the march and surrounding events, and thus the Washington, D.C., rally marks the moment when it became clear how much lesbian and gay rights organizing would be changed by the AIDS crisis.

Seven years later, a Lesbian, Gay, Bisexual and Transgender March on Washington drew close to 1 million people. By this time it was clear that both ACT UP and the wider queer movement were increasingly



connected to larger circuits of social justice; both linked movements were acknowledging far more fully than before the extent of diversity within their own ranks. There are many reasons for this, including increasing attacks from the Christian fundamentalists and others on the right who were using an antigay agenda as a wedge against all strands of progressive social action. The preamble to the march platform states: "The Lesbian, Gay, Bisexual and Transgender movement recognizes that our quest for social justice fundamentally links us to the struggles against racism and sexism, class bias, economic injustice, and religious intolerance. We must realize if one of us is oppressed we are all oppressed. The diversity of our movement requires and compels us to stand in opposition to all forms of oppression that diminish the quality of life for all people."

This preamble, and the shape of the march overall, were the result of much internal struggle between those wishing for a narrower, simpler "gay rights" agenda, and those pushing for this larger vision. And note how those who won out phrased the larger vision. It is the "diversity of our movement" that "requires and compels" this wider understanding. In other words, as more and more people came out, as more and more histories were written, as more and more complicated lesbian, gay, bisexual, and transgender studies emerged, it was impossible to deny the diversity within and across various gay or queer communities. At the same time, there is a recognition, beyond celebrating and protecting this diversity within, that "all forms of oppression that diminish the quality of life" for one group threaten others. ACT UP was both driven by and a driving force in this dual recognition of internal gay diversity and external connection to other communities. Because AIDS cut its swath widely (but not "indiscriminately") across the entire gay, lesbian, and bisexual communities, and beyond those communities, AIDS activism was a key site for this transformation.

From the group's beginnings, many in ACT UP were quite serious in attempting to reach out beyond their gay white male and lesbian core constituency. Because of its closeness to the crisis, ACT UP was among the first to recognize that the crisis had moved beyond the gay community. In trying to assist other communities, however, the group ran up against external and internal obstacles. One might have expected that ACT UP, with its sensitivity to the need for community-specific AIDS education, might have been better prepared for how not only the mean-

ings, but the very course of the disease, differed from community to community, especially across lines of race, gender, and class. But those lines proved very difficult to cross.

As we have already seen, it took years and much prodding for women within ACT UP to convince men in the organization to take seriously the independent educational and medical needs of women generally and lesbians more specifically. Similar blindness emerged around economic and social factors affecting the course of the disease and its recognition and treatment in particular nonwhite, nongay, and/or poor communities. AIDS deaths among intravenous drug users were not recorded as such by authorities for some time, partly because symptoms tended to blend in with other "side effects" of substance abuse and were often different than those affecting middle-class gay men, and partly because the "gay disease" stereotype blinded health officers. As noted above, ACT UP did much to bring this other population of people with AIDS to light, but not always in the most effective or useful ways. ACT UP's rhetoric of crisis, for example, did not necessarily match the understanding of poor people of color for whom crisis mode is just everyday life. Many blacks and Latinos in inner cities saw the advent of AIDS not as a transformative event, but as one more in an ongoing series of assaults on their communities. Where middle-class white professionals felt a deep sense of entitlement to a health care system geared to their needs, blacks and Latinos were often inured to a system utterly indifferent to theirs.

At the same time, both media stereotypes and homophobia, which communities of color were no more immune to than white communities, made gay people of color invisible in AIDS iconography. By stereotype, if you were black or Latino and HIV-positive, you were a drug user, if you were white and HIV-positive, you were gay. These and similarly stereotypical assumptions at work both inside and outside of ACT UP meant that the group's efforts to reach out to communities of color were often received with suspicion. Intensive work on racism within the group, the presence of more gay and straight people of color in the organization, and a shift in national movement priorities gradually lessened these tensions. But ACT UP has seldom significantly crossed the color line (though as of 2002, ACT UP Philadelphia reported that more than half its membership was of color). Nevertheless, many in ACT UP



worked diligently to deepen analyses of the ways in which homophobia, sexism, racism, and class oppression are inextricably interwoven into the AIDS crisis, and argued that all must be fought simultaneously if the crisis is to be ended.

### (De)Constructing Ideologies

To talk about the "overall" ideology of any complex movement is risky business at best. But for ACT UP, to offer such a generalizing characterization would be not only risky but a violation of one of the ideological principles of the (dis)organization itself. The highly decentralized, profoundly anarchistic nature of ACT UP makes an attempt to characterize its general political position extremely problematic and a violation of the members' ideologically self-conscious agreement to disagree ideologically. One student of the movement characterizes the central ACT UP goals as "greater access to treatments and drugs for AIDS-related diseases; culturally sensitive, widely available and explicit safe-sex education; and well-funded research that is publicly accountable to the communities most affected."<sup>15</sup> The life-and-death stakes of an initially mysterious and terrifying disease certainly gave the group a very concrete focus. As one member put it: "People have been fighting for social justice in this country for centuries . . . We're going to get aerosol pentamidine [a treatment drug for pneumocystis pneumonia] a lot quicker than we're going to get social justice."<sup>16</sup> Yet even many of the most pragmatic members of ACT UP soon realized that their concrete goals were inseparable from larger issues of social justice.

At the other ideological extreme from the pragmatists in the organization, but not necessarily inconsistent with their goals, is the radically "deconstructive" position articulated by members like Cindy Patton: "ACT UP groups do not protest or demonstrate; rather they perform, and in their 'actions' they identify the unspoken, inaudible linkages in the power system which are obscured by both the unitary notion of power ('get a government response') and the network notion of power ('decentralize') . . . Coalition, and even agreement, may not be a desirable goal, but only a strategic or tactical moment in denaturalizing identities and the systems of power which construct them in order to control us."<sup>17</sup> For other members, a broad, radically democratic, decentralized but still recognizably "progressive left" perspective was the core ideology of

ACT UP. This element, while wary, worried less than Patton about being absorbed back into the various power systems, and took most seriously the second letter in the acronym, for *coalition*.

Part of ACT UP's ideology was an understanding that all "cultural texts," including actions, are open to widely variant interpretations. Applying this analysis to its own actions meant that ACT UP performed "social texts" that were explicitly designed to leave room for multiple interpretations. This was not to promote some "anything goes," utterly relativistic position—a common misunderstanding of postmodernism—but rather to acknowledge that analyzing the always partly open-ended nature of communication could make one more effective in challenging dominant rhetorics and the social positionings from whence they were articulated. In other words, the postmodernism of ACT UP actors challenged universal claims to truth and representation that they believed often embodied not universal but particular straight, white, middle-class male positions. They opened themselves instead to studying and understanding other, insurgent particularities of race, ethnicity, class, generation, gender, sexual preference, and their intersections. Crimp and Ralston acknowledge the collective nature of ACT UP graphics, and note that the multiple audiences to which they are directed always include themselves: "AIDS activist art is grounded in the accumulated knowledge and political analysis of the AIDS crisis produced collectively by the entire movement. The graphics not only reflect that knowledge, but actively contribute to its articulation as well. . . . They function as an organizing tool, by conveying, in compressed form, information and political positions to others affected by the epidemic, to onlookers at demonstrations, and to the dominant media. But their primary audience is the movement itself. AIDS activist graphics enunciate AIDS politics to and for all of us in the movement."<sup>18</sup> This last point is crucial, for it acknowledges that rather than accepting self-limiting ideas of "preaching to the choir," ACT UP understands that ongoing internal political education and a willingness to grow and change ideologically are critical to a movement's success. Indeed, a healthy if not always pleasant fractiousness has been a hallmark of the organization. The strong decentralist structure that allows room for difference has been crucial in assuring that this contentious ongoing learning process has been more often a resource rather than a threat. Of course, those who would forestall movements can also be fast



learners. And as some critics have argued, a similarly decentralized set of interlocking but semi-autonomous forces of domination characterizes postmodern capitalist society, and those forces are not easily challenged.<sup>19</sup>

### Outside-in Strategies, F(r)actions and Spin-off Groups

ACT UP was from the beginning known best for its uncompromising, in-your-face tactics. Given that its origins lay partly in critique of AIDS service organizations like the Gay Men's Health Crisis, which ACT UP believed had gotten too close to mainstream medical and government institutions, and given its confrontational style, this reputation is well earned. But the picture is also more complicated. Many in ACT UP understood that their pressure was making space for insiders in AIDS medical and government bureaucracies to maneuver. This situation, which I call the outside-in, or push-pull strategy, is common in many movements. Just as Malcolm X proved a useful foil for Martin Luther King Jr., ACT UP served those very organizations, such as GMHC, that it criticized as too moderate.<sup>20</sup> ACT UP members engaged in letter writing, petitioning, and lobbying, in addition to taking direct action. And they often used direct action itself, as had the civil rights movement, to force open a process that led to the kind of negotiation more moderate forces had been unable to initiate.

The complexity of political factions and fractions within ACT UP is also revealed in the number of spin-off organizations it generated. These spin-offs spun in two rather opposite directions: new groups less oriented toward direct action, on one hand, and new radical queer groups that were very direct action-oriented.

As we have seen, women in ACT UP had to struggle to get the gay male-dominated movement to address issues of particular concern to women. The work of women in ACT UP to bring out the issues of HIV-positive women in general, and lesbians in particular, played a key role in seeding a strong, widespread, and diverse lesbian health movement. That effort has led to increased medical attention to a lesbian demographic with regard to breast cancer, sexually transmitted diseases, and a host of other concerns. Some lesbians frustrated by ACT UP's gay male focus spun off to form Women's Health Action and Mobilization (WHAM), a "direct action group committed to demanding, securing, and defending absolute reproductive freedom and quality health care for all women." Like ACT UP, WHAM and other radical women's health

and reproductive rights activists sought more targeted medical research, inclusion of women and lesbians in drug trials, better and more widespread health information for women and lesbian communities, and full reproductive rights. Like ACT UP's bad cop, good cop routine with regard to more mainstream AIDS advocacy groups, these new women's and lesbians' health movement groups brought renewed radical energy and pressure to a scene that had become routinized and limited by institutionalization.

In another vein, because ACT UP was centrally involved in a politics of scientific knowledge, some members moved ever deeper into the arcane dimensions of medical research, developing personal contacts within the medical field whom they influenced through far lower-key tactics (like conversation over coffee) than the image of ACT UP usually conjures. Some in the movement gained through this process a deeper understanding of, if not sympathy for, those who work in AIDS research and increasing intimacy with AIDS bureaucracies led some members to form a spin-off organization called the Treatment Action Group (TAG) in 1992. TAG was a far different organization, not only in focus but also in form. A small group formed by invitation only, it eschewed openness and democracy in favor of expertise and traditional political clout. It became a "parallel institution" of sorts, mediating between AIDS bureaucracies and radical activist critique. TAG's difference from ACT UP is perhaps most dramatically shown by the group's acceptance of a \$1 million donation from Burroughs Wellcome. While criticized by many in ACT UP for elitism and for growing too close to the enemy, TAG has been credited by others with great success in lobbying the government to release promising AIDS drugs more quickly, to improve the FDA clinical trial process, and to better coordinate research activities at the National Institutes of Health through an Office of AIDS Research. That success, however, could not have occurred without, and, indeed, is indivisible from, ACT UP work. But TAG is far more likely to receive official credit for these advances, since the most radical elements in a force field of influence never receive credit from those institutions they influence.

Among the spin-offs of ACT UP that spun rather in the opposite direction, the most notorious is no doubt Queer Nation. Founded in 1990, this short-lived but highly dramatic and influential group sought to take ACT UP's confrontational style back into lesbian and gay organizing.



Queer Nation took some of the radical energy, internal diversity, and tactics of ACT UP into attempts to empower bisexuals, transgendered people, and others who had been excluded from, marginalized by, or toned down by the mainstreaming of aspects of the lesbian and gay movement. Queer Nation's signature actions, often aimed at "queering" public places, included kiss-ins in shopping malls and straight bars, same-sex marriages on the steps of Catholic cathedrals, and "pink panther" patrols bashing back against antigay violence. Like ACT UP, Queer Nation grew rapidly both in cities around the United States and internationally. Though the contradiction between the inclusiveness implied by *queer* and the exclusiveness implied by *nation* wore down many chapters after a few years, the organization's colorful style and imaginative actions did much to bring the category "queer" and some of the theory behind it more fully out into the public sphere.

A second, similar spin-off group, the Lesbian Avengers, founded in 1992, took the energy, style, and direct-action emphasis of ACT UP into an attempt to radicalize lesbian activism. The group's handbook for the New York chapter (like ACT UP and Queer Nation, the group was founded in New York City, but soon spread nationally) speaks in terms that clearly echo its origin. One section of the handbook is titled "Demographics," in homage to the ACT UP book of the same name, and the group's self-description suggests both its ACT UP style and the targets of some of its actions:

Props, floats, shrines, burning torches, papier mache bombs, plaster statues whatever! Demo-graphics need to be eye-catching, meaningful, and visually exciting.

We try to never use a cliché or tired old rhetoric. . . . When we built a shrine to the two gay people burned to death in Oregon, our demo posters said, "Do Not Let Them Rest in Peace." When we dogged the mayor of Denver for 48 hours the signs said "Boycott the Hate State." When we held our New Year's Eve Party, the poster featured a picture of seventies Blaxploitation film star Pam Grier, in hot pants, loading a rifle. The poster advertised "Activist a Go-Go." Our Valentine's Day Action honoring Gertrude Stein and Alice Toklas celebrated "Politically Incorrect Domestic Bliss." . . . So whether the theme is whimsical or angry, our slogans have been clear.<sup>21</sup>

Clearly, the Avengers, like Queer Nation, focused on in-your-face confrontations around a variety of issues affecting their community. Both Queer Nation and Lesbian Avengers appealed especially to a younger

generation of gays, lesbians, and other queers who, raised in a more "out" world made possible by generations of activists who preceded them, pushed further "out," bringing their defiantly deviant selves out into the streets, the malls, the schools, the talk shows.

The various spin-off groups of ACT UP mark both a positive diffusion of energy and internal fault lines in the organization. On the negative side, despite ACT UP's antihierarchical, decentralized form that could contain many positions, both its failures and its successes created some internally irresolvable tensions that could only find resolution in the formation of new groups. On the positive side, ACT UP set off a chain reaction that radicalized communities and fostered a host of new groups. Indeed, a proliferation of both health advocacy groups and radical queer groups constitutes small-scale "cycles of protest" set in motion by ACT UP.<sup>22</sup>

Most followers of ACT UP argue that the group peaked in the early 1990s and declined somewhat in effectiveness thereafter. Urvashi Vaid, one of the most perceptive observers of contemporary movements and a major figure in lesbian, gay, queer organizing, and a sometime member of ACT UP, credits the group with bringing a new generation of activists into their own, but is critical of the lack of follow-up behind ACT UP's spectacular actions:

Direct-action activism emerged in part as a reaction to the conservatism of the gay mainstream, and significantly affected gay movement strategy from 1986 to 1992. ACT UP marked the first (and only) time that this strategy took center stage in national gay politics. A new generation of activists, committed solely and principally to being queer and promoting queer freedom, came into its own. . . . [But] the direct action strategy focused on the glamorous and neglected the obvious. We sought (and got) media visibility, but after our fifteen minutes in the sun, we were left with another round of silence and the need to repeat the old actions, with diminished effectiveness each time. Our coercive moralism and guerilla tactics eventually alienated and angered the people whose decisions we tried to shape. Ultimately, our neglect of dull systematic political organizing left us in 1993 without the political capacity to fight the right locally for our national policy agenda.<sup>23</sup>

ACT UP's very strength—the imaginative, novel, and telegenic aspects of its demonstration—became a liability, both because novelty always wears off, and because being high on direct action can distract from grassroots "dull systematic political organizing."



### Mainstreaming Reappropriations

As I have argued throughout this book, one clear sign of the success of a movement is diffusion/defusion of aspects of its culture into mainstream cultures. In the case of ACT UP the very brilliance of its graphic sense and its theatrical flair no doubt hastened this process. But this is hardly surprising, since ACT UP's own analysis of how the process of cultural politics works anticipated that even the group's opponents would reappropriate their "texts." The group also understood that the process of reappropriation was not a wholly negative one. As in the fable of the wolf that ate the tasty stones proffered by the sheep it planned to eat, eventually the stones limit the mobility and options of the predator.

A key example of this appropriation was the rise of what some have called "AIDS chic." The most ubiquitous emblem of this was the wearing of red ribbons by people in the entertainment industry. Started by an activist group calling itself Visual AIDS, the ribbon moved fairly quickly from a brilliant device to draw attention to AIDS by associating the fight against it with figures in popular culture to a complacency-deepening symbol of how easy it was to feel good about AIDS: just pin on a red ribbon! The more selective and effective version of AIDS chic took the form of fashion shows, art exhibits, and musical concerts that raised millions of dollars for AIDS research and treatment. This kind of mainstreaming, as I argued in chapter 6 regarding what we might dub "famine chic," was viewed skeptically by many in ACT UP but was also recognized as a necessary source of funds that might perhaps be put to more radical uses than the funders may have intended.

Surely, the clearest, most ironic example of mainstream appropriation involves the graphics of the Silence = Death project and the Gran Fury collective being taken up and resignified by pharmaceutical companies. The rise in recent years of ever more specific niche marketing led inevitably to "gay people with AIDS" being moved from "risk group" to "target audience." As Sarah Schulman articulates it in her important book *Stagestruck: Theater, AIDS, and the Marketing of Gay America*: "advertising relies on a philosophy of niche marketing that has become so precise that Puerto Rican girls, poor alcoholics, Christian fundamentalist rock fans, punks of Arab descent, teenagers wanting cigarettes, and terminally ill gay men all have their own interactive relationship

with some area of advertising."<sup>24</sup> In other words, with or without the aid of postmodern theory, advertisers too have learned the virtues of understanding specific "positionalities" and their rhetorical preferences. The powerful images created around anti-AIDS activism proved too tempting for market(e)rs seeking to consume people with AIDS. Magazines like *POZ*, aimed at HIV-positive readers, complete a circle when they publish pharmaceutical ads that incorporate pink triangles and other aspects of the "AIDS activist aesthetic" to sell their products. In appropriating images that ACT UP activists themselves had often appropriated from mainstream advertising styles, these ads remind us of the ongoing, irresolvable problem of resignification that ACT UP's postmodern graphic identity so brilliantly embodied. There is no such thing as a radical image or message; there are only radical "contextualizations" that in turn become "texts" that can be resignified back into the mainstream. This is not a cause for cynicism, just a caution against complacency and a call for ongoing acts of imaginative engagement.

### The AIDS Crisis Is Not Over

As early as 1988 ACT UP felt it necessary to create a poster reading, "The AIDS Crisis Is Not Over," and ever since the group has periodically had to fight the sense that new treatments, new funding, new political promises had brought the crisis to an end. The mainstreaming of AIDS, its normalization, has brought with it another version of this old problem. Though ACT UP groups are still acting up all over the world, they struggle with a new wave of indifference resulting in part from their successes. Positions considered outrageous when articulated by ACT UP a decade ago seem like common sense today. For those who know nothing of the activist organization, this common sense appears from nowhere, while those who give credit to ACT UP sometimes do so in a romanticizing way that mythologizes the movement's past at the expense of its present. Consistent with their very process-oriented sense of social movement, many original members of ACT UP have moved on, and many new positions have been articulated. The development of relatively effective AIDS drug treatments has greatly extended the lives of some people with AIDS, and ACT UP deserves a good portion of the credit for speeding the development of these drugs. Anthony Fauci, director of the National Institutes of Health during the rise of ACT UP,



noted in 2002 that activism profoundly changed not only the process of developing AIDS drugs but also the whole federal approach to drug development.<sup>25</sup>

Sociologist William Gamson observes that “the trick for activists is to bridge public discourse and people’s experiential knowledge, integrating them in a coherent frame that supports and sustains collective action.”<sup>26</sup> In this process, for a while, time is on the side of movements. Claims that by definition always initially come from outside some mainstream frame become less strange through multiple iterations. Over time the chances of those iterations resonating with experiential knowledge grow. In the case of AIDS, the terrible, exponential spread of the disease itself meant that more and more people had the opportunity to match what groups like ACT UP were saying about AIDS and people with AIDS to their experience with someone they knew personally. This too led to normalization of the disease and, sometimes, to greater sympathy for protesters.

But within some of the most deeply affected communities, it also led to a different kind of normalization of disease. In some sectors of some gay urban communities, where infection rates sometimes exceeded half of the population, a deeply romanticized fatalism set in, one that went so far at times as to stigmatize HIV-negative individuals in the community as less authentic, thereby undermining safer sex practices. Hence, another kind of full circle turns, as attempts to undermine stigma inadvertently contribute to the transformation of stigma into a “red badge of courage” that ironically puts new persons at risk.<sup>27</sup>

All of the issues ACT UP has faced over the years remain, in sometimes altered, but distressingly recognizable form: AIDS “profiteering” has only increased as the numbers of potential “customers” have grown; inadequate attention from the federal government has worsened under President Bill Clinton’s and President George W. Bush’s continued downsizing of government; and public indifference, for a time lessened by the power of direct action, has reasserted itself in the face of the illusion that better treatment has ended the crisis. Add to this the problem of dealing with the new wave of desperate, romanticized high-risk behaviors, and you have a formidable set of issues at home. In addition, currently much ACT UP activity in the United States and elsewhere is focused on AIDS in the Third World where infection statistics are staggering, resources far scarcer than in the United States, and racist indif-

ference again apparent. Of the 40 million people in the world currently diagnosed with HIV/AIDS, 70 percent are on the African continent. Rather than simply enjoying the relative advantages of access to life-prolonging treatments provided by their often privileged economic and social location, to their credit, U.S. AIDS activists have moved their critique of AIDS policy more and more into the realm of international politics. This is at once a tribute to the ideological openness and willingness to grow within ACT UP, and part of a more general sense among participants in many progressive movements that they must work on an integrated set of issues and on a truly global stage, even as they attend to the particulars of their place and the specifics of their issues. As we will see in chapter 9, this process of “globalization from below” represents a new wave of activism nationally, transnationally, and internationally.